

# FINAL REPORT PRESENTED TO THE EUROPEAN COMMISSION

Promoting new measures for the protection of women workers with oncological conditions by means of social dialogue and company-level collective bargaining

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### **Preface**

In the course of his/her lifetime, one European citizen in three is expected to get cancer, and one in four to die from a disease of this type. These alarming figures were brought to the attention of the European Parliament, which on 10 April 2008 passed a key resolution in support of the battle against this disease, urging the European Union to take action.

Certain aspects of the resolution of the European Parliament were particularly innovative and noteworthy. Cancer-related issues are a matter not only for healthcare professionals, but also to be shared and discussed among the wider public. And that was precisely the aim of the European Parliament, in an attempt to deal with cancer-related issues by means of a non-specialist approach, in order to facilitate a greater understanding on the part of the general public.

The resolution considers the problem in general terms, highlighting the link between different aspects of the disease: the clinical, psychological and diagnostic aspects, as well as the social and economic factors. Oncological diseases are caused by many factors. This is why an effective programme of prevention should be promoted taking into account all the causes of oncological pathologies, instead of focusing only on one aspect.

One of the most interesting aspects of the Resolution is the fact that the European Commission is assigned the task, by means of legislative measures and effective initiatives, to collaborate with as many economic and social actors as possible, especially industrial relations actors. Thanks to this kind of cooperation, cancer prevention can be strengthened, by reducing occupational and environmental exposure to carcinogenic agents and by promoting a healthy lifestyle and acceptable working conditions.

In this perspective, it is important to consider the proposal of the European Parliament to draft a charter to safeguard workers with cancer and chronic illnesses. Under this charter, employers would have to allow patients to keep their jobs while they are receiving treatment, and to facilitate also their reintegration. From this point of view, Italy is

playing a leading role. It may be said that Italy provides one of the most innovative legislative frameworks in Europe and worldwide. In general, most countries simply make provision for the temporary interruption of the employment relationship for a reasonable period (known as grace period), considering it to be like any other legitimate reason for absence from work.

However, in Italy the Biagi Act, provides specific regulation for workers affected by oncological pathologies. Article 46 of Legislative Decree No. 276/2003 (that is not very well known, and for this reason is worth mentioning) does not simply recognize the right to interrupt the employment relationship (with or without pay). The most significant aspect is the effort to reconcile the sick worker's needs with employment, safeguarding the right to work and to health care, both mentioned in the Constitution. To make this possible, and to respond to the needs of the enterprise and worker's expectations, working hours have to be reorganized in a more flexible and effective way, especially if we consider that the duration of the grace period might be variable and irregular. This is the reason why the Biagi Act provides that all workers with oncological conditions, especially those whose working capacity is affected by life-saving treatment, have the right to modify their employment contract, moving from a full-time contract to a parttime one. This is a right of the individual worker, that has been extended also to public employees, in order to safeguard the right to health care of sick workers, their occupational lives and social life. In addition, the law also provides the opportunity for workers to return to full-time working, as and when their health will allow it.

Since the Biagi Act came into force, it has become clear that it is important to put this provision into practice. However, only a few collective agreements, such as the one for the tourist industry, have implemented these provisions. For this reason, the Code of Good Practice and the Charter of Rights for workers with oncological conditions, the importance of which was highlighted by the European Parliament, are of great importance.

In this connection, Italy could play a leading role in Europe: Adapt, the Italian

Association against Cancer (LILT), and Europa Donna have been entrusted with a pilot scheme promoted by the Directorate-General for Employment of the European Commission, and Italy has promoted a *Manifesto of the Rights of Workers with Cancer*. With the support of the European Parliament, this Manifesto might help us to reflect on this issue even in cases in which it does not concern us personally.

Michele Tiraboschi



### Chapter 1

### Introduction<sup>1</sup>

Marina Bettoni, Simona Creazzola

This report focuses on a topic that requires an appreciation of the specific problem and in particular an awareness of issues relating to industrial relations and employment relations.<sup>2</sup> The partners initially taking part in the project, even though they were aware of the needs of workers with health problems in general, and of women with breast cancer in particular, did not all have an in-depth understanding of the issues and a capacity to take part in the activities. This resulted in a rescheduling of some of the activities, and some changes to the project, allocating more resources to the activities that attracted strong interest and participation on the part of those involved. Among the international partners making a significant contribution, mention should be made in particular of Europa Donna Sweden: thanks to the dedication of their representatives, this organisation played a significant role in each step of the project, and managed to involve an extensive network of bodies and organisations in the region. The project was publicised in newsletters, newspapers, magazines and the websites of all the organizations working for cancer patients, with the sponsorship of Roche Sweden. In Italy a fundamental role was played by the representative of Europa Donna Italia who maintained and developed a network of relations with a number of countries, and disseminated the information gathered in the various stages of the research.

In order to deal with the issue in a holistic manner, there was a need to bring together various actors with specific knowledge of the legal issues relating to the physical and psychological aspects of breast cancer, both during the critical period and in the phase in which women return to work after receiving treatment (see Chapter 2). Effective

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<sup>&</sup>lt;sup>1</sup> As required by the Call for Proposals (p. 19), the report deals with 10 questions, concerning the organisation of the project and future developments. This is reflected in the Introduction

<sup>&</sup>lt;sup>2</sup> Although none of the countries under consideration has norms dealing specifically with people with cancer, some of these countries have provisions of a general nature for people with disabilities that these workers can benefit from. Since there are no specific provisions for cancer patients, there are no provisions designed solely for women with breast cancer

collaboration between the partners involved, that at first sight appeared to come from extremely different contexts, in terms of educational background and cultural factors, made it possible to approach this issue in an effective manner.

In particular, the involvement of voluntary organisations as partners playing a direct and essential role in the project, highlighted the difficulty of working with volunteer groups, even though they were coordinated by leading organisations, in the planning and operational phases of project of this kind, covering such a large number of countries.

For those operating in the research sector, voluntary organisations are a major resource as they have such an extensive network of contacts, facilitating the widespread dissemination of the project, in addition to providing direct access to workers with an oncological condition and their families, and direct contact with the institutions, employers and trade unions. At the same time, the voluntary nature of these organisations is characterised by certain limitations. Although they are well organised to carry out their work at territorial level and to provide representation at a national and international level, they are not necessarily well equipped to take part in a coordinated project with professional bodies and research centres. It should be noted that the research project was extremely ambitious in terms of the objectives laid down. The work carried out with the involvement of various actors in a large-scale project was particularly significant in terms of defining the parameters of a research project that can serve as a model for future initiatives aimed at cooperating with the voluntary sector for experimental programmes for achieving certain social objectives.

The methodology in the experimental phase of the research project in Italy and Sweden may be considered to be a fundamental resource, to be disseminated as a form of good practice in the countries where it was found difficult to elicit a response on the part of the relevant actors. The experience gained in this project and the results obtained lead us to believe that this experimentation provides an effective approach for the dissemination of the results obtained and for engaging the EU countries in a reflection on the outcomes that a research project of this kind can achieve in terms of raising awareness among

employers, the social partner organisations, workers, associations and other actors.

One of the difficulties encountered was undoubtedly that of the existence of so many languages at a European level. The fact that a number of documents were available only in the original language (and not in languages other than English) gave rise to problems in terms of making the documents available on the websites of various ministries, trade unions, employers' associations and voluntary associations in various countries. This sort of invisible barrier gave rise to unexpected delays in the sharing of the material since a considerable effort was required to translate the summary reports or country profiles into English, in order to make them available to the researchers involved.

However, the contacts made available by the Adapt and Europa Donna network, and by the partners involved in the various phases, enabled us to gather documentation and information relating to the following States (see Chapter 3): Austria, Bulgaria, Denmark, Finland, France, Germany, Hungary, Italy, Lithuania, the Netherlands, Portugal, Romania, Spain, Sweden, the United Kingdom.

A leading partner in terms of commitment to the project, both in terms of its size, and its political and administrative influence in Italy, was the Milan City Council, which played a key role in distributing the questionnaire to a large population of possible respondents (see Chapter 4), consisting of the employees of the Council. One of the most effective forms of support of Milan City Council was to involve the experts from the statistical office, who carried out a methodological analysis in the design phase of the questionnaire. The later stages of the project saw the involvement of the central administrative offices, and the councillors for employment policy and health programmes, in order to deal with all the necessary steps: the involvement of the directors of the various departments, an information campaign among the employees on protective measures for workers with an oncological condition, and the administration of the questionnaire.

During the project further support came from Roche Italia, a leading pharmaceutical

company that is part of a European group that plays a major role in oncological diagnostics and treatment. Roche Italia made available its human resources and financial support to implement the administration of the question among the employees of the Pharmaceutical Division in the establishment in Monza and in the production facility in Segrate (Milan), and also among the employees of the Diagnostics Division. In addition, thanks to the active support of Roche Italia, it was possible to set up a collaboration with the Swedish subsidiary of Roche, and to launch and experimental information campaign among the employees on the existing protective measures for workers with an oncological condition.

Both in the case of Milan City Council, and in the case of Roche Italia and Roche Sweden, it was possible to experiment with and fine-tune an innovative working method: a training and information programme run by the Adapt experts in the various organisations taking part, with the participation of the human resources managers, and the other managers responsible for health, employment policies and internal communication.

This initial phase was found to be indispensable in dealing with a certain degree of suspicion about the issue, and for setting up an active partnership network that is continuing to work on the project objectives, although officially the project actions have now been completed.

Before the research project was launched the topic was practically unknown to human resources experts and industrial and labour relations operators, as shown at a comparative level by the collective agreements that were examined and, more generally, by the fragmentary and incomplete nature of the legal provisions that have been adopted. It may therefore be claimed that, in spite of the difficulty of raising awareness of the issue among company managers and trade union officials, the impact of the project was extremely significant since, for the first time the labour relations experts in the countries taking part now have a series of factsheets and studies providing an overview of the rights of workers with cancer.

In particular, even before the resolution of the European Parliament of 10 April 2008, our research group had proposed drafting a code of ethics to submit to the European Commission (see Chapter 4). In addition, we set up a series of interdisciplinary exchanges that finally made it possible to bring together different areas of expertise that previously did not communicate among themselves and that now have access to scientific protocols and a shared language.

As mentioned above, taking account of the lack of awareness and limited knowledge of the isse on the part of the social and industrial relations actors, the actions taken so far point to the need to adopt, as requested by the European Parliament, practical initiatives to provide training and information aimed at involving the actors in the industrial relations system in the management of the problem of the protection of the women and men with an oncological condition in the workers.

Considering the importance of the topic and the ethical dimension of the proposals put forward, it is clear that the Resolution deserves to be implemented. In addition, discussion of the topic should not be restricted to a small circle of experts. The strategy proposed by the European Parliament includes a mainstreaming approach: in other words, the question of cancer should not be considered to be only a specialised and technical matter.

The resolution calls for an integrated and holistic approach to the problem and possible responses to it, and this was the position taken by many of the partners during the implementation of the project. This means achieving a better integration between the multiple aspects, not only clinical, psychological and diagnostic, but also the social and clinical dimensions of cancer. Oncological conditions are generated by many factors and appear in various stages. It is for this reason that it is essential to work towards a new paradigm of cancer prevention concentrating in a balanced manner on the causes relating to lifestyle and personal habits, and on occupational and environmental factors, thus reflecting the actual combition of different factors, instead of concentrating only on isolated factors and remedial treatment. All of this was taken into account in the draft

Code of Good Practice, reflecting the opinions of those who responded to our appeal for support.

Adapt firmly believes that the promotion of industrial relations aimed at the active inclusion of these workers is an essential part of the modernisation of the labour market and the European social model promoted by the Lisbon Strategy, in which well-being, health and safety take on an absolute value for all age groups and social categories, bringing benefits in terms of higher levels of productivity, competitiveness and prosperity. The implementation of Article 152 of the Treaty on European Union, dealing with health matters, has always been based on a mainstreaming approach, due to the fact that health and well-being are indispensable for a better quality of life, and this is a precondition for the advancement of the economy and undertakings.

It is the intention of Adapt to continue with the work undertaken with this project, and to bring together the materials produced, and to publish them together with a series of draft "provisions" to be submitted to the Commission and the social partners at European and national level for the purposes of implementing them in collective agreements or in legislative measures.

Adapt is planning to publish studies both in Italian (in the Adapt-Marco Biagi Foundation series, published by Giuffrè<sup>3</sup>) and in English (*The International Journal of Comparative Labour Law and Industrial Relations*, Kluwer Law International<sup>4</sup>) thanks to the contribution of the researchers taking part, in the belief that it is not sufficient to conclude the project with a draft code of good practice but it is necessary to pursue the fundamental objective of fostering the dissemination and consolidating best practices and guidelines in order to make the provisions for workers with an oncological condition

<sup>&</sup>lt;sup>3</sup> The studies published in the ADAPT / Marco Biagi Foundation book series are supplemented with web-based materials, providing additional documentation and allowing for a constant updating of the contents of the publication. All the material is continually updated by means of the ADAPT newsletter.

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<sup>4</sup> The International Journal of Comparative Labour Law and Industrial Relations is an important forum for the international academic community, publishing peer-reviewed papers on labour law and industrial relations in the European Union and globally. Recent issues have included papers on developments in Australia, Canada, China, Israel, New Zealand, South Africa and Tanzania, as well as the EU, including the new Member States.

more effective, by means of a number of specific initiatives that have not yet been put in place:

- the involvement of institutional actors who serve as a bridge between the world of work and the trade unions on the one hand, and the associations providing support for people with cancer on the other, enabling these actors to play a wider role and enabling them to take part in talks with company management with a view to improving the conditions laid down in the employment contract and the organisation of working hours, in order to strike a balance with the need to take time off for diagnostic procedures, treatment and rehabilitation;
- measures to enhance the role of these institutional actors in disseminating information about legal provisions and social security benefits for supporting workers who have or have had an oncological condition.

These actions are continuing both in Italy and in Sweden, even after the completion of the official phase of the project, thanks to the response elicited among human resources managers, labour consultants and among the public at large.

Requests have been received from many organisations asking us to provide speakers and testimonials for conferences in order to outline the project objectives and to disseminate the code of good practice. For this reason, together with the other partners, Adapt has decided to follow up with further action based on the initiatives taken so far.

In the short term, the project will be presented at an international level in the form of a seminar as part of the Seventh Annual Conference in commemoration of Prof. Marco Biagi, to be held in Modena, Italy, on 19-20 March 2009.

**Brief outline of activities** 

The project on Promoting new measures for the protection of women workers with

oncological conditions by means of social dialogue and company-level collective

bargaining, was implemented in three main phases on the basis of the timeframe initially

laid down.

Phase One – Research phase concerning the issues arising from the employment

conditions of people with oncological conditions, and in particular women with

breast cancer.

Period: 5 November 2007 - 31 March 2008

In this phase we organised the public presentation of the project to the parties concerned

and to the general public. The event coincided with the Sixth International Conference in

Commemoration of Prof. Marco Biagi on Workers' rights protection in a new world of

work, The case for a comparative and interdisciplinary approach to Labour Relations,

Modena (Italy), 17-19 March 2008.

During this Conference, attended by delegates from every continent, a Special Forum was

held to discuss this topic, with the participation of international scholars and researchers,

and the project partners. A monographic study was distributed to all the participants to

provide an initial outline of the legal provisions at national level: Adapt Dossier no. 3, 4

March 2008, on the rights of workers with an oncological condition (in Italian), edited by

Rosa Rubino, Isabella Spanò, Chiara Todeschini. In addition, the Dossier was made

available on the website and sent to some 6,000 subscribers to the Adapt newsletter

(Bollettino Adapt).

In this phase the subsequent work plan was more clearly defined and work began on:

the study of legislative and collective bargaining provisions facilitating the

return to work and safeguarding career prospects and employment rights of

workers with cancer in line with European Union equal opportunities

policies;

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the first draft of a Country Profile for each of the Member States analysed;

the analysis of the social and individual career development implications

associated with oncological conditions;

the design and testing of the questionnaire;

the construction of a special section on the website www.fmb.unimore.it

promoting the project, both in Italian and English.

Phase Two – Involvement of the social partners.

Period: 1 April 2008 - 30 June 2008

Starting from the first phase the social partners played an active role in gathering

materials and giving critical opinions on the existing provisions allowing workers with

oncological conditions to return to work, and to strike a balance between working hours

and time off required for medical treatment.

For each country submitting materials, a definitive Country Profile was drafted providing

an overview of the provisions already in place and an initial assessment of their

effectiveness. In order to facilitate an exchange of information with all the international

partners and researchers, these Country Profiles were all translated into English and

posted on a special section of the website www.fmb.unimore.it.

In this phase two important events were planned, to be held in a later phase: first, the

presentation to the President of the Republic of Italy, Giorgio Napolitano, of a Manifesto

on the rights of people with cancer, promoted by LILT (the Italian Association against

Cancer), with the participaton of Adapt, the Marco Biagi Centre for International and

Comparative Studies, the Marco Biagi Foundation, Europa Donna Italia) and a workshop

for an in-depth study of the issues with the Europa Donna partners that was held in

Brussels at the end of July.

In this phase numerous meetings were held to disseminate the activities taking place and

to extend the network supporting the project. In addition, planning meetings were held

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with the organisations that had agreed to administer the questionnaire, and these continued also in the subsequent phase.

Phase Three – Drafting of the research report and dissemination of the results.

**Period: 1 July 2008 - 4 November 2008** 

In this phase the Dossier presented at the March conference in Modena was updated, with the publication of Adapt Dossier no. 6, *The Rights of Workers with Oncological Conditions*, edited by Alessandra Servidori and Michele Tiraboschi, to raise awareness about the project, also in an international dimension.

An integral part of this phase was the drafting of a Code of Good Practice for the protection of workers with an oncological condition. This document was closely linked with the results achieved in the comparative research and negotiation phase between the partners involved.

The Code of Good Practice was presented to the press and the general public by means of an international conference organised in Milan the 20 October 2008, with the participation of Milan City Council and the Minister of Labour and Health. All the project activities and documentation were made available on the website <code>www.fmb.unimore.it</code> (Italian and English version) and widely disseminated. In this phase all the steps relating to the administration of the questionnaire were implemented in Sweden and Italy (see Chapter 4, <code>Employment</code> and <code>oncological</code> conditions).

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# Chapter 2

### The Condition of Women with Breast Cancer

Sara Mignoli, Maurizio Montella, Michele Tiraboschi

### 2.1. The physical consequences of surgical treatment of breast cancer

In medical terms, the surgical removal of the breast results in a modification of the structure of the thorax, depending on the weight of the organ and the extent to which muscular tissue is removed. This can result in an alteration in the balance between the left and right hemithorax: the vertebral column has to work harder on the side where the breast is still present, compared to the side where it has been removed. This can lead to strain on the vertical column, respiratory problems, problems relating to movement, and the insurgence of back pain and arthrosis. The condition of the patient will worsen in cases where there is osteoporosis and loss of muscular strength associated with the menopause, resulting in a weakening of the thorax due to loss of bone tissue, and to the lack of support from the chest muscles.

The removal of one or all of the lymph nodes from the axillary region, especially in the case of women who have undergone a radical mastectomy, can result in the appearance of a type of oedema known as lymphoedema *of the* upper limb after axillary node dissection. "The oedema is caused by the difficulty of lymph drainage, as a result of the removal of the axillary lymph node; [...] The lymph drainage gradually improves when collateral channels come into operation".<sup>5</sup>

Taking account of the fact that the incision of muscular tissue, the removal of one or more lymph nodes, and the resulting scar tissue can give rise to pain, restricted movement, and a lack of lymphatic drainage, for the purposes of proper anatomical rehabilitation, it is essential to assess the mobility of the upper limb and shoulder in order to reduce the level of pain for the patient after surgery. In addition, there is a need to deal with inadequate posture and breathing, to reduce the risk of secondary damage due to the lack of mobility, and to enable the limb to rapidly resume its normal function,

<sup>&</sup>lt;sup>5</sup> G. RICCI, M. LISE, *Chirurgia per infermieri professionali*, Piccin, Padua, 1980, 285-286. 33

reactivating the collateral lympho-venous channels. The patient will also need to take certain precautions to protect the limb on the side where the axillary lymph nodes have been removed in order to guard against immobility, irritation, infection and trauma. In particular it is advisable not to hold the arm in a downward position for long periods as this tends to reduce the drainage of the lymph nodes. In addition it is important to avoid carrying out heavy repetitive manual work. In cases in which the arm starts to feel heavy, the patient should take a break and rest her arm on a cushion at shoulder level in order to facilitate the drainage of the lymph nodes.<sup>6</sup>

# 2.2. Psychological and social aspects.

From the description in section 1 it should be clear that the physical condition of women who have had breast surgery will have an impact on their return to work. Full rehabilitation is achieved only when the woman recovering from breast cancer manages to achieve a balance with regard to the psychological and social changes taking place in her life due to surgery.

Whereas in the early phases of breast cancer the immediate concerns are the diagnosis, surgical treatment, and follow-up treatment, once the operation has taken place, there is a strong awareness of the amputation that has been carried out, with feelings of frustration, guilt and anger, at times directed against the self, and this has an impact on relations with those closest to the woman who has undergone surgery.

The psychological and social dimension of daily life has a strong impact on the self-esteem and the quality of life of every individual, but especially so for those who have had an oncological condition. The numerous experiences and individual histories collected by Europa Donna<sup>7</sup>, in all the European states where it is active and also in those

<sup>&</sup>lt;sup>6</sup> M. A. NOSENZO, "Attività possibili e mansioni post-operatorie sconsigliate", in *Tumore al seno e tutela delle lavoratrici*, December 2005.

<sup>&</sup>lt;sup>7</sup> This is a movement set up in 1991 by the oncologist Umberto Veronesi to combat breast cancer and to raise awareness of the issue among the general public. Its main aim is to draw attention to the need to deal with breast cancer with adequate resources and in an effective manner, by collecting information and knowledge from the 41 European countries taking part in the campaign against breast cancer, and disseminating information by means of cultural and scientific exchanges. For more information www.europadonna.org.

where it is not<sup>8</sup>, clearly show how important it is for women who have, or have had, breast cancer, to continue in employment. Returning to work provides confirmation of their role as active and productive members of society, looking ahead to the post-operative phase of their lives. The return to work for women who have had breast cancer can be part of the transition to a state of well-being, even though women may find that returning to the labour market is not particularly easy, either in physical or psychological terms, due to the feelings of tiredness that they may not have had before, and which they try to conceal, and due to anxiety about the oncological risk, which remains a constant factor.

From psycho-oncological studies<sup>9</sup>, casting light on the psychological, social and interpersonal aspects of this condition and the related treatment, it is clear that oncological conditions and employment are linked by the fact that whereas work plays an ethical role and is an essential part of the woman's existence, enabling her to maintain social relations and to support herself, the oncological condition gives rise to a loss of precious resources, such as emotional stability, personal and social relations, career prospects, economic stability, and so on.

In the case of breast cancer, gender also clearly plays an essential role: in relation to oncological conditions, there is a tendency for men to react first of all by trying to obtain information about treatment and medical procedures, whereas women focus their concerns in particular on the emotional aspects, and on the impact the condition will have on other members of the family. This tendency appears to be reflected in the working environment in the preconception, that is strongly rooted in Western culture, that associates the male sex with determination, strength, emotional control, and the ability to play an active role, whereas the image tends to be of women as fragile, week, with a lack of control over their emotions.

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<sup>&</sup>lt;sup>8</sup> Austria, Belarus, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Georgia, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Kazakhstan, Latvia, Lithuania, Luxembourg, Malta, Moldavia, Monaco, Norway, the Netherlands, Poland, Portugal, Romania, Russia, Serbia and Montenegro, Slovakia, Slovenia, Spain, Sweden, Switzerland, Turkey, Ukraine, the United Kingdom.

<sup>&</sup>lt;sup>9</sup> In this connection see the paper by GRASSI L., "Aspetti psicologici del ritorno al lavoro", in: *Tumore al seno e tutela della donna lavoratrice*, Conference Proceedings, Bologna, November 29-30, pp. 5-8.

In this perspective, the proposal by an employer to assign the worker to other duties on a temporary basis may be misinterpreted as an attempt to exclude her from her functions or to put pressure on her to leave the company, with a negative impact on the quality of human relations in the workplace. Ideally, the assignment to new duties should be jointly agreed by the employer and the employee, after all the relevant information has been made available, highlighting the challenges the employee has to face, and at the same time safeguarding the interests of the employer, who needs to be sure the tasks assigned to the employee will be properly carried out.

Unfortunately, the lack of awareness and understanding of the problem and its human and social implications can give rise to the emotional responses of the employee being stigmatised: in many cases, women returning to work are aware of a change of attitude on the part of the employer and other workers, and this change in attitudes can be hard to deal with.

Moreover, when an assignment to other duties is not an option, the woman risks dismissal. Recent studies have shown that one-fifth of women who have or have had breast cancer do not return to work, even when they are certified as medically fit, and that women in particular may find they are earning less and may also be subjected to harassment or mobbing.

Although the official statistics provide only a partial indication of the percentage of women workers who are obliged to quit after a diagnosis of cancer, the numerous personal accounts collected by Europa Donna<sup>10</sup> show that this is one of the key issues that women have to face in the post-operative phase. In many cases a change in attitudes towards women who have had breast cancer may be the first step towards behaviour such as harassment. Relations with the employer and with other colleagues may lead to cases of mobbing, when there is a general lack of reliable information that gives rise to acts of discrimination against workers with cancer. In the case of women with breast cancer, these acts of discrimination arise as a direct consequence of the oncological condition and

<sup>&</sup>lt;sup>10</sup> Many of the individual accounts that were used for the drafting of this section are to be found on the Europa Donna website, Europa Donna, <u>www.europadonna-italia.it</u>.

are intended to put pressure on the woman to quit, since she is no longer considered to be productive but rather a burden on the company or organisation, which unexpectedly finds itself employing "a cancer patient" or "an ex-cancer patient" who would be well advised to stay home and enjoy her freedom. The question that may be asked is: What good comes from overcoming cancer when the woman's life breaks down, and everything that she has worked for over the years, often at the cost of great personal sacrifice, comes to nothing? The woman is no longer considered as an individual, but is labelled on the basis of the part of her body that developed cancer. This is not a matter of her own choosing.<sup>11</sup>

It is clear that discrimination against women workers who have or have had breast cancer, in particular in the form of an unjustified assignment to lower-grade tasks, tends to force them to leave their jobs, as they are considered to be no longer productive. These workers are assigned to tasks that require very little commitment on their part and a low level of responsibility. The fact that they are forced out of the production process, and in general no longer play an active role in society, may result in depressive illness. It is important that women who have managed to get over the acute phase of their illness are given a useful role to play on their return to work, and that they should not be treated as if they were dead when they can still contribute a great deal to society.

# 2.3. Problems relating to the management of the employment contract.

The problems concerning women with breast cancer, or who have had breast cancer, when they return to work are of various kinds. These include not just the physical consequences of the necessary surgical treatment (section 1 above), and the psychological and social aspects (section 2 above), such as the difficulties encountered by woman who are required to lift heavy objects or to adopt a particular posture, and the attitude of the employer and the other employees, but they also concern the problems arising from the absence from work and the return to work in the management of the employment contract.

 $<sup>^{11}\ \</sup>underline{www.europadonna-italia.it}.$ 

Relations with the employer may be subject to stress, reflecting the difficult situation in which the worker finds herself, both during the acute phase of the illness, when the treatment gives rise to the need for long and repeated periods of absence from work, and in the subsequent phase, when the problems of rehabilitation and the return to work have to be dealt with. Many employers are not capable of dealing with the problems of women who have, or have had, breast cancer. In this situation there is a need to strike a balance between the requirements of the company and the time necessary for medical treatment, and the need for retraining and re-employing the woman when she returns to work.

The survey carried out by *Astra Ricerche*<sup>12</sup> for *Europa Donna Italia*, on "The psychological, social and occupational repercussions of breast cancer", analyses the psychological, social and occupational consequences of breast cancer surgery of more than 500 women who underwent surgery between 1980 and 2006, in nine oncological centres<sup>14</sup> that took part in the survey. In relation to the women who were active in the labour market prior to their operation, accounting for 62% of the sample, the figures show that more than half of those interviewed, 52%, found that there were no significant repercussions from the operation: the work they carried out was the same as before, without any major differences. One significant finding was that a quarter of the women who were employed prior to their operation made further progress in their career, or managed to reach a mutually satisfactory agreement with their employer. On the other hand, 21% of these women workers reported a significant worsening of their condition. In response to a specific question on this issue, 65% of the women who had had breast surgery reported no significant impact on their employment status, whereas 32% reported

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<sup>&</sup>lt;sup>12</sup> Astra is a consultancy firm set up in 1983. In 1992 it was further developed and enlarged, covering such areas as marketing strategy, market positioning studies, the evaluation of brand names and companies, social research, marketing and medium-term forecasting in the most dynamic market sectors. Further information is available at: <a href="https://www.astraricerche.it">www.astraricerche.it</a>.

<sup>&</sup>lt;sup>13</sup> Research by Astra Ricerche commissioned by Europa Donna in January 2006, carried out between June and December 2006 by means of questionnaires filled in by the respondents, based on a sample of women undergoing breast surgery between 1980 and 2006 who were contacted by the oncological centres where the mastectomies were performed.

<sup>&</sup>lt;sup>14</sup> The following oncological centres took part in the study: Azienda Ospedaliera di Padova; Azienda Ospedaliera Sant Andrea di Roma; Azienda Ospedaliera Sant Elia di Caltanissetta; Centro per lo Studio e la Prevenzione Oncologica di Firenze; Istituto Europeo di Oncologia di Milano; Istituto Nazionale Tumori Regina Elena – IRCCS di Roma; Istituto Tumori "Giovanni Paolo II" – IRCCS Istituto Oncologico di Bari; Ospedale Morgagni Pierantoni di Forlì; Presidio Ospedaliero Universitario di Sassari.

negative effects as a result of their condition.<sup>15</sup> These effects were mentioned above all by those in a weak position in the labour market<sup>16</sup>. In this connection, there is a need to adopt effective measures to improve work organisation and to facilitate a work-life balance by means of a reorganisation of working hours, sick leave and annual leave. Measures are needed to enable women to remain in employment and to return to work after receiving their treatment, and to continue to receive health insurance, social contributions and pensions contributions. It is important to point out that this protection should not be limited to the worker with cancer but should be extended also to the family member taking care of the worker with cancer, who has been chosen to provide support in a particularly difficult physical and psychological phase.

The support of the family of the worker with cancer is essential to be able to deal with problems of this kind: the worker with cancer should have the right to choose a non-professional carer from his or her family who can provide support in this difficult phase. At the same time, this family member should be able to choose whether to carry out this role on a full-time or a part-time basis, and to be able to do so in a way that is compatible with his or her work. The surgical treatment for cancer and the subsequent life-saving treatment to combat the illness require a considerable amount of time and periods of sick leave. As a result, it is necessary to adapt working hours to the need for medical treatment, taking account of the difficulty of organising the work to be performed in a flexible manner, conciliating the needs of the worker and of the employer.

Part-time employment would appear to be the most effective way to conciliate the needs of the employer to remain competitive, with the needs of the worker to receive medical treatment, especially women with breast cancer. The flexible organisation of working hours, in terms of the total number of hours and their distribution can facilitate greater

<sup>&</sup>lt;sup>15</sup> For an in-depth account, reference should be made to the research report at su <u>www.europadonna-italia.it</u>.

<sup>&</sup>lt;sup>16</sup> Of this 32%, 39% were in the 45-54 age range; 46% were resident in southern Italy (Campania, Puglia, Basilicata, Calabria, Sicily) and 39% in the centre of Italy (Liguria, Toscana, Emilia-Romagna, Marche, Umbria); 53% were salaried employees, and 48% had only primary schooling or no educational qualification.

social inclusion and the conciliation of different interests, not only in the case of workers with breast cancer, but also for other workers with a serious medical condition.

# 2.4. Oncological conditions and breast cancer: implications in the world of work. The Italian model

In Europe, breast cancer accounts for 22% of malignant tumours among women.<sup>17</sup> This type of cancer is the most frequent among women, affecting 27% of these who with malignant cancer. Italy has 30,000 cases, with a mortality rate of approximately 1 in 3. In the course of her lifetime, one woman out of 10 suffers from breast cancer. Although these data are cause for grave concern, we need to take into account that this type of cancer has the highest survival rate: the European Institute of Oncology, reported that 90% of patients recover from cancer.<sup>18</sup> This is a serious issue that needs to be considered, along with its implications for the patient's social life.

In combating cancer, especially breast cancer, there are two factors that help to treat the disease. Undoubtedly, an early diagnosis is fundamental to make possible effective and immediate treatment. But it is also important to have a positive state of mind, allowing patients to receive treatment and to reduce the effects on their life, especially working life. <sup>19</sup> If we also consider that women today play a leading role in social and working life, the workplace becomes a key site of engagement. For this reason, a new policy on Corporate Social Responsibility (CSR) has been developed recently, mainly with the aim of setting up a communication network in relation to the disease. <sup>20</sup>

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<sup>&</sup>lt;sup>17</sup> For an overall analysis of cancer trends in Italy, reference may be made to: E. Crocetti, R. Capocaccia, C. Casella, S. Ferretti, S. Guzzinati, S. Rosso, C. Sacchettini, A. Spitale, F. Stracci, R. Tumino, "Cancer trends in Italy: figures from the cancer registries (1986-1997", in *Epidemiol Prevention*, March-April 2004, No. 2, Suppl., 1-112.

<sup>&</sup>lt;sup>18</sup> For an overall analysis of cancer mortality rates in Europe, see J.L. Botha, F. Bray, R. Sankila, D.M. Parkin, "Breast cancer incidence and mortality trends in 16 European Countries", in *Eur J Cancer*, 2003, 1718-1729.

<sup>&</sup>lt;sup>19</sup> In this regard, see S. Prestigiacomo, *L'impegno delle Istituzioni: diagnosi precoce e comunicazione*, and G. Sestini, *L'impegno delle Istituzioni: donne e lavoro*, in the meeting *La comunicazione sulla salute femminile. Un'opportunità di impegno sociale per le aziende*, held on 29 October 2004, in Milan.

<sup>&</sup>lt;sup>20</sup> In this connection, see *Green Paper – Promoting a European Framework for Corporate Social Responsibility*, presented by the Commission on 17 February 2001; the *ABC of the main instruments of Corporate Social Responsibility*, published by the European Commission in 2004; see also *Final report* &

Despite a number of awareness-raising campaigns promoting preventive screening, the initiatives facilitating access by women workers to preventive health services are still limited. This situation is partly due to the nature of Italian system of production, mainly characterised by small and medium-size enterprises that are reluctant to meet medical costs.21

There are also cases that show how the dignity and privacy of workers with oncological conditions is often affected, in contrast with existing laws and basic human rights (see the case reported by La Repubblica of a Chieti enterprise that posted a list of workers on sick leave for oncological conditions on the company notice board.<sup>22</sup>

It is also important to point out that, in the employment relationship, there are additional issues relating specifically to breast cancer treatment. In this connection, enterprises have difficulties in meeting the needs of the worker. In most cases, they are not prepared to deal with people with cancer. In addition to problems in reconciling productive needs and medical appointments, there is also a need to consider issues relating to vocational retraining and the return to work of women workers (this is mainly due a lack of information concerning this condition, such as the legal measures used to support women workers and their relations with the employer in this difficult situation. Once they overcome their breast cancer, they may also have to face prejudice and distrust, as well as inflexible working arrangements.

In this connection, the enterprise has to provide a lead, promoting the public interest in order to facilitate social development and cohesion, adopting a company policy to deal with all the issues relating to the health problems of women workers. In many cases the fact that a woman worker has been diagnosed with a serious medical condition is considered by the company as an immediate loss. To the company, she is useless and no

recommendations by the European Multistakeholder Forum on CSR, held in Brussels on 29 June 2004. With regard to the Italian position on Corporate Social Responsibility, see Il Contributo italiano alla campagna di diffusione della CSR in Europa, published by the Ministry of Labour and Social Policy.

<sup>&</sup>lt;sup>21</sup> For further details of good practices in CSR, reference may be made to Responsabilità sociale delle *imprese: esempi di buone pratiche italiane*, published by the Ministry of Labour and Social Policy in 2005. <sup>22</sup> "Gogna" in azienda per malati di tumore, in *La Repubblica*, 10 September 2005.

longer a productive worker. As a result, she may end up being forced out of the company.

### 2.5. The employment contract: the grace period

When a woman is diagnosed with breast cancer, she has to face a number of issues directly relating to the disease, as well as those linked to her current employment position. The surgical operations and life-saving treatments that are necessary to combat the disease require a considerable amount of time and sick leave, even after the worker has returned to work. This situation calls for suitable means to strike a balance between medical needs and working time.

In order to protect the right to health care (Articles 30 and 32 of the Constitution) and the rights of women in the labour market, and in order to reconcile their needs and those of the employer (Article 41 of Constitution), the law provides that during the grace period, the employer cannot dismiss the worker who has or who has had cancer. As a result, during the grace period, a worker with cancer will continue to receive remuneration, according to legal provisions, collecting bargaining, and the entitlements of the worker on sick leave. However, at the end of this period, and in any case in accordance with the rules on dismissal, she can be dismissed.

This is when women workers with cancer are particularly in need of protection, because they may need a grace period that is longer than the one provided in collective agreements. In this regard, a leading role is played by collective bargaining, that often fails to provide appropriate provisions for the grace period for employees with oncological conditions.

Collective bargaining has to specify the duration of the grace period, which depends on the worker's employment grade and length of service. The employer and the workers' representatives pay special attention to women workers with cancer only in a few cases. Especially in the initial stages of breast cancer workers need to take time off for treatment and need flexible working time, some national collective bargaining agreements have made specific provisions for the grace period. This shows how collective bargaining could take responsibility for the issue, by proposing suitable provisions.

In the event of a serious condition requiring life-saving treatment, some public service collective agreements, for instance, provide for periods of hospitalisation, day-hospital treatment, and time off for treatment to be remunerated and not to considered as sick leave (in this regard, see Local Authority Collective Agreement 14 September 2000, the School Collective Agreement 26 May 1999, the Cassa Depositi e Prestiti Collective Agreement 2 July 2002, the Ministerial Collective Agreement 16 February 1999, at www.fmb.unimore.it, index A-Z, under the heading Patologie oncologiche e lavoro).

In addition, the legislator provides for the grace period to be extended, by granting special leave that can be added to the existing period provided by national collective agreements. Act No. 104/1992 allows women workers to take leave in order to receive medical treatment. This right is also granted to the worker's relative who looks after her during treatment.

A worker with cancer is entitled to two different types of benefit: some of them are provided in the case of permanent disability, others in the case of "disability of a grave nature". An application for disability benefits can be submitted by all women who have undergone a quadrantectomy, a mastectomy or a simple tumorectomy, and this recognition is necessary to obtain social benefits and working facilities.<sup>23</sup>

In case of the recognition of "disability of a grave nature" Article 33, Act No. 104/1992 provides that the worker is entitled to two hours' leave a day, or three days' leave a month. The law allows the worker to choose the place of work that is closest to her home, wherever possible; it also establishes that the employer must not transfer her to another place of work without her consent. Finally, in cases in which the worker has a percentage of invalidity greater than 50%, she also has the right to take up to 30 days' paid leave a

<sup>&</sup>lt;sup>23</sup> For further information about how to evaluate disability and the facilities provided, see the interview with E. Quaglia, "Invalidità civile e tumore del seno", in *Europa Donna Informa*, 2002.

year, not necessarily on a continuous basis, for medical treatment relating to her condition.

The regulation was supplemented by Article 3-bis added to Article 6 of Legislative Decree No. 4/2006 and the conversion No. 80 of 9 March 2006. Pursuant to this provision, a medical panel has to assess the oncological patient's temporary disability in the acute stage within 15 days of the submission of the application. Moreover, the result of the assessment enables the worker to receive benefits immediately.

With reference to the 30 days' leave granted for medical treatment, and the related remuneration and benefits, the Ministry of Labour issued an opinion on 5 December 2006 in reply to a request for clarification on the part of the General Confederation of Italian Crafts of Prato. Referring to the consolidated view taken by the Court of Cassation, the Ministry established that absence due to a medical condition is covered by Article 2110 Civil Code, and therefore it must be calculated as paid leave. On the other hand, social security benefits are not paid, because they are subject to the provisions of the National Institute of Social Insurance relating to solar, climatic, and thermal treatments.

# 2.6. Part-time employment: the right to change the employment contract introduced by the Biagi Act in favour of workers with cancer

The need to conciliate medical treatment and working time, to give the worker the opportunity to protect her right to work and to receive medical treatment, cannot be dealt with only by the provisions concerning sick leave. Protection of the employee is also necessary in the initial stages of the condition, and immediately after the return to work. One of the main issues for both the worker and the employer is to organize the employment relationship in a flexible and suitable way, trying to respond to the needs of both parties. In order to facilitate agreement between the parties, a step forward was taken with the changes provided in the regulation of part-time work, through Article 46 of Legislative Decree No. 276/2003 implementing the Biagi Act on labour market reform.

It is important to remember that part-time working is not particularly widespread in Italy, whereas it is frequent in the other Member States of the European Union.<sup>24</sup> The flexible organization of working time, in terms of the total number of hours and their distribution, has facilitated the social inclusion of women.<sup>25</sup> With reference in particular to workers with breast cancer, and considering the main purposes of the regulatory scheme, Article 46 (1) (*t*) of Legislative Decree no. 276/2003 allows workers with oncological conditions, whose working capacity is limited especially due to the effects of life-saving treatment, the option to change from full-time to part-time employment (Article 46 (1) (*t*) of Legislative Decree no. 276/2003 provides supplementary provisions in relation to Article 12-bis, Legislative Decree No. 61/2000).

For women with breast cancer, the advantage of part-time employment is that it makes it possible to reconcile the employer's need to maintain industrial competitiveness with the worker's need to remain in employment. The Ministry of Labour and Social Policy brought attention to this objective in Circular no. 9, 8 March 2004.

The entry into force of Legislative Decree no. 276/2003 was generally welcomed by the social partners, who have implemented it in many recently renewed collective agreements Mention should be made, by way of example, of the TV and Radio Collective Agreement, 25 April 2005: Article 45 of this agreement provides the right to change over from full-time to part-time employment; the Film Distribution Cooperative Collective Agreement of 2 July 2004; the General Confederation of Italian Commerce and Tourism Collective Agreement of 2 July 2004. These agreements are available at www.fmb.unimore.it, A-Z Index, Patologie oncologiche e lavoro.

The right of workers to change from full-time to part-time working is an individual right,

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<sup>&</sup>lt;sup>24</sup> For detailed information relating to part-time work in Europe, see European Commission, *Employment in Europe 2002*, DG Employment and Social Affairs. See also M. Tiraboschi, "La disciplina del lavoro a tempo parziale, un quadro comparato di sintesi", in M. Biagi (ed.), *Il lavoro a tempo parziale*, Il Sole 24 Ore. Milan. 2000.

<sup>&</sup>lt;sup>25</sup> For an in-depth study of part-time work, and the way it has been modified by the Biagi Act, see A. Russo's comment, "Il lavoro a tempo parziale", in M. Tiraboschi (ed.), *La riforma Biagi del mercato del lavoro. Prime interpretazioni e proposte di lettura del d.lgs. 10 settembre 2003, n. 276*, Giuffrè, Milan, 2003, 179.

and it is aimed at safeguarding the worker's health and employment. For this reason, the law considers it to be a right that should always be granted.

The parties have to agree on the reduced working hours, and the distribution of hours over a certain number of days. Considering the rationale of the law and the individual nature of the right, however, it can be assumed that working time will be organized on the basis of the worker's specific individual needs.

Article 46 of Legislative Decree no. 276/2003 also lays down that a medical panel of the local health authority has to certify the worker's state of health. Furthermore, in order to safeguard the right to work, the law provides that the worker has the right to change back from part-time to a full-time working. Some commentators have considered the rule as unconstitutional; its selective criteria and its scope only in relation to people affected by oncological conditions would appear to violate the principle of equal treatment, because it does not apply to people with other pathologies, who need flexible working hours for medical treatment.<sup>26</sup>

Paragraph 44, Act No. 247, 24 December 2007 incorporates Article 46 of Legislative Decree No. 276/2003. The fact that the principle laid down in the Biagi Act was incorporated in its entirety shows the effectiveness of this rule. However, Act No. 247/2007 extends the rights granted to women workers also to their relatives – partners, parents, children – as well as to their cohabitants, if the worker has a permanent and total incapacity for work that has been assessed as "serious" pursuant to Act No. 104/1992 and if the worker has a total permanent invalidity. This extension is, however, limited in scope, because in this case the change from full-time to part-time work is no longer a right, but an option.

The other provision contained in Act No. 247/2007 is important, yet rather enigmatic in its wording: a worker, either a man or woman, who has changed to a part-time contract

<sup>&</sup>lt;sup>26</sup> In this connection, see S. Scarponi, *Il lavoro a tempo parziale*, Working Paper C.S.D.L.E. "M. D'Antona", 2004, n. 31, and the references therein.

"has priority in opting to change to full-time employment in which he/she performs the same duties as those relating to the part-time contract".

# 2.7. Protection against mobbing and harassment

In addition to the issues relating to the management of working time, the worker with breast cancer also has to face other difficulties, linked to her relationship with her employer and colleagues. In addition to a widespread lack of information and awareness of the issue, in many cases the worker is subject to various forms of discrimination, which in some cases can be considered as mobbing.

What is known as "strategic mobbing" is often a direct result of the diagnosis of the disease. It is aimed at putting pressure on the worker to quit, because she is considered no longer productive by the enterprise, that is concerned about costs.<sup>27</sup> In many cases the worker is considered to be unproductive, and pressure is brought to bear to encourage her to quit. At present, the protection of workers subject to harassment of this kind is governed by a variety of rules (concerning transfers, discrimination, equality of treatment, etc.) that are mostly applied in the workplace, provided by Article 2087 Civil Code, which establishes that employer is required "to protect the workers' physical and moral wellbeing".

Considering the wide range of rules regulating this matter and the protection laid down in Article 2087, a woman worker subjected to harassment of this kind will have difficulty in the case of litigation. In taking legal action she would have to demonstrate her employer and colleagues' poor behaviour, as well as providing evidence of the harm suffered.

In addition, even if the worker succeeds in making her case, she will be entitled to compensation only if the damage suffered is a proven consequence of harassment. Making a case is arduous, because the tort action, which is typical of harassment, is valid

<sup>&</sup>lt;sup>27</sup> In this regard, see A. Vallebona, *Mobbing senza veli*, and A. Corvino, *Mobbing: ne vale la Pena?*, both in *Boll. Adapt*, 2005, no. 34, at *www.fmb.unimore.it*, including the bibliographical references.

only if it is of an objective nature, and not based on the worker's specific psychological state. Workers with breast cancer are clearly in a vulnerable psychological condition.

In order to provide more effective protection for women workers subject to psychological stress in the workplace, a Consolidating Act on mobbing, presented to the Senate on 25 July 2005, was recently proposed.<sup>28</sup> In this way, greater protection against the harassment of women workers can be achieved.<sup>29</sup>

Although the legislation aims to provide more protection for mobbed workers, it does not seem to provide a definite response to all difficulties linked to this issue and to strategic mobbing towards women workers with breast cancer. Rather, the setting up of a committee consisting of employer and bargaining representatives, one of the changes provided by the proposed Consolidating Act, seems to be particularly useful for monitoring this issue.

The harassment or mobbing of workers with breast cancer is mainly due to a general lack of awareness of the condition.<sup>30</sup> Even in the case of prejudice, then, prevention appears to be the best cure, but prevention can only be ensured by effective corporate social responsibility, resulting from information and education activities. This is the only way to develop a corporate culture to help and to protect people with oncological conditions in general and breast cancer in particular.

### 2.8. The importance of information and education

Education and information can play a key role not only in cancer prevention, but also when the worker returns to work following treatment. For this reason it is important to draw attention to breast-cancer issues. In order to do this, awareness-raising initiatives

<sup>&</sup>lt;sup>28</sup> The proposal submitted to the Senate can be consulted in *Boll. Adapt*, 2005, no. 34; the Consolidating Act can be consulted in *Boll. Adapt*, 2005, no. 29.

For a critical examination of the measures contained in the proposal for a Consolidating Act, see A. Vallebona, *Mobbing senza veli*, cit., 6.

<sup>&</sup>lt;sup>30</sup> See G. Fiorentini, *La formazione di nuovi manager dell'impresa sociale*, part of the meeting on *La comunicazione sulla salute femminile. Un'opportunità di impegno sociale per le aziende*, that took place in Milan on 29 October 2004.

should concern both employers and women workers.

These initiatives should be aimed at facilitating continuity of employment for the worker, especially through an understanding of flexible working opportunities. Identifying the means to balance company needs and those of the worker might be useful to limit cases of strategic mobbing, together with an in depth-knowledge of cancer issues. Employers need to consider workers with cancer as a human resource that can serve the company in the future.

Awareness-raising initiatives should help working women to become acquainted with legal provisions to balance working life and medical needs and to support their return to work. This is particularly important for workers after a prolonged absence from work. By means of awareness-raising initiatives, we will be able to create an effective labour law for workers with an oncological condition in general and breast cancer in particular.

# 2.9. Prevention and early diagnosis of breast cancer: the role of social and cultural factors

Every year about 40,000 new cases of breast cancer are diagnosed in Italy. The probability of developing this type of cancer is 1 in 11, and about 6.3% of all women are affected. There are about 350,000 Italian women with breast cancer. Breast cancer is considered to be a condition for which a good deal has been done in terms of prevention and early diagnosis, but the interventions and results vary greatly in relation to the geographical area and other socio-economic factors. Thirty to forty years ago this condition was normally treated by means of radical surgery, with devastating consequences and modest chances of survival. Today it has become more treatable, especially in the case of early diagnosis. Today a patient with a tumour diagnosed at the initial stage has a 90% better chance of survival, and minimal aesthetic consequences. These results are due to the dissemination and effectiveness of early diagnosis, enabling women to recover without psychological or physical complications. The recorded

survival rate of women with breast cancer shows that strong regional imbalances exist in Italy. The survival rate is 10% lower in Southern Italy than in Northern Italy.

On the basis of these figures, it appears that there are major delays in prevention and diagnosis and an inadequate supply of social and health services. Evidently, in the South people have services of a lower quality from this point of view. The lack of breast-cancer prevention usually results in the postponement of the diagnosis (and treatment) by about three to six months. Late diagnosis of breast cancer is more frequent in the case of women defined as havintg access to lower quality medical programmes, belonging to the social categories with a low level of educational attainment and resident in rural or peripheral areas. These women normally have a shorter life expectancy compared to women who have an early diagnosis.

It may be argued that the delay in prevention and diagnosis is linked to the culture and level of education of people who live in peripheral areas or who are socially disadvantaged, and who often do not pay the necessary attention or do not recognise the first symptoms of cancer, especially in the case of superficial tumours (easily visible and diagnosable): the role of the patient and her relatives is fundamental in this regard.

In the US late diagnosis depends in part on racial or ethnic factors: it is normally women of Hispanic, black or Chinese origin who receive late diagnosis, while in Europe it depends more on geographical location and is more widespread in the South, where there are lower levels of social and economic development.

Late diagnosis depends on a series of factors that partly concern the women themselves; they are partly attributable to the medical practitioner who carries out the examination, and partly to the efficiency of the health system as a whole. The extent and participation in screening campaigns is also significant.

In the past 20-30 years in Europe there has been a progressive increase in the number of cancer cases diagnosed at an early stage due to the Europe against Cancer programme, a

European Union project aimed at reducing the mortality rate at the beginning of twenty-first century by means of a substantial investment in prevention, education and information campaigns. This programme has contributed to a decline in the number of cases diagnosed at a late stage.

In the oncological institution in Naples that hosts more than 600 new cases of patients with breast cancer, the number of T3-T4 cases (greater than 4 cm) has decreased from 15.5% in the period 1989-1991 to 3% in recent years; also T2 cases have decreased in the same period from 29% to 26%. On the other hand, the percentage of smaller tumours (less than 2 cm) has increased from 55% to 70% in the same period.

Since 2000 the Italian Association against Cancer (LILT) has reinforced its efforts in breast cancer prevention by launching the *Nastro Rosa* or Pink Ribbon campaign providing medical examinations free of charge and check-ups at LILT. Since 2000 the data demonstrate a further improvement, with T3-T4 tumours decreasing to 2% while T2 remain stable at 27%, and T1 cases have increased to 71%.

These results confirm the widespread belief that also in Southern Italy there has been an increase in the early diagnosis of breast cancer. In the North the increase was due to the efficiency of breast-cancer screening, while in the South it is due to the different attitudes to breast cancer of older women belonging to the disadvantaged classes, who have started to consider it only recently as a curable and preventable condition.

There are some peripheral areas where breast cancer is diagnosed at a late stage but it can be argued that overall the prevention campaign has had some success also in cases where screening services are inadequate, as in Southern Italy.

However, there are two new problems:

- the difficulty of improving the early diagnosis of T2 tumours, considering the age of women normally affected, as they are normally fairly young. In this case the mammography is not always trustworthy; in addition, psychological

- characteristics (and the proper training of healthcare professionals) are fundamental for determining the most successful outcomes;
- the difficulty of providing all women with equal treatment in terms of surgery and reconstruction.

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These difficulties can be partly overcome through the setting up of a network of different actors in the process of prevention, diagnosis and treatment (medical practitioners, breast-cancer specialists, hospitals, centres of excellence) for integrating and monitoring the different phases (diagnosis, treatment, follow-up).

In spite of the results achieved so far in terms of preventive diagnosis and the overall improvement of survival rates, it is necessary to continue to invest in prevention, research and health education in order to combat cancer in an effective manner.

## Chapter 3

Comparative analysis of good practices for workers with oncological conditions in the European countries

Simona Creazzola, Emmanuele Massagli, Rosa Rubino, Isabella Spanò

## 3.1. – Framing the issue

For workers with oncological conditions, a full recovery also means being able to return to work.

In order to receive medical treatment, workers with oncological conditions often need to take sick leave, and employers do not always know how to deal with these absences. For this reason, and due to the fact they may be unable to carry out their work, these workers may experience feelings of isolation and uneasiness. This is particularly true for women workers, who in many cases are already at a major disadvantage in terms of working conditions. Breast cancer, still the most common cause of death among women of working age, has major consequences from a physical and psychological point of view, but also in terms of employment.

A recent survey conducted in Italy and presented in Verona by AIOM (Italian Oncology Association) showed that 60% of women who had breast cancer have considerable difficulty in returning to work. Out of a total of 131 women, only 40 per cent in the 20 to 65-year age group succeeded in returning to work within 60 days of the diagnosis, while 74% of women workers return to work in the 24 months after they have been diagnosed with this condition

This issue has been given serious consideration by the European institutions and national associations, in order to provide legal, social and economic protection for workers with oncological conditions, by means of resolutions and agreements. Despite the fact they are not binding, these measures represent a valid instrument to encourage European countries to adopt specific provisions.

The most important are:

- the Charter of Paris (4 February 2000), which was signed at the New Millennium World Cancer Summit;
- the European Charter of Patients' Rights, which was drafted by Active Citizenship Network and 12 citizens' organizations (including the Belgian Federation against cancer) at the conference on *The Future Patient* (Brussels, 14-15 November 2002);
- the Joint Declaration on the Rights of People with Cancer (Oslo, 29 June 2002), and the European Guidelines for the Rights of People with Oncological Conditions, (Athens, 16 April 2005), which were approved at the general meeting of the European Associations against Cancer, ECL, (31 countries);
- the 2005 European Framework for of protection for sick workers, drafted, once again, by ECL;
- the European Parliament Resolution on breast cancer (5 June 2003);
- the 2007 Manifesto on *Preventing Cervical Carcinoma in Europe*, promoted by the European Association against Cervical Cancer, and supported by the International Association and the European Organization against Cancer;
- the European Parliament Resolution (25 October 2006), focusing on women workers with breast cancer;
- the European Parliament Resolution against cancer in the enlarged European Union (10 April 2008).

As we have seen, significant efforts have been made at a European level to provide legal protection for workers with these conditions. At a national level, however, limited attention is paid to the issue. In most cases, the new member states are still working to comply with EU policies in terms of protection. This is particularly true in those member states where health-care restructuring is still in progress. In these cases, research is given priority, and the establishment of social legislation safeguarding sick workers becomes a matter of secondary importance. It is in this context that for most of these countries accession to the European Union could become a real opportunity to cooperate in the field of medical research, to promote information campaigns, and to launch screening programs aimed at providing early diagnosis. In most of them, this is the only way to improve conditions for workers with cancer at the moment.

Another issue is whether social legislation in a particular country applies also to people with cancer, and if and when they are classified as disabled. In this connection, paragraph 34 of European Parliament Resolution (10 April 2008), "calls on the member states and the Commission to develop a common definition of the term 'invalidity', in order to include people with chronic diseases and cancer. It also calls on the member states which have not done so to classify them as people with disabilities".

In paragraph 35, "the Parliament formally asks the Commission to draft a charter for the protection of workers with cancer and chronic diseases, according to which enterprises should allow employees to maintain their job during treatment, also facilitating their return to work".

Whereas a number of countries have already met European standards in terms of legal protection (e.g. France, Italy, Spain, the United Kingdom), the classification of cancer as a disability in social legislation in the rest of Europe has not yet been implemented, as the definition of this term is not clear (e.g. Lithuania). In other cases, a panel of experts is entrusted with the task of assessing the state of health of the cancer patient, but procedures for certifying individuals as disabled are extremely strict. Furthermore, the type of legal protection is not the same for all countries, ranging from sickness benefits (Lithuania, Bulgaria), to individual return-to-work programmes (Germany, Finland, the Netherlands).

With so many variables, provisions relating to people with this condition are very few, and only concern the opportunity to change from full-time to part-time work (Italy, Germany), and to apply for sick leave (even though in many cases it cannot be extended as necessary, and the employee runs the risk of dismissal).

In order to record all cases of cancer, and to analyze the relationship between patients' social conditions (habits, lifestyle, etc.) and their condition, a considerable number of European countries have set up Cancer Registers. They have become a reality in the US,

because they are essential to monitoring the course of the illness. In this connection, see the website of AIRTUM, the Italian association of cancer registers, *www.registritumori.it*. These registers play a useful role, serving as an important source of date for research and for promoting health and safety at work. In this connection Finland, which set up the National Cancer Register in 1952, is in the forefront.

According to the available data, individuals on low incomes, manual workers, and those who are already at a distinct disadvantage (because of a lack of schooling, or racial discrimination) are more likely to develop cancer. Hungary is emblematic in this connection: Roma women with breast cancer, for instance, are three times more likely to die from this condition than other women.

In this context, citizens' organisations and voluntary associations need to play a leading role, especially because they promote early diagnosis. Statistics show that breast-cancer screening is an effective measure to combat this disease, and cancer mortality rates have fallen in those countries (France, Germany, the Netherlands, Spain and the United Kingdom) that have launched a screening campaign. The same cannot be said of Bulgaria and Denmark, that are still working to raise public awareness of the issue.

Scientific research is making a major contribution to combating cancer, also because of the high prevalence of this condition among women. More should be done, however, in terms of labour law. In this connection, the above-mentioned organizations are working to provide effective legal protection for individuals with this condition.

With regard to good practices, the World Health Organization (WHO) has supported new measures to improve the protection of workers' safety and health (Work Plan 2006-2010, Work Health Organization - Global Network of Collaborating Centers in Occupational Health). At a national level, a considerable effort has been made by local associations and entrepreneurs in terms of protection for women workers with cancer.

Europa Donna has promoted Cancer Day (15 October); in the UK, People Management has launched the campaign *Working through Cancer*, and Macmillan has drafted the *Management Guidance on Cancer in the Workplace* and a *Cancer Guide* (www.macmillan.org.uk). In addition, LILT has conducted a survey to estimate the out-of-pocket expenses for women with this specific condition. In Denmark, the Faroe Islands Society against Cancer has organized courses and seminars for women with breast cancer, while in Hungary, the Hungarian League against Cancer plays an active role in promoting screening.

There are many other examples of national good practices that are noteworthy. The key point, however, is to understand the importance of providing a benchmark for further research on breast cancer. In this connection, the conference in Milan at the end of 2008 offers a real opportunity to make people more aware of this issue.

## 3.2. General overview of legal protection for workers with disabilities

All the countries considered in the survey provide legal protection for workers classified as disabled by means of specific legislation, which applies at national level. However, providing a generally accepted definition of the term "disability" is a difficult task, because of considerable socioeconomic and cultural differences between the EU Member States. This is also due to significant differences in terms of administration, health, insurance, and social security systems between the countries. For more detailed information, please refer to the country profiles below. Generally speaking, the level of disability is calculated considering the "percentage" of reduced working capacity (ranging from 67% in Hungary to 30% in Germany). Depending on this percentage, workers are entitled to a disability allowance, and they can also change their employment contract. In other words, the parameters for the assessment of disability do not just take into account workers' state of health, but the type of task they are expected and able to carry out, and their medical condition. There are, however, more general evaluation criteria. In Lithuania, for instance, there are three degrees of disability, depending on the seriousness of physical or mental disability (congenital or acquired), according to which

individuals are classified as "partially" or "completely" unable to lead a social and private life, to enjoy their rights, and to perform their duties. As we have seen, the definition of "disability" that is adopted concerns national welfare and insurance systems, as well as work organization.

In some cases, the cost of disability benefits disbursed to people with this specific condition has led governments to reform the insurance scheme, rewriting evaluation criteria and requirements for thos receiving social security benefit. In this connection, in the Netherlands, after the social security reform, the number of people classified as disabled was reduced from 100,000 to just 18,000 over a three-year period. The reform succeeded in reducing public expenditure, but it also raised doubts about its effectiveness in terms of legal protection and equality of treatment between people with different states of health. This is particularly true if we consider that, at least in theory, in these countries, 'direct' or 'indirect' discrimination based on health factors is prohibited, pursuant to Directive 2000/78/CE.

In this connection, the case of Sweden is emblematic. Here, since March 1994, before the above-mentioned Directive was issued, employers have had to provide workers with disabilities with optimal working conditions, in order to avoid cases of psychological harassment (mobbing) at work.

Mention should also be made of Germany: in 2002 a Document on Equal Opportunities for People with Disabilities was adopted, aimed at promoting the integration of individuals with disabilities into the working environment and society. In the Netherlands, the National Plan for Equal Opportunities of 2003 is also noteworthy, because it laid the foundations for the setting up of a National Committee for the occupational integration of people with disabilities. Furthermore, the Committee has been charged with the task of highlighting the achievements of enterprises that are outstanding in terms of good practices.

There is an increasing awareness of the issue also among new EU member states. In Hungary, for instance, the Constitution did not provide any legal protection for those who are discriminated against on the basis of their state of health. In the last five years, however, the government has issued a number of provisions against discriminatory conduct, setting a deadline for their implementation and completion. In the event of discrimination, the sick worker has the right to appeal to the authorities, to bring such conduct to an end, and to obtain compensation for moral damages, and in some cases (Finland, France), the application of criminal sanctions.

The law also provides that agreements resulting from discrimination based on the individual's state of health must be regarded as void (this is the case also in Italy, pursuant to Act no. 300/70, and to Legislative Decree no. 216/2003). In general terms, the issue of "double discrimination" affecting women with disabilities has not attracted much interest in these countries. Only Germany and Spain provide ad hoc legislation on the matter (discrimination based on gender and health status). It is evident, and also statistics prove it, that with the same health conditions, women face more difficulties than men in terms of employment and social integration. In these cases, providing effective positive measures and legal instruments aimed at combating discrimination at a practical level is even more important. Apart from these specific considerations, it is clear that these provisions are related to a welfare-oriented system, and the need for effective legal protection. Clearly, in the latter case, medical facilities should be provided, as well as social and administrative facilities. It should also be noted that, although the provision of aids and benefits appears more costly to the State, it actually requires a minimum investment in terms of structures, resources and people involved.

In Bulgaria, Romania, and, to different degrees, in Lithuania and Hungary, institutional reform is still in progress. Despite the considerable effort of governments to conform to European standards (Hungary was the first country to ratify the UN Convention on the Rights of Persons with disabilities, 2007 (www.un.org/disabilities), there are still many difficulties in healthcare and welfare management. There are, however, some important initiatives aimed at facilitating the employment of workers with disabilities. Besides Hungary, Lithuania has also made significant progress in this direction, providing

financial aid for enterprises that hire disabled people (or those with a disabling illness, more generally), and to those that acquire the facilities allowing them to carry out their tasks. People with disabilites are also covered by specific dismissal procedures. However, the legal protection for workers with disabilities in these countries is mainly based on the disbursement of disability benefits, the amount and duration of which depend on the seriousness of the illness and the contributions paid (except in the case of very serious disability). Therefore, a "two-tier system" still exists in Europe, since the remaining countries have developed social policies based on rehabilitation programmes and occupational integration.

Finally, with regard to provisions for equal opportunities for disabled people at a practical level, mention should be made of legislation facilitating access to the labour market. Besides prohibiting discrimination against disabled people at the time of recruitment, most EU member states promote positive measures, establishing for instance a number of posts within the company reserved for people with disabilities. This provision applies in Germany, Italy, Lithuania and Spain, even though the quota of disabled workers to be employed varies (5% in enterprises with more than 20 employees in Germany; 2% in enterprises with more than 50 employees in Lithuania and Spain, and in Italy the percentage is calculated on the basis of the company size). In Germany, individuals with disabilities who are unable to find employment are also entitled to unemployment benefit for at least three years. Since 2003, in addition to reserving a number of posts for disabled workers, the Italian government has given local authorities the opportunity to sign framework agreements, also with social cooperatives. Furthermore, individuals with disabilities have been provided with two new types of contract arrangements (see related files for further information): "access to work contracts" for people classified as "seriously disabled", providing individual training programmes helping workers to acquire special working skills to be used in a specific working environment. The other contract arrangement includes "ancillary work on an occasional nature" allowing individuals to work on an intermittent basis.

At the time of the onset of a medical condition, after recruitment or during the course of employment, many countries provide sick workers with a number of provisions allowing them to maintain their employment position, and to promote their career advancement, wherever their state of health status will allow it. In this connection, Austria and the Netherlands have also set up rehabilitation programmes to improve conditions for sick workers. In Germany, "individual occupational integration" programmes are the result of cooperation between the employer and social security. Finland and Sweden provide similar ad hoc programmes, also because in these countries the social services and local authorities play an active role in this connection (for example, by means of home medical assistance, psychological support, and transport facilities). In France and Italy, disabled workers can be reassigned to another occupation, more compatible with their state of health, and their work can be reorganized in a more flexible way whereas in Germany, for instance, they are exempt from overtime.

Furthermore, it is also significant that France and Italy grant sick workers the right to choose the workplace closest to home. As for Italy, this provision also applies to parents and family members of the employee up to the third-degree, who provide continuous assistance. Moreover, they cannot be transferred against their will. However, it is clearly important for the worker to be able to take sick leave in order to receive medical treatment. Provisions are made for such leave by the Italian legislation, and by collective bargaining, more specifically, especially because it is difficult to determinate the maximum leave period allowed during the employment contract (for further information, see country profiles at the end of this chapter). Workers with serious health problems can change their employment contract from full-time to part-time, in cases in which their poor state of health affects their ability to work, or they need to take time off to receive medical treatment. In France there is provision for "therapeutic part-time": it has a maximum duration of three years, and covers medical treatment and convalescence. In Italy, the opportunity for the worker with an oncological condition to modify his/her working time is considered to be a right, also because of the invalidating effects of lifesaving treatment. Many countries (see following country profiles: France, Germany, Spain, and the United Kingdom) provide specific legal protection for sick workers in the event of dismissal arising from discriminatory action. These "special provisions", according to which employers have to prove there are no suitable assignments for the worker in the company, apply only to disabled workers.

It is also important to underline that Italy and Spain grant legal protection to relatives taking care of workers with a medical condition. More specifically, they are entitled to ask for special sick leave (which is also granted to workers), and to reduce their working hours, when this is provided in the collective agreement (for more detailed information, please see country profiles below).

In the light of the above, it is evident that legal protection for workers with disabilities is not standardised among the various countries examined. It is also true, however, that it should not be difficult to extend to other countries the implementation of the provisions that have already proved to be effective, especially if we consider them as "corrective measures", (that is, relatively inexpensive and time-saving measures).

#### 3.3. The case of workers with oncological conditions

Most European countries provide protective measures at national level safeguarding the worker at the onset of the oncological condition. EU member states, more specifically, are required to comply with the Community directives on this matter, including Directives 83/477 and 91/382 on the protection of workers from the risk related to exposure to asbestos, and Directive 90/641 on ionizing radiation.

Mention should be made, by way of example, of provisions in force in Hungary (see the country profile for more detailed information). In 2000, on the basis of the above-mentioned directives, the government passed a decree on legal protection for nuclear industry workers, and for people with cancer, more generally. In this country, the decree safeguarding workers who are exposed to radiation in the workplace came into force in 2002

Spain has also adopted measures against occupational exposure to carcinogens, in particular Royal Decree 665/1997, subsequently amended in 2000 and 2003. Special provisions have been adopted for workers who are classified as having a "temporary incapacity to work". Individuals with this status are entitled to sickness benefit for a maximum of 12 months. This is particularly important for cancer patients, who need to take time off work for medical treatment, or to take part in rehabilitation programmes.

In Lithuania, after the Provisions on Safety at Work were adopted in 1993, a research project was set up to study occupational diseases, and oncological pathologies, more specifically. The Ministry of Labour and Social Security played an active role in this project, and today the data collated are used to monitor the evolution of the situation.

In the United Kingdom, the Department of Health has launched a five-year plan aimed at combating cancer. The plan includes the promotion of preventive measures, diagnosis, and medical treatment. It also aims at involving associations and organizations representing people with health problems in consultations, in order to promote effective measures for people in this category.

Since 1997, German law has provided safeguards for people who have developed cancer following exposure to harmful agents in the workplace. A compulsory insurance scheme (for industrial associations, farming, and public services) provides sickness benefit in the event of occupational disease. In Bulgaria, the status of disability is recognised for a period of five years from the time of the diagnosis, and a committee helps workers to keep their employment position open.

All European countries have adopted specific provisions for terminally ill patients. In Denmark the law provides both home and hospital medical assistance and treatment for individuals in this situation. This includes physiotherapy, psychological support, personal care, and the provision of medical apparatus and palliative care.

In Spain, people diagnosed with cancer are entitled to sickness benefit, because in such cases there are no minimum requirements in terms of contributions. In France, national insurance covers the cost of hospital treatment and medical tests. In addition, from the time of diagnosis, workers with cancer, or any other disease included in a special list, receive a daily sickness allowance from national insurance, that is 50% of their daily earnings. The sickness benefit is recalculated annually, and can be increased if the workers have dependent children. After three years' sick leave, they can be certified as permanently disabled if they are still unable to work, and they are granted a disability pension. If they are not self-sufficient, a 40% increase in the pension can be provided. In the case of a seriously debilitating condition, employees are entitled to early retirement, even in cases in which they are not yet 60.

In Italy, the government has adopted similar provisions, but for people with a serious medical condition generally speaking. For more detailed information, please see the previous paragraph, or the country profile. It is worth mentioning, however, some aspects of legal protection for workers with cancer. In this connection, Legislative Decree no. 276/2003 is a key document, because it grants people with oncological conditions the right to change their employment contract from full-time to part-time, both horizontal (concerning the reduction of the working time with respect to normal daily working hours) and vertical (in cases in which the employee works a full day but for a reduced number of days). In cases in which their state of health allows, they also have the right to return to full-time employment at a later date.

In addition, Act No. 80/2006 (responding to a proposal put forward by the Italian Federation of Cancer Volunteers' Associations), provides oncological patients with a "fast track" for the assessment of disability, with an obligation on the part of the medical commission or panel of the local health authority (ASL) to carry out an examination within 15 days of the date of the application. This assessment is mandatory also in the event of temporary disability, resulting from a period of chemo or radiotherapy. With regard to case law, on several occasions since 2003 the Court of Cassation (Supreme Court) has granted people in this situation the right to "invalidity assistance benefit"

(equivalent of a 40% increase of the pension in France), whenever they require permanent assistance to walk, and to carry out they daily tasks.

In order to apply for this benefit, the applicant is required to submit documentation providing evidence of the medical condition, the part of the body concerned, and treatment required. This allows the medical panel to certify the disability, even after the initial assessment (which, as we have seen, is based on a fast-track procedure). As a result, the workers concerned need to be fully informed about their rights and responsibilities.

With regard to equal treatment for people with oncological conditions, Spain has adopted special provisions promoting equal opportunities, also with a view to avoiding gender discrimination. At the end of 2006, Spain Council of Ministers adopted the *Plan de acciòn 2007 para las mujeres con discapacidad*, aimed at combating "double discrimination" against women with disabilities, by means of preventive measures, based on a series of criteria, such as gender equality, positive action, cross-sectoral policies, active participation, and mainstreaming. The *Ley Orgànica* no. 3/2007, dealing with gender equality, provides legal protection for women workers within the enterprise, by means of Equality Plans. These plans represent an effective example of good practice, and might also be applied at an international level.

In concluding this section, it is evident that provisions aimed at safeguarding people with oncological conditions are still not adequately implemented in the countries of the European Union. The same can be said about protection for women with breast cancer, despite the high incidence of this condition among women, and a significant increase in cancer rates, highlighting the need for more effective measures.

## 3.4. Administrative procedures: plans, programmes, services, and departments

The health service reform taking place in some European countries is of particular interest, since it has produced a positive effect in relation to oncological issues due to the adoption of preventive measures. In Austria, the 2005 health care restructuring aimed at

reducing cancer rates by 15%. The reform also introduced the "New Preventive Check-up", under which new screening programmes were created, especially for older people (e.g. colonoscopy). The health service has been reformed also in Hungary. An automated Health Portal has been created (known as "e-health"), while an Electronic Card, the "e-Europe smart card", has been issued to users.

With respect to people with disabilities, new provisions have been adopted, with the aim of safeguarding their interests. In the Netherlands, the Ministry of Work and Social Affairs has set up a National Committee for the occupational integration of people with disabilities. In addition, the Committee has been charged with the task of looking for and rewarding enterprises that are outstanding in terms of *Disability Management*, in order to promote them as a role model. In Spain, special attention has been given to the legal protection of people with disabilities. On 30 January 2004, the *Comisión de Protección Patrimonial de las personas con discapacidad* (Commission for the protection of people with disabilities) was set up. It is an external collective body acting in consultation with the Ministry of Labour and Immigration. Most European countries also grant individuals with disabilities a number of facilities, helping them to deal with their condition, and to afford the costs of health care.

According to statistics, people on low incomes are more likely to develop cancer. For this reason, health centres are working to promote free screening programmes, at least for some types of cancer. A number of facilities are also granted during the period of sickness. In Italy, for instance, people with cancer are exempt from prescription charges, medical examinations (whether they are carried out in public facilities, or in private facilities having an agreement with the national health service), and rehabilitation programmes, even outside Italy. Finland and Germany also grant financial support to people with camcer, while Lithuania and Romania have set up special programmes aimed at reducing the cost of medical services, and providing the reimbursement of medicines.

In addition to cancer registers, the European Union and the national governments have also created a number of databases, in order to collect up-to-date information and data on cancer. At a European level, the most important project is EUROCARE (EUROpean CAncer REgistry-based study on survival and CARE - www.eurocare.it), a cancer

research project on the survival of European cancer patients. The project is based on an agreement concluded in 1989 between the *Istituto Nazionale Tumori* (Milan, Italy), the *Istituto Superiore di Sanità* (Rome, Italy) and a large number of population-based cancer registries, from 12 European countries, with epidemiological and survival data available. The study has also provided regular and increasingly comprehensive publications on cancer survival rates in Europe. In addition, EUROCARE has collected and analysed survival data on patients diagnosed from:

1978 to 1984 (EUROCARE-1)

1978 to 1989 (EUROCARE-2)

1983 to 1994 (EUROCARE-3)

1988 to 2002 (EUROCARE-4)

EUROCARE is also involved in other projects:

- CONCORD (www.lshtm.ac.uk/ncdeu/cancersurvival/concord): The CONCORD study began in 1999, and its objective was a population-based comparison of survival rates among people (15-99 years), including data from 31 countries.
- EUROCHIP (European Cancer Health Indicator Project www.tumori.net/eurochip), was the first project to be financed by the EU for the period 2001 2003, with the task of creating a list of cancer health indicators, considering some key aspects, such as demography and macro-economics. From 2003 to 2008 the study continued to focus on actions against inequalities in cancer health in the EU, improving information and knowledge in support of cancer control.
- HAEMACARE (www.haemacare.eu), is a research project focusing on Haematologic malignancies (HMS), and based on information provided by cancer registers. Individuals with these conditions need to take sick leave to take clinical tests and to receive follow-up treatment. For this reason, they require special attention in terms of legal protection.

RARECARE – (Surveillance of rare cancers in Europe www.rarecare.eu), this project aims at finding a suitable definition of statistically less frequent cancers, and a list of cancers meeting this definition.

With regard to individual member states, Germany makes use of the data collected by the Robert Kock Institute (www.rki.de/EN), and those collected by the 11 regions involved, which have created their own register. In Lithuania, all cancer cases have been recorded in a special register since 1957. Researchers from the University of Vilnuis update the register, on the basis of the data collected by the National Institute of Oncology, where more than 50% of all cancer patients go to receive medical treatment. In Austria, the Cancer Statistics Act 1969 and the Cancer Statistics Ordinance 1978 provided for the creation of a national cancer register. As for Italy, the project known as ITACARE has made a significant contribution to research. In Hungary, the national cancer register was set up in 2000, enabling researchers to identify a number of factors causing the disease, and subsequent information campaigns have succeeded in reducing cancer death rates (please consult country profiles for more detailed information). The data collected have highlighted a number of significant aspects, which are of considerable interest in terms of legal protection. In Germany, for instance, it has been found that the death rate among the unemployed is much higher than that among those who have a non-manual job.

The main objective of EU member states is to reduce cancer death rates, and to improve the quality of life of cancer patients by 2012. In this connection, many strategies and related policies have been set up, such as the 2007 Plan against Cancer launched in the Netherlands. In the United Kingdom, the Department of Health has launched a five-year plan, aimed at promoting cancer prevention and treatment. In Spain, the 2006 Estrategia en cancer del Sistema Nacional de Salud provided useful data and statistics, and promoted preventive measures to safeguard people with cancer.

In Sweden, the government has launched a national plan promoting safety at work, and occupational reintegration, and aiming at reducing the percentage of sick leave. In Lithuania, in 1993 the Ministry of Labour and Social Policies launched a research campaign, to study occupational diseases, paying special attention to oncological conditions. In addition, the 1993 Provisions on Safety at Work allowed the Public Health State Service to identify and classify them. In Hungary, the "Ten-year Health Plan" (*Johan Béla Programme*) contained in Resolution no. 46 (2003), aimed at increasing national life expectancy, and providing equality of treatment in terms of medical

treatment. Furthermore, the government launched the Hungary National Cancer Control Programme in 2006, with the aim of promoting effective measures to reduce death rates, and supporting early diagnosis and nationwide screening. Denmark launched a similar initiative, issuing the 2002 National Plan Against Cancer.

It is also important to highlight the active role played by local authorities in supporting individuals with oncological conditions. In Sweden, for instance, the Stockholm County Council provides people with medical assistance (preventive measures and medical treatment). Pursuant to the legal provisions, every county council has to set up a Patients' Advisory Committee, which is empowered to provide information, and a number of services. In Italy, the municipality of Milan is involved in a series of initiatives aimed at safeguarding workers with cancer. In Austria, the *Land* of Vorarlberg has taken part in the project called CINDI (Countrywide Integrated Noncommunicable Disease Intervention Programme) since 1985, which promotes cooperation between industrialized countries, in order to combat the most common pathologies, such as cancer.

Local authorities play a key role also in the provision of palliative care. The Danish Parliament, for instance, established that it is for the districts to provide this medical treatment, and to create hospices for terminally ill patients, while in Romania, non-governmental palliative care organizations have rapidly developed (an example is Brasov-based Casa Sperantei Hospice).

In order to achieve significant results in cancer prevention, cooperation between all the institutions involved is fundamental. There is a need to set up a common plan, to safeguard people with cancer, involving public and private facilities, and local authorities at a national level. Finland, for instance, has succeeded in promoting this cooperation. All institutions (public and private facilities, insurance bodies, and so on) have a duty to report all cases of cancer, providing useful information on the factors which cause the illness, which can be consulted by all those concerned. In Sweden, the FAS, which is the Swedish Council for Working Life, was set up in 2001. The main objective of the council is to increase scientific knowledge about working life issues, to provide scientific information, and to promote basic research.

It is often the case that prevention and early diagnosis are not generally recognized as important. In this connection, there are considerable differences between countries, and

even between cities, in the provision of social and health services. Furthermore, the cultural gap between various regions within the same country has resulted in an increase in death rates in the more disadvantaged areas. This is particularly true in Romania; in rural areas, only a small percentage of women receive cancer screening, mainly because of ignorance or prejudice against cancer, not to mention the lack of adequate facilities. In Hungary, discrimination based on ethnic differences still exists.

Spain, on the other hand, provides examples of good practice in this connection. The region of Navarre was the first to launch an effective screening programme, resulting in a significant reduction in cancer rates, especially when compared to data from other regions, which launched similar initiatives at a later date. In other countries, such as Finland, organizations known as Cancer Societies held intensive awareness-raising campaigns, aimed at making people aware of the issue uniformly across the country.

As we have seen, these countries, implementing the Community directives, have made provisions for safeguarding workers from the risks relating to exposure to carcinogens. Furthermore, special attention is paid to workers who have contracted cancer in the workplace. Only in a few cases, however, is it possible to prove the causal link between the working environment and the illness. In Germany, for instance, the compulsory insurance scheme provides a sickness benefit if the pathology is work-related. Environmental factors are not considered to be a "pre-existing clause". The same applies in Lithuania, where the Ministry of Labour and Social Security, in cooperation with the Public National Health Service, has launched a wide-ranging research campaign, to determinate this relationship. In Hungary, an interesting initiative has been carried forward in this connection. Here, patients have been asked to fill in a medical questionnaire, in order to identify the connection between prolonged exposure to certain substances in the workplace and some types of cancer. In Italy, this connection has already been recognised, even though, unlike Germany, national legislation is not clear about the definition of "environmental factors".

As already noted, workers with cancer may be subject to harassment in the workplace. In most cases, they are not welcome in the workplace, due to the expenses employers incur by having sick workers in their employment. At times they do not receive support from

other employees, because they may experience a feeling of uneasiness, especially from a psychological point of view.

In this regard, some countries provide people with cancer with legal protection. In Sweden, for instance, in 1993 the National Board of Occupational Safety and Health issued a new set of measures that have to be taken in relation to psychological violence in the work place. On the basis of these measures, it is for the employer to provide the best working conditions, also involving the employees and their representatives. These provisions represent an effective legal instrument, because for the first time they provide specific legal protection against mobbing.

# 3.5. Good business practices for workers with oncological conditions, with special reference to women with breast cancer

The number of companies giving priority to the legal protection of workers is still limited. In most cases, legal measures safeguarding their interests are poorly implemented, because they give rise to additional costs, without an economic return. Under these conditions, the development of good practices becomes a very difficult task, especially if the main objective of enterprises is to maximise profits. This is particularly true for individuals with cancer, especially when the cause and effect relationship between the working environment and the illness is established. Research plays a key role in defining such a link (in the United Kingdom, many companies cooperated with the University of Manchester in the planning of special projects, aimed at monitoring all cases of occupational disease), but it is also important to reduce major risk factors that contribute to the development of cancer. Only a few companies give priority to this key issue, but they might provide a role model helping to promote a reform of company law, according to which companies should include the principles of corporate social responsibility in their articles of association. The reform should also provide an award for enterprises that achieve outstanding results in terms of good practices. In this regard, a leading role is played by Macmillan, a British organisation which supports people with disabilities and with cancer. The organization provides them with a pleasant working environment, also supporting employees who are indirectly affected by the illness. At the time of recruitment, sick workers are also granted paid sick leave, flexible working hours, training, and psychological support. Furthermore, in terms of social costs, the implementation of this policy has also improved enterprise performance. In Sweden the Värö Bruk, an enterprise involved in a three-year Work and Health Plan, set up a similar initiative, promoting a physical wellbeing programme for employees. In 2001, the company was named Company of the Year by the National Institute of Public Health. According to this programme, a healthy and friendly working environment results in a significant reduction in sick leave. In 2007, the Amsterdam-based Academic Medical Centre came to the same conclusion, carrying out a study on the difficulties faced by people with disabilities when they attempt to return to work. In this regard, rehabilitation programmes and psychological and physical support can help the sick worker to recover sooner. In Belgium, the Catholic University of Leuven deals with this issue, paying special attention to women with breast cancer, and highlighting the importance of a pleasant working context. In 2003, during the Peer Review Meeting, the Netherlands was mentioned as a positive example in terms of good practices. In Finland, in 2008, the Finnish Institute of Occupational Health conducted a study on how to reduce sick leave by setting up an "Occupational Health Plan". By means of medical questionnaires, the study identified those who are most likely to take sick leave, such as cancer patients, also showing that leave of absence can be reduced if people with serious conditions are granted adequate psychological and physical support. Lassila & Tikanoja provides a good example of best practices, as in this company a study was carried out on the expenses incurred by the employer who has sick workers in his/her employment. The conclusion was that it is worth investing in the health and safety of its workers, not only from an economic point of view, but also in terms of corporate social responsibility. The company also provides adequate medical assistance and psychological support in the event of sickness. Workers who are unable to carry out their previous work after recovering from their condition, even after a rehabilitation programme, are reassigned to more suitable work. If it is not possible, the company helps them to find new employment. In Spain, the 2008 Manifesto promoted by the National Federation Against Cancer encourages employers with sick women in their employment to promote new practices in the ambit of corporate social responsibility, providing them with the necessary support.

In Italy, an increasing number of enterprises, such as food businesses, telecommunications companies, and banks (please refer to country profile for further information) provide other examples of good practices, using media exposure to launch information campaigns and fund-raising events, and to fund scientific research. In addition to supporting AIRC (Italian Association for Cancer Research), by funding scholarships for young researchers, they also promote awareness-raising campaigns, aimed at emphasizing the importance of preventive measures and early diagnosis. These events are now operational, and they take place on fixed days of the year. Thanks to these initiatives, funds have been collected, and statistics also reveal a decrease in cancer rates (especially for breast cancer).

#### 3.6. The role of voluntary associations

A significant number of private institutions deal with the protection of people with cancer. All their effort goes into funding scientific research, and providing sick individuals and their families with adequate support. The main purpose is to meet everybody's need, on the basis of their state of health and medical condition. In Italy, there are around 50 associations, federations, foundations, research institutes and centres providing these services nationwide (see the country profile). The most important are: the Italian Cancer Registry Association, the Italian Group for Breast Cancer Screening, the National Institute for Research and Cancer Screening, the Federation of Parents' Associations of Children with Pediatric Onco-hematology, the National Task Force against Breast Cancer, and the Federation of Cancer Volunteer Organizations.

There are many associations dealing with this issue in Europe. In Austria, for instance, the Austrian Cancer Support Society is an organization funded by private donations, which provides useful information on cancer prevention and medical treatment. Similar information is also provided by the Austrian Breast and Colorectal Cancer Study Group. In Belgium, the Catholic University of Leuven is involved in a research project on breast cancer, studying the way the family, the employers, and the welfare system support sick people. In the Netherlands, in 2007, the Amsterdam-based Academic Medical Centre completed a study on the difficulties faced by people with disabilities when they attempt to return to work. In this connection the Dutch Cancer Society plays an active role in

supporting disabled workers and promoting research, by launching information campaigns and funding information centres.

In Romania, the Romanian Cancer League, which is a non-profit organisation, has launched several initiatives against cancer. More specifically, it has promoted an antismoking campaign, and a number of initiatives providing support service for people with this specific condition. It also set up a programme focusing on the importance of a healthy diet, according to the report released by the American Institute of Cancer. In addition, the Association of People with Cancer in Romania (Asociatia Oncologic Rom) supports people with cancer in their return to work. In the United Kingdom, the private network GMTV has set up a hotline, to provide general information on colon cancer during a three-minute programme. In Hungary, there are many associations that deal with the illness, such as the Hungarian League against Cancer, and the National Association of Cancer Patients. In France, Europa Donna is conducting a wide-ranging awarenessraising campaign, also planning social events, such as marathons, which are popular there. In other cases these organizations have succeeded in cooperating with the government. In Bulgaria, for instance, the Bulgarian Association against Cancer, named Apoz & Friends, organized a summit with the patronage of the President of Bulgaria, and supported by Members of Parliament and medical experts, in 2008. After this meeting, the Ministry of Health decided to allocate a large amount of funding for a screening programme, and to draw up a Memorandum outlining the importance of cancer checkups. In Sweden, the Breast Cancer Organization has the largest number of members, and represents 33 local associations. It also has a representative on the National Council on Health and Safety in the Workplace. It stresses the importance of mammography screening, announcing an award for those who achieve outstanding results in terms of medical treatment and scientific research, and promoting the Pink Ribbon Campaign.

## **3.7.** Country profiles

#### **Austria**

Legal protection for workers with disabilities, including those with oncological conditions.

In Austria, insurance cover for workers in the event of industrial injury is provided in accordance with the Bismarck Plan for Social Policy developed in Germany. On the German model, a mandatory insurance scheme against accidents at work (Insurance against Accidents at Work Act), was set up between 1887 and 1888. A health insurance program for workers was also established in the same period.

In 1948, the Central Association of Austrian Insurance Institutions was set up, while in 1956 the General Social Insurance Law (ASVG) entered into force, reforming the social security legislation for employees. [Source: *Austria – Health System Review*, Health System in Transition, vol.8, n.3, 2006].

The Austrian Welfare Institution against Injuries (*Allgemeine Unfallversicherungsanstalt*, AUVA) is the body governed by public law, which deals with general issues linked to health and safety at the workplace.

In addition, three other bodies are specialized in providing legal protection for specific categories of workers (e.g. farmers) in case of industrial injuries or occupational diseases. These institutions also manage regional, company, and special health insurance funds (nine, eight, and four funds respectively), which are financed by revenues from compulsory contributions, or, if necessary, from tax revenues (provided by the government).

It should be noted that these bodies also provide the workers with rehabilitation programs at their own expense, in order to enable them to continue working.

Insurance cover is provided for employees, unemployed workers who benefit from social security measures (social security cushions), and people who are enrolled in vocational rehabilitation programs.

Sickness benefit is usually equal to 50% of previous gross salary (according to the law it is payable for 52 weeks. It is granted, however, for 78 weeks, if provided by special insurance funds), increasing to 60% after 43 days (Source: *Cancer and in general long-term illnesses at workplaces*, European Parliament, 2008).

## Administrative procedures related to legal protection

The Cancer Statistics Act 1969 and the Cancer Statistics Ordinance 1978 provided for the creation of a national cancer register, and the data from this register are used to launch appropriate screening programs.

With the 2005 health care restructuring, the Austrian government also aimed at reducing cancer rates by 15%.

In addition, prompted by health insurance funds, a number of *Länder* fixed many other objectives, in order to meet both local and national needs.

The reform introduced the "New Preventive Check-up", under which new screening programs have been created, especially for older people (e.g. colonoscopy).

In order to implement the WHO Ottawa Charter directives, since 1985 the *Land* of Vorarlberg has taken part in the project called "CINDI" (Countrywide Integrated Noncommunicable Disease Intervention Programme), which promotes cooperation between industrialized countries, in order to combat the most common pathologies, such as cancer. At a practical level, CINDI played a very active role, launching a number of initiatives, such as anti-smoking and anti-alcohol campaigns.

Recently, within the National Health Council, a special commission has been set up, dealing with general issues on health at work and occupational diseases.

#### National Best Practices (overview)

## For people with oncological conditions

In Austria, a significant fall in cancer mortality occurred in the period 1980 - 2004. In fact, cancer death rate in the country decreased by 20% (from 213 to 170 cases per

100,000 inhabitants), while in Europe an 8% decrease was reported (Source: *Austria – Health System Review*, Health System in Transition, vol.8, n.3, 2006).

Today, 36,000 people are diagnosed with cancer every year in the country.

The Austrian Breast and Colorectal Cancer Study Group, (ABCSG, www.abcsg.at/english/index.html), plays a very active role in scientific research.

Founded in 1920, the Austrian Cancer Support Society (www.krebshilfe.net/home.shtm), is a non-profit organization funded by private donations, which provides useful information on cancer prevention and medical treatment. The Tyrol-based office, the **Tyrol Cancer Research Society**, also founded the **Tyrol Cancer Research Institute** (www.trci.at).

#### For women with breast cancer

Compared to the number of inhabitants, the number of people who die of breast cancer is significant (6-7 cases per 100,000 inhabitants in 1999). [Source: American Association for Cancer Research, 96<sup>th</sup> Annual Meeting, Los Angeles].

The Austrian Breast and Colorectal Cancer Study Group, as the name suggests, is engaged in the fight against breast cancer.

It should be noted that the comparative study *Breast cancer trends: opportunistic screening in Austria versus controlled screening in Finland and Sweden*, carried out by Christian Vutuc and other researchers, published in the *European Journal of Cancer Prevention* (vol. 15, n.4, pp. 343 - 346) in 2006, found that the prevalence and mortality of the disease are higher in Finland and Sweden (controlled screening) than in Austria (opportunistic screening).

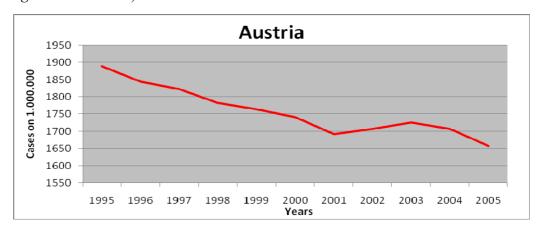
The Europa Donna Austrian office (www.europadonna.at) has launched the Breast Friends Initiative recently, which involves women from show business in a wide ranging awareness campaign.

#### **Statistics**

Analysis of the processed 2006 Eurostat data. Mortality for cancer (standardized data considering 1.000.000 cases)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
Austria	1889	1845	1823	1782	1764	1741	1692	1708	1725	1707	1658	
%	0,189%	0,185%	0,182%	0,178%	0,176%	0,174%	0,169%	0,171%	0,173%	0,171%	0,166%	
		-	-	-	-	-	-			-	-	
Variation		0,004%	0,002%	0,004%	0,002%	0,002%	0,005%	0,002%	0,002%	0,002%	0,005%	

**2006** Eurostat data progress chart. Mortality for cancer (standardized data considering 1.000.000 cases)



#### **Further Information**

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#### Bulgaria

Legal protection for the worker in case of disability and oncological conditions.

In Bulgaria, considerable changes have been made to the legal system, in order to bridge the gap in legal protection with the other countries belonging to the European Union. It is difficult, however, to apply such changes at a practical level and to raise public awareness of them. The transition is still in progress and it is very challenging. In fact, in the year 2000 the Ministry of Health of the Italian Republic and the Ministry of Health of the Republic of Bulgaria signed an agreement, promoting the provisions of the Memorandum of Understanding between the two governments in the area of health and medical science. Even today, in Bulgaria information and scientific research are given priority, while limited attention is paid to workers' legal protection. This is due to the fact that, according to many scholars, the accession of Bulgaria to the European Union primarily represents a way to cooperate in research. Besides this, the other aspect to consider is that the government has introduced several reforms aimed at semi-privatizing the health system and the social security scheme. Such reforms will have negative effects on everyday life, due to the presence of significant social and economic inequalities in the country, and individuals on low incomes will not be able to afford the cost of health care and mandatory health insurance.

In 2000, the entry into force of a reform in **the social insurance system**, subsequently amended several times, introduced effective legal protection for people with disabilities, providing them a disability pension or benefit, depending on whether the disability was permanent or temporary.

In case of permanent disability, there are no minimum requirements in terms of contributions for individuals under the age of 20, for those who have a serious disability (blindness), and workers who have suffered an industrial injury causing invalidity with a percentage higher than 71%.

In other cases, at least one year of contributions is required for disabled people aged up to 25, for those, who became disability before starting to work and for disables since their birth, three years of contributions for those aged 25 to 30, and five years of contributions for those who are older than 30 years old. Ministry of Health Expert Panels evaluate the level of disability, and the degree of loss of individual working capacity.

The amount of the pension depends on the number of years' contributions, the age of the disabled person and his/her percentage of invalidity (for further information, please consult www.scribd.com/doc/1930107/social-security-bulgaria).

The above-mentioned panels also assess the existence of a disability, in order to allow the disbursement of the pension, which level is as follows:

- for persons, who have lost their ability to work at 90% and more at least 115% from the level of the minimum pension for the length of service for the country;
- for persons, who have lost their ability to work from 71 to 90 %-at least 105% from the level of the minimum pension for the length of service for the country;
- for persons, who have lost their ability to work from 50 to 70,99 %-at least 85% from the level of the minimum pension for the length of service for the country

The Ministry of Labour and Social Policy (www.mlsp.government.bg/en/index.htm) is responsible for the development and the coordination of Social Policy, and the insurance issues are managed by the National Insurance Institute. National Social Welfare Institution deals with social welfare issues.

#### Specific Legal Protection for people with cancer

According to the law, the status of disability is recognized for a period of 1 to 3 years from the day of the diagnosis, and a committee helps workers to keep their employment position. In some cases (especially when the working conditions could provoke worsening of the illness) the employers should transfer the worker or employee at a job with better working conditions.

The person should apply again for recognition of disability, when the period of recognized disability has been finished. In cases of very heavy illnesses, disability for life (or permanent disability) could be recognized, as well as for all the persons, who are 65 years old or more.

Most of disables, including all of those having cancer, are protected by the law in case of redundancies. They could be redundant only with permission of the General Labour Inspectorate (Executive Agency). This concerns also cases of dismissals because of inappropriate selection or placement of the employee, changes in the requirements of the job, or disciplinary procedures.

Disables because of cancer illnesses have the same rights like the other disables-pensions, benefits for social integration (for example cash benefits for transport, telecommunications, diet food and medicines, prophylaxis, rehabilitation and recreation, education and others) and other means, necessary in specific cases, like wheel-chairs and others. They could also buy cars with reduced prices

For some disables the commissions could permit using of personnel assistance and determine additional benefits for payment of such services.

Disables could use some tax benefits (they should pay reduced local taxes, reduced income taxes, if they are employed or do have another incomes and others).

According to the Law for Health Insurance, all the disables should not pay so-called consumer taxes, when visiting doctors .

#### Specific Legal Protection for women with breast cancer

The legal protection of the women with breast cancer are just the same like for the other disables with cancer.

The level of disability for cases of breast cancer varies. It could be 50-80% in cases of early surgery intervention or 70-100 % in more heavy cases.

## Administrative procedures related to legal protection

Special programs of the National Employment Agency for employment, qualification, consulting or adaptation of disables

Programs for social integration of disables , implemented by the National Agency for disables

Programs of the National Insurance Institute and "Prophylaxis, Rehabilitation and Recreation" Plc., which is public company, managed by National Insurance Institute According to the procedures of the Ministry of Health, periodically preliminary medical examinations of women (check for breast cancer) should be made.

Most of the policies and procedures related to the women with breast cancer are initiated by the NGO-s and even by businesses. Some NGO-s organise campaigns for prophylaxis and some companies financed periodically mass examinations

## National Best Practices (overview)

#### For people with oncological conditions

In Bulgaria, considerable investments are made in information, and the government is using all kinds of means of communication, including the Web, to promote preventive measures such as anti-smoking campaigns. (In this regard consider, for instance, that cigarettes are comparatively inexpensive when compared to the cost of food).

In May 2008, the Bulgarian Association against Cancer, named Apoz & Friends, organized a summit (please consult www.cancerworld.org/CancerWorld/home.aspx?id\_sito=2&id\_stato=1), with the patronage of the President of Bulgaria, also supported by Members of Parliament and medical experts. After this meeting, the Ministry of Health decided to allocate 10 million euros for a screening program for some kinds of neoplasia, while Parliament drew up a Memorandum on the importance of improving cancer checkups.

#### For women with breast cancer

Recently, more than 130 projects have been set up by many Bulgarian municipalities, holding public debates on the issue. A group of doctors and concerned women from the region of Gabrovo focused the attention on the necessity of discussing the matter on public debates promoted by the municipality, in order to improve breast cancer

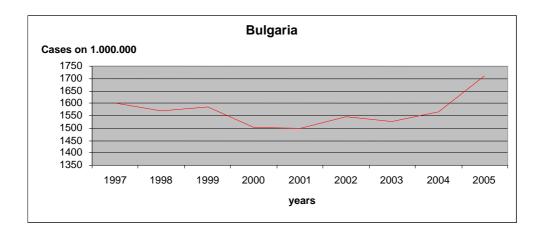
prevention. As a result, an information campaign was launched to encourage early diagnosis, including film shows, radio and TV advertisements and sport events.

#### **Statistics**

Analysis of the processed 2006 Eurostat data. Mortality for cancer (*standardized data considering 1.000.000 cases*)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
Bulgaria			1602	1568	1584	1504	1500	1548	1525	1565	1710	
%			0,160%	0,157%	0,158%	0,150%	0,150%	0,155%	0,153%	0,157%	0,171%	
				-		-			-			
Variation				0,003%	0,002%	0,008%	0,000%	0,005%	0,002%	0,004%	0,015%	

**2006** Eurostat data progress chart. Mortality for cancer (standardized data considering 1.000.000 cases)



#### **Further Information**

There are some problems in the implementation of the law and administrative procedures in relation to the people with cancer, including women with breast cancer. Sometimes the treatment takes long time and the medicines are too expensive. There have been cases, when because of the deficits of expensive medicines some of people have been pressed to

pay the medicines or the taxes of medical procedures. There is also corruption in the health care system, but in most of the cases the corruption practices could not be proved. There is very popular story in Bulgaria about a women, Teodora Saharieva, who understood she had a breast cancer 10 years ago and who was not treated in appropriate way, mainly because of the deficits of medicines. She decided to go to the law with the government and judicial procedure finished successfully for her. Currently the government should pay compensations to her. She is in a better health and she established together with other persons (doctors, social workers and others) a NGO for protection of the healthcare rights of the people (see also www. czpz.org). There are also another NGOs, including associations of the people with cancer.

## Europa Donna Bulgaria

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### **Denmark**

Legal protection for workers with disabilities, including those with oncological conditions.

The first legislation providing legal protection for workers dates back to 1873, and in 2005 new provisions came into force. An example is Act no. 268 of 18 March 2005 on the working environment, or Directive no. 239 of 6 April 2005 on youth work, with the latter implementing Council Directive no. 94/33/CEE of 22 June 1994.

On 14 August 2000, Denmark also ratified ILO Convention no. 182 on child labour, put into effect by Directive no. 62 of 11 December 2000.

Directive no. 239 of 6 April 2005 on child labour provides several restrictions on the engagement of individuals aged 13 to 15, also establishing that those in the 16 to 18-year age group can perform only tasks classified as "not dangerous".

It should be noted that in Denmark, people start to learn about occupational safety at school. Since 2006 (European Week for Safety and Health at Work), the Ministry of Labour, the Ministry of Education, and several associations of workers and employers have worked together to provide students with an ad hoc literature [Source: European Environment and Health Committee (EEHC)].

### Specific Legal Protection for people with cancer

The law provides both home and hospital medical assistance and treatment to terminally ill patients. It is for the local authorities to provide medical treatment, including physiotherapy, psychological support, personal care, and the provision of medical apparatus and palliative care.

Recently, the Danish Parliament has also established that local counties should make an arrangement with districts on the creation of hospices, in order to receive public funding. [Source: *Denmark – Health System Review*, Health System and Transition, vol.9, n. 6, 2007].

# Specific Legal Protection for women with breast cancer

With regard to legal protection for women workers, Denmark ratified Directive no. 559 of 17 June 2004, implementing Council Directive no. 92/85/CEE of 19 October 1992, according to which governments should make efforts to improve health and safety at work for pregnant women [Source: European Environment and Health Committee (EEHC)]. It was not possible to gather information regarding legal protection for employed or unemployed women with cancer.

# Administrative procedures related to legal protection

After issuing National Plan against Cancer in 2000, an ad hoc committee stated that Denmark did not comply with the rest of Europe in terms of palliative care, even though the provision of palliative treatment was different from place to place. In order to bridge the gap, Danish government decided to invest more resources in this field, also promoting scientific research. Furthermore, a series of palliative care program plans were promoted in 1999 and in 2001. According to the Association County Councils 2001 Report, however, very few counties complied with national directives; there were only ten hospices nationwide.

To the extent that, in 2003, a national research group was set up to understand how to give momentum to the palliative care service.

On an organizational level, in 1996 the national medical board issued guidelines, subsequently modified in 1999, on the management of palliative care services, on the basis of WHO directives on the matter.

Palliative care service consists of basic and specialized medical treatment. In the first case, it is for the national health system to support the patient, also involving GPs, home-based assistance, and public facilities. Specialized medical treatment is provided by palliative care professionals in private hospices. [Source: *Denmark – Health System Review*, Health System and Transition, vol.9, n. 6, 2007].

### For people with oncological conditions

Denmark is a country with very high cancer rates. More specifically, the smoking- related cancer death rate is among the highest in Western Europe. In fact, 13,000 Danish people die from cancer every year (Source: WHO/OCSE survey).

The Danish Cancer Society (www.cancer.dk) published a handbook, "When an employee gets cancer", containing useful advice for managers and caregivers. The Society is a member of the ECL, the European Cancer Leagues (www.europeancancerleagues.org), and deals with scientific research, cancer prevention and patients care, trying to reduce the effects of the disease at a physical, psychological, and social level. The Copenhagen-based head office coordinates the activities of several local associations, research centres, and a considerable number of volunteers nationwide. Research focuses on a variety of issues, such as "Food, cancer, and health", "Environment and health", "Genetics and medicine", "Cancer from a psychosocial point of view", and "Viruses, hormones, and cancer". In addition, in 2004, researchers conducted a study under the aegis of the government on the risks of prolonged exposure to radiations from mobile phones, which in the past had become an issue with extensive media coverage in the country.

In order to carry out specific research programs, the Society has also created a number of medical centres, such as the Cancer Epidemiology Institute, the Cancer Biology Institute, and the Genotoxic Stress Research Centre.

While the latter focuses on the environmental factors which damage human cells, the Cancer Epidemiology Institute has recently conducted a study on the risk of developing brain and breast cancer, and leukaemia for those workers who are exposed to electromagnetic fields (It was published in May 2007 on *Occupational and Environment Medicine 2007*, 64: 782 - 784). Tests, however, showed that there is no evidence of such a link (28,224 individuals were tested).

With regard to patient care, the Society is concentrating its effort on the creation of new support facilities. In terms of best practices, the aim is to build new medical centres as close as possible to the therapy centres, following the example of the "Maggie Centres"

in the UK, in order to facilitate the coming and going of patients, relatives, and medical staff. The Society also plans to launch specific hospice projects, to provide greater levels of medical assistance and palliative care.

The "Six-a-day" campaign, involving several institutions, health organisations, and trading companies is intended to increase consumption of fruit and vegetables, as a preventive measure against cancer. In 2004, daily per capita consumption rose from 280 to 380 grams, thanks to a similar initiatives [Source: the Nordic Cancer Union (www.ncu.nu/index.shtml)].

In Denmark, as well as in Finland, the Netherlands, Sweden, and the United Kingdom there are ad hoc screening programs aimed at preventing cervical cancer.

### For women with breast cancer

The Danish Environmental Protection Agency is indirectly involved in combating cancer (www2.mst.dk/common/Udgivramme/Frame.asp?http://www2.mst.dk), and mainly deals with environmental issues in Danish enterprises. Recently, it has launched a campaign called "Baby chemi", to protect pregnant women and women who breastfeed against chemical substances contained in cosmetics, children's products, and toys.

The Bispebjerg hospital is one of the several facilities providing palliative care for terminally ill patients. Palliative treatment is ensured by an interdisciplinary team of experts, also involving company medical officers. The Bispebjerg hospital has also launched an experimental project with the aim to involve volunteers in the provision of palliative care, even though in the country their contribution is usually unnecessary [Source: *Denmark – Health System Review*, Health System and Transition, vol.9, n. 6, 2007].

Founded in 1979, the Faroe Islands Society against cancer (www.krabbamein.fo), is a charitable association mainly funded by private donations and charity events. It is a member of the ECL, and it has always worked in cooperation with the institutions,

prompting local authorities to provide effective measures for the detection of cancer cases.

Its assistance office provides advice to as many people as possible (patients, relatives, and anyone concerned). Private nurses provide home and hospital visit to patients, also giving classes and seminars in schools on this issue.

The Society participates in many initiatives, such as the one called "A day without smoking". It also looks after the families of children with cancer (Recently, it has organized a trip to Denmark for them).

Denmark is the country with the highest breast cancer death rate in Europe (out of a total of 100,000 cases, 38 women died in 1999, while in 2005 the number fell to 25 individuals). [Source: *Recommendations for Cancer Screening in the European Union*, edited by the Advisory Committee on Cancer Prevention, after the Conference on Screening and Early Detection of Cancer, Vienna – American Association for Cancer Research, 96<sup>th</sup> Annual Meeting, Los Angeles].

Compared to the number of inhabitants, the number of people who die of breast cancer is also remarkable (6-7 cases per 100,000 inhabitants in 1999). [Source: American Association for Cancer Research, 96<sup>th</sup> Annual Meeting, Los Angeles].

Recently, the Danish Cancer Society has also funded the building of the Danish Centre for Transnational Breast Cancer research – DCTB, which has attracted prominent Danish academics and professionals.

The Faroe Islands Society against cancer formally requested the introduction of breast cancer screening in the country. A number of lectures were also held on breast cancer and post-mastectomy rehabilitation, and since 2002, a growing number of classes have been given to women who recovered from cancer.

The society also participated in the Pink Ribbon campaign.

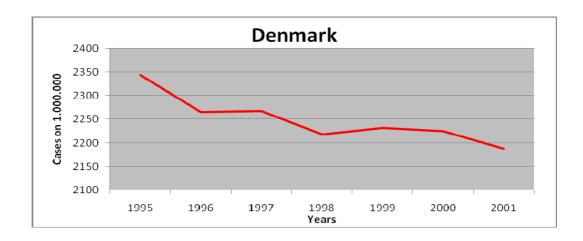
In October 2007, the Danish Division of Europa Donna organized a symposium on future developments in the treatment of breast cancer, and on how political leaders and economic bodies can help to promote them. The symposium took place in the Danish Parliament building, in order to attract the interest of the media and local authorities.

### **Statistics**

Analysis of the processed 2006 Eurostat data. Mortality for cancer (standardized data considering 1.000.000 cases)

	1995	1996	1997	1998	1999	2000	2001
Denmark	2344	2265	2268	2218	2232	2225	2188
%	0,234%	0,227%	0,227%	0,222%	0,223%	0,223%	0,219%
Variazione		-0,008%	0,000%	-0,005%	0,001%	-0,001%	-0,004%

**2006** Eurostat data progress chart. Mortality for cancer (standardized data considering 1.000.000 cases)



### Further information

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Chairman: Jákup N. Olsen mail: jno@lv.fo

### Nordic Cancer Union - www.ncu.nu/index.shtml

Collaboration for improved cancer control in Scandinavia since 1980.

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### **Finland**

Legal protection for workers with disabilities, including those with oncological conditions.

The 21/2004 Non Discrimination Act prohibits 'direct' or 'indirect' discrimination based on health factors. It also provides that people with disabilities should be protected by means of effective measures, in order to ensure equal treatment in terms of job opportunities, work performance, and career advancement at a practical level. It is important to consider that discriminatory conduct is punishable as a criminal offence, under the Finnish Criminal Code.

In this regard, local authorities play a very active role, as they are entrusted by national and local legislation with the task of developing effective social policy on the issue.

The Social Welfare Act 2001 and The Act on the Status of Rights of Social Welfare Clients, as well as other special provisions, show that the social security and health system in Finland aim at supporting disabled persons and people recovering from long-term illnesses, facilitating their return to work, and offering them individual assistance, home medical treatment, free public transport, and other support services.

It is also for local authorities to provide breast cancer screening programs (for further information on local administrators and the available services, please consult www.yle.fi/news/index.html), as social security legislation clearly states (Employees Pension Act of 01.01.2005).

By law, many services are provided to people with disabilities, depending on whether the disability is permanent or temporary. In the first case, a *disability pension* is paid to those individuals aged 16 to 64 years who suffered from a complete loss of working capacity. A *disability allowance* is granted to people in the same age group (16 to 64 years) who have not retired yet, and to retired people who do not receive the maximum pension. The Social Security Agency (*www.kela.fi*) has to evaluate any significant change in the individual's health conditions. Likewise, it is for the sick person to report to the Agency any improvement of his/her state of health. A *disability allowance* or a *pensioner's care* 

*allowance* is provided to people with a long-term illness, and to those classified as disabled, depending on whether they are younger or older than 16.

In addition, at the end of the insurance cover provided by the Social Security Agency, people in the 18 to 62- year age group with a reduced capacity to work of at least 60% are granted an *earnings-related disability pension*.

Finland provides medical assistance also to immigrants in the 16 to 64 age group who are not in receipt of a disability allowance, provided they have lived in the country for at least five years.

Pursuant to law, individuals classified as partially disabled have a reduced capacity to work caused by injury or disease ranging from 40% and 59%.

In this case, the Agency sets up a rehabilitation program together with the doctors, to facilitate their early return to work.

In Finland, legal protection during illness is provided by either public and private insurance schemes.

In this regard, the first 10 days' absence are paid by the employer (at full pay in the case of an employer with at least one month's service; at half-pay in the case of new recruits), while all succeeding days up to 300 days (not counting Sundays) are covered by the insurance body. There are a number of differences, however, in the case of industrial injuries (for further information on Welfare Institutions against Industrial Injuries, please consult *www.vakes.fi*). More specifically, the amount of the disability pension is calculated on the basis of the period of hospitalization (more or less than four weeks).

In the event of permanent disability, the amount the above-mentioned pension is calculated considering 20 levels of severity, as well as other factors, such as the worker's age and economic status. The rehabilitation treatment is provided free of charge, as well as medical expenses for long-term illnesses.

Medical assistance and hospital services are provided by the municipalities, or by the Federation of municipalities, under the Ministry of Health and Social Security supervision (www.stm.fi).

Most of them are services for which a charge has to be paid, but the Welfare Institution offers high reimbursement rates for major expenses.

### Administrative procedures related to legal protection

Finland has five million inhabitants, and 2.5 million workers. The small number of inhabitants, and the high employment rate have made it possible for the creation of extensive records, containing information on people's state of health, working conditions, and habits.

The *Finnish Cancer Registry* (set up in 1952) plays an important role in the country. Public and private facilities have the duty to record all cases of cancer on the National Register (www.cancerregistry.fi/eng/registration/lomakekleng.pdf).

It is updated regularly, and it also contains cancer-related mortality rates. Residents in the country are given a personal code, which is the same as the one reported on the Register. This means that anyone concerned can consult data, including people with an illness, provided privacy is protected.

With Provision no. 717 of 17 August 2001, a new register was established, which includes people who are exposed to substances and productive factors causing cancer at the workplace. There are two more registers, the *Finnish Register of Occupational Diseases* (*FROD*), and the *Register of Occupational Injuries and Diseases*, (*Työtapaturma – ja ammattitautirekisteri, TPSR*). The latter is a 'combined' register, because it contains the cases of all occupational diseases and industrial injuries in the country. (It is mandatory for insurance companies to provide such data). Thanks to this register, the *Federation of Accident Insurance Institutions* is able to ascertain the figures in terms of workplace accidents and diseases. Unlike the situation in some other countries, in Finland it is also possible for researchers to identify the relationships between people's lifestyle and oncological pathologies. They discovered, for instance, that breast cancer in women is often related to traumatic events in their lifetime.

### National Best Practices (overview)

# For people with oncological conditions

The *Cancer Society of Finland* has 12 organizations and four associations of patients. With 150,000 members, it runs several nursing homes, providing information on related

campaigns, rehabilitation and screening programs, laboratories, etc., also by means of a hotline (*www.cancer.fi*). In this connection, many awareness campaigns are held, usually in October, aimed at making people aware of the issue uniformly across the country.

The above-mentioned associations provide useful information also to the *Finnish Institute* of Occupational Health (www.ttl.fi/Internet/English/default.htm). In 2008, the institute conducted a study on how to reduce sick leave by the creation of an "Occupational health plan". In this connection, people at 48 medical centres were asked to fill in a questionnaire, in order to identify those who are "at high, medium, and low" risk in terms of sick leave (that is those who are more or less likely to take sick leave). The study revealed that in the first case, which includes cancer patients, leave of absence can be reduced considerably if sick people are granted adequate psychophysical support. Provided by a multidisciplinary team of experts (psychologists, social workers, etc.), this action plan should help sick workers to live with their condition. Unfortunately, less than half of the OHS (Occupational Health Services) provide such services, but Finland aims at developing them, also adopting a policy of "low tolerance" in terms of leave of absence.

Lassila & Tikanoja provides a good example of best practices, as in this company a study was carried out on the expenses born by the employer who has sick workers in his/her employment. The conclusion was that it is worth "investing" in the health and safety of its workers, not only from an economic point of view, but also in terms of corporate social responsibility. Besides promoting sport events and recreational activities, the company also provides adequate medical assistance and psychological support in the event of sickness. Workers who are unable to carry out their previous task after recovering, even after a rehabilitation program, are reassigned to more suitable ones. If it is not possible, the company helps them to find new employment.

### For women with breast cancer

The Breast Cancer Association in Finland was founded in 2006. The main goal of the association is to provide information and arrange self-help group meetings among patient sand ensure equal treatments for all patients. The self-help group meetings are held twice a month in the centre of Helsinki. Patients with recurrence have their own meetings.

Medical professionals train the team leaders of the self-help group meetings.

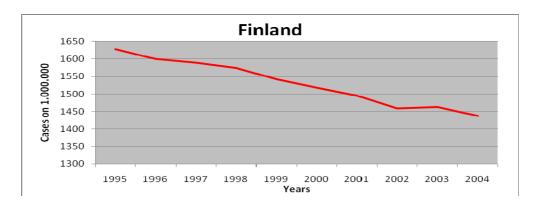
The Finnish Breast Cancer Association has many activities for its members. The association is creating relationships with the medical professionals and other important groups and has shown the need for a group for breast cancer patients in Finland.

### **Statistics**

Analysis of the processed 2006 Eurostat data. Mortality for cancer (standardized data considering 1.000.000 cases)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
Finland	1629	1601	1590	1575	1543	1519	1496	1459	1463	1438		
%	0,163%	0,160%	0,159%	0,158%	0,154%	0,152%	0,150%	0,146%	0,146%	0,144%		
Variazione		-0,003%	-0,001%	-0,002%	-0,003%	-0,002%	-0,002%	-0,004%	0,000%	-0,003%		

2006 Eurostat data progress chart. Mortality for cancer (standardized data considering 1.000.000 cases)



### Further information

# **Europa Donna Finland**

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# **Finnish Cancer Organisations**

www.cancer.fi

# Finnish Institute of Occupation Health

www.ttl.fi/Internet/English/default.htm

### France

## Legal protection for the worker in case of disability and oncological conditions

In France, there are no specific rules providing legal protection for women. The principle of non-discrimination is adopted, and it runs for the entire duration of the employment contract. In the event of discrimination, the employer might be subject to civil and criminal penalties. There are, however, some exceptions. Before recruitment, employees may be asked to undergo a series of medical examinations testing eyesight and hearing, in order to verify their driving skills and to ensure their physical fitness for a specific task. In this regard, bus drivers, railway operatives and airline pilots, for instance, undergo regular medical examinations.

In addition, after a period of sick leave, workers are required to undergo a medical checkup, in order to verify their ability to start to work again.

The company medical officer can also propose some changes in the employee's working conditions, such as more flexible working time, part-time working, or a new assignment. The medical officer might also ask for a new work place, in order to allow the worker to be closer to home. In any case, the employer has the responsibility to provide the worker with the best employment conditions, according to his/her health status.

In case of sickness, a full-time contract might be changed into a part-time one. It is granted by the national insurance and has a maximum length of three years. Generally speaking, it is provided during medical treatment or recovery, allowing the worker to return to work and to receive sickness benefits.

In case of dismissal (because there are no suitable assignments for the worker, or because it is too expensive for the employer to guarantee adequate working conditions, especially in relation to his/her productivity) the employer is responsible for this decision, and has to prove it has been made in the interests of the enterprise.

In the event that, after the sickness, the worker is often absent, the courts might be asked to decide if the number of the absences is such as to compromise the structure of the company. In this case, he can also agree to his/her dismissal, even though the employer has to prove he has done his/her utmost to avoid it. If the dismissal takes place, severance pay that is as much as twice the usual severance pay, is due to the worker.

### Specific Legal Protection for people with cancer

People with cancer receive specific legal protection, as cancer is included in a list of chronic diseases.

In case of cancer, national insurance covers all expenses of hospital treatment and medical examinations, while the sick person has to pay only for his/her personal expenses, such as the cost of phone calls and a room with TV.

The employee with cancer or any other disease included in the above-mentioned list is covered by the following provisions:

- from the day of diagnosis, the national insurance grants him/her a daily subsistence allowance for sickness, that is 50% of his/her daily earning (the worker receives the remaining amount only if provided by the applicable collective agreement with a specific clause);
- the employee has to undergo a medical examination provided by the National Welfare and Assistance Fund (as well as the one provided by the enterprise, if the worker is paid sickness benefit);
- if provided by the collective agreement, or at the request of the worker after a ministerial order, the sickness benefit might be recalculated annually, according to wage developments within the enterprise;
- an increase of such sickness benefit is provided if the worker has more than three dependent children;
- the sick person who absents him/herself from his/her domicile without

justification, or who has another occupation, will forfeit his/her sickness benefit.

After three years' sick leave, the worker can be certified as permanently disabled if still unable to work even in another occupation, and he/she will be granted a disability pension or, where possible, a retirement pension. Social security contributions paid while in receipt of sickness benefit or a disability allowance are taken into account if the worker applies for a retirement pension, and are added to contributions paid while working.

In the case of a seriously debilitating condition, the employee is entitled to early retirement, even though he/she is not 60 years old yet (that is the mandatory retirement age). In any case, if the worker retires after obtaining a disability pension, and if he/she is not self-sufficient, a 40% increase of the pension can be granted. (The same applies in Italy with the '*Indennità d'accompagnamento'*). In some cases, occupational funds provide a supplementary pension, usually allocated according to the period of illness.

National Best Practices (overview)

### For people with cancer

In France, the National Cancer Institute plays an active role (www.e-cancer.fr).

Key Partners:

The Ministry of Science and Technology (Ministère de la recherche) - www.enseignementsup-recherche.gouv.fr

The Ministry of Health (Ministère de la santé) - www.sante-jeunesse-sports.gouv.fr

The National League Against Cancer (*Ligue Nationale contre le Cancer*) - www.ligue-cancer.asso.fr

The Association for Cancer Research (Association pour la Recherche sur le Cancer - ARC) - www.arc.asso.fr

The National Sickness Insurance Fund (Caisse Nationale d'Assurance Maladie des Travailleurs Salariés - CNAMTS) - www.ameli.fr

The National Social Insurance Mutual Benefit Fund (Caisse centrale de la Mutualité Sociale Agricole - MSA) - www.msa.fr

The National Institute for Medical Research (Institut National de la Santé et de la Recherche Médicale - INSERM) - www.inserm.fr/fr

The National Institute for Scientific Research (Centre National de la Recherche Scientifique - CNRS) - www.cnrs.fr

The Private Hospitals Association (Fédération de l'Hospitalisation Privée - FHP) - www.fhp.fr

The Association of French Hospitals (Fédération Hospitalière de France - FHF) – www.fhf.fr

The Association of Private Hospitals and Assistance (Fédération des Etablissements Hospitaliers et d'Assistance Privés - FEHAP) – www.fehap.fr

The National Federation of French Cancer Centers (Fédération Nationale des Centres de Lutte Contre le Cancer - FNCLCC) - www.fnclcc.fr

### For women with breast cancer

Europadonna France is conducting a wide-ranging awareness-raising campaign, planning social events (such as marathons, that are very popular in France), and publishing many

articles on the newspaper and brochures, then distributed through doctor's surgeries. In addition, many specialists, such as gynecologists, including some who are retired, that have a leading position in the organization, are collaborating with the National Cancer Institute (see above)

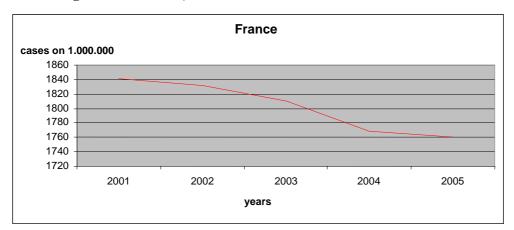
www.europadonna.fr

### **Statistics**

Analysis of the processed 2006 Eurostat data. Mortality for cancer (standardized data considering 1.000.000 cases)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
Francia							1841	1832	1810	1768	1761	
%							0,184%	0,183%	0,181%	0,177%	0,176%	
Variation								- 0,001%	- 0,002%	- 0,004%	- 0,001%	

**2006** Eurostat data progress chart. Mortality for cancer (standardized data considering 1.000.000 cases)



# **Further Information**

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----/

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Fax: 01 47 26 04 75

e-mail address: contact@arc.asso.fr

### **The National Federation of French Cancer Centers**

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### Fédération des Stomisés de France

www.fsf.asso.fr

# Société Française de Sénologie et de Pathologie Mammaire

www.senologie.com

# Institut de Veille Sanitaire

www.invs.sante.fr

Regards sur la maladie cancéreuse: Festival de films organisé par l'UICC www.reellives.org

**Association Eve** (for the implementation of cervical cancer screening in Alsace) www.eve.asso.fr

### **Germany**

### Legal protection for the worker in case of disability and oncological conditions

Germany safeguards the interests of people with disabilities in a number of ways, by providing, for instance, disability benefits or by promoting training courses. In addition, the employer can benefit from tax relief, according to the number of disabled persons hired by the enterprise (consider, for example, that enterprises with 20 employees are required to employ at least one disabled worker. Otherwise, they may be subject to a penalty).

In this regard, the main legal sources are the *SGB IX*, the Ninth Book of Social Code 2001, (*Neuntes Buch des Sozialgesetzbuches*), and the *BGG*, the 2002 Document on Equal Opportunities for People with Disabilities (*Behindertengleichstellungsgesetz*), as well as the 2004 reform that promotes job opportunities and training courses for people with disabilities. Such reforms pay particular attention to women with disabilities, aiming at facilitating their integration into the working environment and society.

Pursuant to the SGB IX, a disabled individual is a person who suffers for a period of more than six months from a mental or a physical deficiency, that is unusual among people with the same age. The degree of disability, ranging from 20 to 100 per cent, is assessed by the Versorgungsamt with a procedure that guarantees impartiality of judgment. An individual with a 50% disability is considered 'seriously disabled', but this status also includes people with more than a 30% disability who are unable to find an occupation because of their condition. In this case, the disabled worker is paid sickness benefit, but he/she is not entitled to other facilities, such as free public transport. Therefore, such provisions are very effective, because, as noted earlier, they aim at facilitating the integration of people with disabilities into the working environment, even of those with reduced capacity to work, and therefore considered as 'seriously disabled'. In this sense, the disabled worker has to be provided with necessary instruments to increase his/her capacity to work, and it is for the national insurance to cover their cost, if the employer is

unable to afford it. In the event of an additional reduction of individual working capacity, the worker is entitled to change from full-time to part-time working. In addition, the German legal system safeguards workers also in the event of dismissal. The employer cannot dismiss workers without offering them another position compatible with their health status. In this case, the *Integrationsamt* has to give its approval. Such approval is almost mandatory also in the following cases:

- in the case of a reduction of the workforce, if the employer has the required number of workers with disabilities:
- in the event of a factory closure, on payment of monthly salaries;
- in the event there is not a clear link between the worker's disability and his/her dismissal:
- in case of consensual resolution of the employment relationship, if the contract has a term of less than six months, or if the worker is less than 58 years old and he/she is already in receipt of sickness benefit.

People with serious disabilities are also entitled to an additional week of leave every year and cannot work overtime. Those who are unable to find employment are entitled to an additional unemployment benefit for a period from three to eight years (the eight-year limit applies to older workers).

If there are more than five disabled workers in an enterprise, they have the right to appoint a representative, whose main task is to verify the implementation of the above-mentioned provisions.

Those who cannot carry out any working activity are paid sickness benefit and have the opportunity to participate in training courses to improve their working skills.

# Specific Legal Protection for people with cancer

Since 1997, German law system has provided safeguards for people who have contracted cancer if they have been exposed to harmful agents on their working place. In Germany, as well as in the rest of Europe, an unhealthy lifestyle has caused a significant increase of cancer. According to German law, however, compulsory insurance (related to industrial

associations, farming and public services) will provide a sickness benefit only if the pathology is the result of the work activity. This is the only case in which the Eighth Book of the SGB provides a compensation scheme for sick-workers. In this regard, the HVBG, Hauptverband der gewerblichen Berufsgenossenschaften (www.hvbg.de/pages/index.html), an important insurance company, plays a leading role.

### Administrative procedures related to legal protection

Germany took two years to set up a database that includes the most common forms of cancer and their incidence. In order to do so, they used the data collected by the *Robert Kock Institute* (known as "cancer registers") and personal data from the Federal Statistic Centre. Ten regions have created their own register, while a common register is used by the others. This mechanism allows them to publish an updated report each year, and to predict the future incidence of the disease. It is also possible, for instance, to evaluate the relationship between social conditions and the treatment of this medical condition. In this regard, they have noticed that the death rate among the unemployed is much higher than that among those who have a non-manual job.

### National Best Practices (overview)

### For people with cancer

There are several associations that support people with oncological diseases and their family. In this sense, the most important is the *Deutsche Krebshilfe* (www.krebshilfe.de/english.html), that aims at helping and supporting the sick person also from an economic point of view, with the creation of smaller organizations.

#### For women with breast cancer

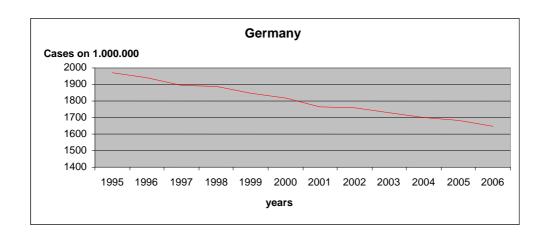
The *Deutsche Krebshilfe* is carrying out several research projects, aimed at determining whether cancer can be transmitted genetically. In addition, a screening campaign involving many families has been launched, and women classified as being at high risk undergo medical examinations periodically.

### **Statistics**

Analysis of the processed 2006 Eurostat data. Mortality for cancer (*standardized data considering 1.000.000 cases*)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
Germania	1970	1941	1895	1890	1850	1820	1765	1758	1730	1698	1680	1650
%	0,197%	0,194%	0,190%	0,189%	0,185%	0,182%	0,177%	0,176%	0,173%	0,170%	0,168%	0,165%
							-	-	-	-	-	-
Variation		-0,003%	-0,005%	-0,001%	-0,004%	-0,003%	0,005%	0,001%	0,003%	0,003%	0,002%	0,003%

2006 Eurostat data progress chart. Mortality for cancer (*standardized data considering* 1.000.000 cases)



# **Further Information**

# **Europa Donna Germany**

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# Hungary

Legal protection for the worker in case of disability and oncological conditions

In Hungary, the economic gap between the various regions, and the social-demographic diversity between the various cities have been the main causes of a rise in discrimination in social and professional context.

In 2003, it was estimated that the total number of people with disabilities was 900,000 and only 10% of them were able to find employment.

In 1998, the government passed Act no. 26 against discriminatory conduct, which includes the prohibition of discrimination against people with disabilities (the Constitution does not provide special legal protection in this connection) and aims at changing the government's paternalistic attitude towards disabled people. Despite these measures, however, employment among people with disabilities has not increased, and the health system fails to provide effective rehabilitation programmes, guaranteeing only passive welfare measures.

In 2003, the government passed Act no. CXXV on Equal Opportunities for People with Disabilities, and approved the National Development Plan for 2004 to 2006, focusing on the necessity to set a national policy on the issue. By setting a deadline for the completion and by using EU funds, the aim of the programme is to provide the disabled person with: effective means of communication, information, transport, adequate medical facilities, equality of treatment in medical care and education, adequate rehabilitation, and the opportunity to participate in cultural events, sport and recreational activities. In addition, they should be supported when they return to work.

The plan also provides the setting up of a Commission to coordinate the work, establishing that, in the case of discriminatory conduct, the disabled worker is entitled to apply to the authorities.

With respect to economic support for people with disabilities, the 1997 provision on benefits was amended a year later, with the introduction of private benefits. In general, sickness benefit is provided to people with a reduced capacity to work that is more than 67%, without an occupation, or depending on low wages before the disability (especially when compared to the benefit). The amount of the benefit is usually calculated on the basis of the degree of disability (there are three degrees of disability) and the insurance period, and can be increased if there is a total disability. If the worker has suffered an industrial injury causing a total disability, or a degree of disability greater than 67%, contributions are not taken into account. Furthermore, a series of special allowances can be provided for the disabled person, depending on whether the disability is permanent or temporary. They are also entitled to free medical care and life-saving therapies in public facilities. In the case of absence from work due to medical treatment, the company provides paid sick leave for two weeks. Starting from the sixteenth day, this financial support is provided by national insurance for a maximum of one year.

Despite the fact that Hungary was the first country to ratify the 2007 UN Convention on the rights of people with disabilities, there is considerable difficulty in its implementation. In this connection, in autumn 2008, 13 organizations representing disabled persons formally asked the Prime Minister to establish a Parliamentary Committee, empowered to verify the effectiveness and the application of the convention at a practical level.

# Specific Legal Protection for people with cancer

The EU directives that safeguard workers in the case of exposition to harmful substances have been implemented gradually. In this connection, on 30 November 2000, the government passed Decree no. 26 on legal protection for people with cancer, mostly based on the provisions provided by EU directives 83/477 and 91/382, regarding the risks caused by exposure to asbestos. Decree no. 16 of 8 June 2000, makes provision for nuclear industry workers, and complies with EU directive 90/641 on ionizing radiations.

# Specific Legal Protection for the women with breast cancer

It is noteworthy, however, that there is a widespread discrimination against women and people with disabilities, even though the government has made a considerable effort to ensure equal opportunities in the working environment (see the data provided by the National Statistical Office in http://portal.ksh.hu).

### Administrative procedures related to legal protection

The main goals of the "Ten-year Health Plan" (*Johan Béla Programme*) contained in Resolution no. 46 (2003), are: to increase national life expectancy, in order to conform to the European standards; to improve quality of life, by reducing health risks; to provide equality of treatment in terms of medical treatment, and to improve people's living conditions (see *www.eum.hu*).

Furthermore, on 7 April 2004, Hungary ratified the *WHO Framework Convention on Tobacco Control*, and announced the Tobacco Reduction Strategy 2005 to 2006.

### National Best Practices (overview)

### For people with cancer

A Cancer National Register, which was set up in 2000, contains all information related to new cases, such as type of cancer, diagnosis and medical treatment. This Register has enabled researchers to identify a number of factors causing the disease, and subsequent information campaigns have succeeded in reducing cancer death rates, after 25 years.

Another relevant aspect is that health system has been reformed. In order to provide and share medical information at a national level, an automated Health Portal (see <a href="https://www.magyarorszag.hu">www.magyarorszag.hu</a>) has been created (known as "e-health"), while an Electronic Card (known as the "e-Europe smart card") has been dispensed to the users.

The impact of this reform was discussed in February 2008, at the International Congress in Budapest, which involved representatives of the *World Health Organization*.

Furthermore, the active role played by patients in research (in filling in a medical questionnaire) has made it possible to identify the connection between prolonged exposure to certain substances in the work place and some types of cancer, such as lung cancer. The 2006 Hungary National Cancer Control Programme is also noteworthy. In the view of IARC (International Agency for Research on Cancer) this programme plays a key role. It aims at promoting effective measures to reduce death rates, and to support

early diagnosis and nationwide screening, following the World Health Organization guidelines and parameters. In the same way, The Hungarian League against Cancer is deeply involved in promoting prevention campaigns, and raising public awareness on screening.

### For women with breast cancer

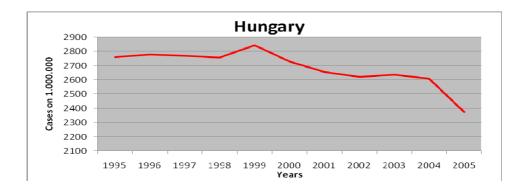
Starting from 1999, Primavera Mobil Mammography Programme and the US embassy launched a wide-ranging awareness campaign, to promote screening nationwide. It should be noted that social, cultural and economic differences among local women are considerable. Many other events have been organised since then, such as the Walk Across Budapest's Chain Bridge, which took place for the first time in October 2005, and is now held each year. They have resulted in effective media coverage, and they also have contributed to changing women's approach to the issue. The latest statistics show that the breast cancer death rate has fallen. In order to be effective, however, information campaigns should focus on women who are members of ethnic minorities, especially those belonging to the Rom community, as they have been classified as being at high risk. The statistics show that Roma women with breast cancer are three times higher more likely to die than other women (see www.errc.org/cikk.php?cikk=2136 for further information on Roma women). In this regard, many associations have mobilized to face the issue: the National Public Health and Medical Officer Service (ANTSZ), the Hungarian Association of Public Health Nurses, the Hungarian Red Cross, the National Institute for Health Development, the Hungarian League Against Cancer, the National Association of Cancer Patients, and the Social Innovation Foundation.

# Statistics

Analysis of the processed 2006 Eurostat data. Mortality for cancer (standardized data considering 1.000.000 cases)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
Hungary	2762	2780	2772	2759	2845	2730	2656	2623	2638	2608	2374	
%	0,276%	0,278%	0,277%	0,276%	0,285%	0,273%	0,266%	0,262%	0,264%	0,261%	0,237%	
							-	-		-	-	
Variazione		0,002%	-0,001%	-0,001%	0,009%	-0,012%	0,007%	0,003%	0,002%	0,003%	0,023%	

2006 Eurostat data progress chart. Mortality for cancer (standardized data considering 1.000.000 cases)



# **Further Information**

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# Italy

Protezione generale in materia di lavoro da parte della legge in caso d'invalidità, compresa la patologia oncologica

Act No. 104/1992 (the framework law on assistance, social integration, and the rights of people with disabilities), which implements Articles 3 (2) and 4 of the Constitution, provides guidelines on how to protect disabled people, safeguarding their rights and dignity. It also provides that people with this condition should be granted the necessary medical assistance and treatment, and ad hoc rehabilitation programmes, in order to avoid their social exclusion. Special legal measures are provided to facilitate their access to employment (Act 68/1999 Disability "Eligibility criteria" provided by Decree of the President of the Council of Ministers of 10/06/2004). In addition, employers are legally obliged to hire a certain number of individuals with a disability greater than 33%, (which includes disabled servicemen, people with a visual impairment, and people with a major hearing/speaking impairment). More specifically, they are obliged to reserve a number of posts for people classified as disabled (the *quota di riserva*). This number depends on the company size:

- at least 7% of employees for enterprises with more than 50 employees;
- at least two employees for enterprises with 36 to 50 employees;
- at least one employee for enterprises with 15 to 35 employers.

All employers in Italy are subject to the law, with very few exceptions.

Moreover, Article 14 of Legislative Decree 276/2003 facilitates the occupational integration of disabled people, providing that trade unions, employer's organisations, and social cooperation associations should cooperate to develop framework agreements at a local level.

Article 33 (6) of Act 104/92 gives workers with major health problems, and their relatives up to the third degree of kinship, the right to choose the workplace nearest to home, also providing that such employees cannot be transferred against their will. Article 21 gives public employees priority in the choice of work in the case of transfer, if such an

employee has a disability exceeding two-thirds. As for regulation by means of collective bargaining, Italian legislation grants workers with disabilities the right to remuneration during sick leave, and to reassignment to other duties, according to their state of health. It is also important to underline that individuals with a disability greater than 50% have the right to 30 days' paid leave, and to receive medical treatment (Art. 26 of Legislative Decree 118/1971, and Art. 10 of Legislative Decree 509/1988). In the case of a serious disability, Art. 33 of Act No. 104 grants parents and family of the sick employee who continuously and exclusively assist a family member up to the third degree of kinship paid sick leave for up to two hours a day, or three days a month. In addition, Act No. 53/2000 also recognises the right to paid leave of absence of three working days a year in case of the certified serious disability of a spouse or parents or grandparents, or an unmarried cohabitant on condition that stable cohabitation is proven. The definition of "serious disability" was open to interpretation. For this reason, the Ministry of Labour, with the Ministerial Decree No. 278/2000, provided a list of conditions coming under the definition of "serious disabilities", in order classify the cases in which paid sick leave should be granted to the worker. Legislative Decree No. 276/2003 provides people with this a serious disability with two types of contract arrangements: and "access-toemployment contract", for people classified as "seriously disabled", which covers individual training programmes, helping workers to acquire special working skills, to be used in a specific working environment. The other type of contract makes provision for "ancillary work on an occasional nature" (Act No. 80/2005 and Act No. 133/2008) allowing individuals to work on an intermittent basis. With regard to the working environment (Legislative Decree No. 626/94), the employer must safeguard disabled workers' health and safety at work, also providing ad hoc facilities (step-free access, bathrooms, etc). Therefore, the working environment should also be equipped with all necessary facilities, especially in case of emergency, and should take into account the disability of the worker (Ministerial Circular No 4/2002, referring to the safety of people with a disability in the event of fire). In this regard, government issued a number of provisions prohibiting direct and indirect discrimination against workers with a disability (Legislative Decrees No. 215/2003 and No. 216/2003). Pursuant to law, there is also a difference between "invalidity" and the "disability". In this regard, Act No. 222/84,

defines invalidity in relation to: "the insured party, whose working capacity in work that suit his natural skills is permanently reduced to less than one-third due to infirmity or a physical or mental impairment" (Art. 1). Individuals in this category are entitled to disability benefit, which can be renewed every three years if the medical condition persists. After reaching retirement age, this benefit is converted to a retirement pension (Art. 4).

Art 1 also states that in the event of infirmity, or a physical or mental impairment, the individual is absolutely and permanently prevented from performing all working activities. He/she is also granted a disability benefit until recovery. A disability pension is also paid to retired people who need continuous assistance (Art. 5 of Act No. 222/84). Legislative Decree No. 216, implementing Directive 2000/78/CE, is a key document, because together with Act No. 300/70 (Statuto dei lavoratori), it provides equal treatment in terms of legal protection for people with disabilities. Act No. 67/2006 also provides that in the event of discriminatory conduct, the worker with a disability has the right to apply to the authorities, in order to obtain the elimination of this conduct, compensation for injury, and the application of criminal sanctions. People who look after individuals with this condition are also provided with legal protection. In addition to paid sick leave, public and private employees who take care of people with a serious disability, are entitled to a continuous or intermittent leave (depending on the applicable collective agreement) for a maximum of two years (Art. 4 of Act No. 53/2000). During this period, carers cannot be dismissed, even though they cannot perform their work. Art. 4 bis of Act No. 53/2000 is also noteworthy. This article specifies that an employee who is the mother or father, either natural or adoptive, or in the event their death, a cohabitant brother or sister of the seriously disabled person, has the right during the entire period of leave of absence to a monthly allowance corresponding to the last salary with contributions up to maximum annual amount of 35,000 euros. Moreover, Legislative Decree No. 151/2001 (provisions relating to the protection of maternity and paternity), widened the range of protective measures, while Article 42 (6) states that an employee who is the parent of a seriously disabled person may take leave, time off and holidays. An individual who is caring for a disabled person cannot be required to work a night shift.

Act. No. 53/2000 (Provisions on parental and training leave and the provisions for supporting motherhood and fatherhood, for the right to provide care, and the right to training), provides a legal instrument allowing those who look after individuals with disabilities (parents or relatives) to conciliate working times and family life. Furthermore, the Personal Data Protection Code of 27 June 2003 provides that information on leave of absence may not be communicated to third parties, as it is considered to be "sensitive data". This is very important for cancer patients, who cannot be discriminated against because of their medical condition.

Italy is a signatory of the UN Convention on the Rights of Persons with Disabilities. It was amended on 28 November 2008, providing that a national observatory should be set up in each country, to safeguard the rights of people with disabilities.

# Specific legal protection for people with cancer

Specific legal protection for people with cancer was introduced in 2000. However, there was considerable difficulty in its implementation, because of time-consuming procedure for certifying the medical condition.

As a result, in 2006, Parliament passed Act no. 80/2006, which introduces a fast-track procedure for the assessment of disability, in the case of oncological conditions, with the obligation for the medical commission or panel of the competent local authority to carry out an examination within 15 days of the date of the application.

In terms of legal protection, Act. No. 53/2000 is also effective. More specifically, Decree No. 278/2000 enacting Article 4 states that: "serious reasons should be taken to include [...] acute and/or chronic conditions determining permanent or temporary reduction or loss of personal autonomy including chronic diseases such as cancer" and those "chronic and acute conditions requiring continuous assistance or frequent clinic, hematochemical and instrumental monitoring".

In 2003, Article 3 (106), Act No. 350/2003, repealed the clause in Article 42, Legislative Decree No. 151/2001, requiring at least five years of serious certified disability for the granting of paid leave pursuant to Article 4 (2) of Act No. 53/2000 allowing access to the benefits to a number of family members of the worker with an oncological condition.

Article 46 of Legislative Decree No. 276/2003 relating to the provisions on part -ime work is also important. It provides the right to change the employment relation from full-time to part-time, either horizontal or vertical, for workers with oncological conditions, also with a reduced working capacity because of the invalidating effects of treatment which must be duly certified by the medical commission of the competent local health authority. It is up to the interested parties (the employer and the worker) to establish the reduced working time, according to their specific needs. This article also lays down the obligation to change employment contract from part-time back to full-time following a request submitted by the employee: in any case the provisions most favourable for the employee remain in force.

On 1 January 2008, Parliament passed Act No. 247/2007, explicitly stating that the norm is applicable in the private and public sector, and introducing an important principle: recognition of priority for changing the employment contract from full-time to part-time also in cases where oncological conditions concern the spouse, children or parents of the employee. Act No. 247/2007 provides priority in hiring an employee who has changed the employment contract from full-time to part-time where the activity is the same or equivalent to the part-time employment.

In this regard, Art. No. 85 of 2001, the Finance Act, (Act No. 388/2000) is also noteworthy. It provides that for women aged 45 to 69 years who take part in cancer screening once every two years this service is free of charge.

### Administrative procedures related to legal protection

In Italy, the National Health Plan 1994 - 1996 included "Preventive measures and medical treatment of oncological conditions", and in 2006, the National Observatory issued specific guidelines on this matter. With the National Health Plan 1998 - 2000 (approved by the Decree of the President of the Council of Ministers of 23/07/1998), screening programs were provided at a national level. On 8 March 2001, the Ministry of Health and the Autonomous Provinces of Trento and Bolzano signed an Agreement providing guidelines on preventive measures, early diagnosis, and medical assistance for people with oncological conditions. Furthermore, on 29 November 2001, a Decree of the

President of the Council of Ministers issued a list of the essential services that the National Health System should provide for citizens, such as free screening for breast, cervical, and colon-rectal cancer. The Minister of Health later issued another decree laying down parameters to be used to monitor the provision of these service at regional level. The National Health Plan 2003 - 2005 (Point 3.2.2), which was approved by the President of the Republic on 23 May 2003, dealt with cancer, giving priority to medical treatment, preventive measures and information. After the Council Recommendation 2003/878/EC of 2 December 2003 on cancer screening, the Government set up the National Health Plan and the National Observatory 2004 - 2006 (Art. 2 bis of Act No. 138 of 26 May 2004), aimed at "reducing social inequalities among regions in terms of cancer prevention, launching (breast and cervical) cancer screening programmes, and promoting biomedical research". The National Plan for Active Prevention was issued on 6 April 2004, following the Sanità Futura Forum, promoted by national and regional authorities, on the basis of the Community Action Programme for Public Health 2003 -2008. The Plan focused on active prevention, that is to say it aimed at making people more aware of preventive measures and of the key role of regions in combating the illness. On 3 November 2004, the Minister of Health issued a Decree setting up three workgroups (for breast, cervical, and colon-rectal cancer, respectively), for the implementation of the Screening Programme (2 December 2004) on the basis of Act. No. 138. In this regard, funding is allocated to the Regions and Provinces to promote screening measures. Moreover, in order to monitor their activities, the Ministry of Health and the National Observatory signed an agreement on 21 March 2005. Two days later, the State and the Region concluded an agreement on the National Health Plan 2005 -2007, with the aim of promoting the screening programme at national level. On the basis of Act No. 138 and the 2005 agreement between the State and the Region, the government issued new guidelines on the promotion of screening at a regional level on 28 April 2005, which included a Handbook explaining how to present a screening project. On 18 October 2005, the Ministry of Health set up the three workgroups again, with the aim of implementing the new guidelines on the basis of the 8 March 2001 Agreement.

On 21 July 2006, the Ministry of Health set up a Special Cancer Programme, focusing on "preventive measures, medical treatment, rehabilitation programmes, technological innovation, and international cooperation".

In this connection, an agreement between the government and the Region of Basilicata was concluded on 11 December 2006, to promote screening measures in the south of Italy.

For further information on regional screening programmes, please consult www.osservatorionazionalescreening.it/ons/screening/regioni.htm.

The National Health Plan 2006 - 2008 was approved by Presidential Decree of 7 April 2006.

On 19 January 2006, the Decree of the President of the Council of Ministers provided that a National Cancer Survivors Day should be held on the first day in June (if the Republic Day is celebrated on that day, it is postponed to the following Sunday). A similar initiative takes place in the USA, and it aims at focusing the attention on people in this group and their families.

The National Institute of Health (ISS) plays a key role in combating illness, also working with IRCCS. In addition to receiving special fund for research (according to Ministerial Decree of 21 July 2006), the Institute is also involved in a number of European projects on cancer prevention (an interdepartmental group studying the disease has been set up in this connection), promoting activities related to this issue.

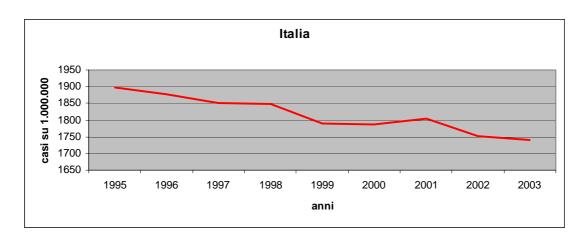
More specifically, the Institute is taking part in four projects, the most important of which is "La Medicina di Genere come Obiettivo Strategico per la Sanità Pubblica: l'Appropriatezza della Cura per la Tutela della Salute della Donna" (which aims at providing medical treatment for women with cancer). Presented on 9-10 December 2006, this project was funded by the Ministry of Health, Labour, and Social Policy (with funding of 2.7 million euros). Several institutions were also involved in the project: the Regions of Tuscany, Sardinia and Sicily, the National Institute for Occupational Safety and Prevention, representatives from the Rome Social Services Agencies, two institutes for scientific research and treatment, and a number of universities (Cagliari, Firenze, Messina, Modena, Piemonte Orientale-Novara, Roma- La Sapienza, Roma Tor Vergata, Sassari).

# Statistics

# Analysis of the processed 2006 Eurostat data. Mortality for cancer (standardized data considering 1.000.000 cases)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
Italia	1898	1877	1850	1848	1790	1788	1805	1753	1740			
%	0,190%	0,188%	0,185%	0,185%	0,179%	0,179%	0,181%	0,175%	0,174%			
Variazione		-0,002%	-0,003%	0,000%	-0,006%	0,000%	0,002%	0,005%	0,001%			

# 2006 Eurostat data progress chart. Mortality for cancer (standardized data considering 1.000.000 cases)



Deaths and standardized data - Tumours Istat data 2006

	Numero	decessi	Tasso standardizzato 1.000.000			
	2003	2006	2003	2006		
Tumori	167.133	172.096	2864	2776		
Tumori maligni dello stomaco	11.024	10.884	189	175		
Tumori maligni del colon, retto e ano	17.255	18.558	295	298		
Tumori maligni della trachea, bronchi e polmoni	32.264	33.275	554	542		
Tumori maligni della mammella della donna	11.461	11.480	197	186		

#### Further information

#### **National Websites**

Ministry of Health, Labour, and Social Policy – www.ministerosalute.it

Europa Donna Italy – www.europadonna-italia.it

ACC – Alliance against cancer – www.iss.it/acca

AEIOP – Italian Association of Pediatric Hematology and Oncology – www.aieop.org

AILAR – Italian Association of Laryngectomees – www.laringect.it

AIMAC – Italian Association of Cancer Patients – www.aimac.it

AIOM – Italian Association of Clinical Oncology – www.aiom.it

AIRC - Italian Association for Cancer Research - www.airc.it

AIRTUM – Italian Association of Cancer Registries – www.registri-tumori.it/cms

AIS – Breast Surgery Association - www.senologia.it/rivista/default.html

AISTOM – Italian Ostomy Association - www.aistom.org

Alliance Against Cancer - www.e-oncology.it

ALTEG – Association of Young People with cancer - www.alteg.net

ALTS - Breast Cancer Association - www.alts.it

ANAPACA - National Association of Psychological Assistance for Cancer Patients - www.anapaca.it

ANDOS - National Association of Women who have had Breast Surgery - www.andosonlusnazionale.it

ANGOLO – National Association of People Recovering from Cancer - www.associazioneangolo.it/angoloweb/home.html

ANVOLT – National Voluntary Association Against Cancer- www.anvolt.org

Association against Children's Cancer-www.iodomani.it

Italian Association of Geriatric Oncology - www.aiote.org

ATTIVE - www.attive.org

CCM - National Centre for Disease Prevention and Treatment - www.ccm-network.it

CRO – Oncologic Research Institute - www.cro.sanita.fvg.it

EpiCentro - National Center of Epidemiology, Surveillance and Health Promotion - www.epicentro.iss.it

Europa Uomo – Men's Cancer Association – www.europauomo.it

Italian Federation of Cancer Volunteers Associations - www.favo.it

FIAGOP - Italian Federation of Parent's Associations of Children with Pediatric Hematology - www.fiagop.it

FIRC - Italian Foundation for Cancer Research - www.fondazionefirc.it

Cancer National Association - www.antnet.it/pubb

Faro Foundation - www.fondazionefaro.it

Gigi Ghirotti National Foundation - www.ghirotti.org

Nerina e Mario Mattioli Foundation - www.fondazionemattioli.it

Umberto Veronesi Foundation - www.fondazioneveronesi.it

Fondo Edo Tempia - www.fondoedotempia.it

National Task Force Against Breast Cancer - www.senologia.it/foncam/default.html

GISCi – Italian Group for Cervical Cancer Screening - www.gisci.it

GISMa - Italian Group for Cancer Screening - www.gisma.it

IEO – European Institute of Oncology - www.ieo.it

ISPO – Institute for Cancer Study and Prevention - www.cspo.it

National Institute of Health - www.iss.it

Cancer in Italy – Portal for Cancer Epidemiology- www.tumori.net/it

Italian Association against Cancer - www.legatumori.it

OncoCare, Online reference sources for cancer - www.oncocare.it/it/default.htm

ONDA – National Observatory for Women's Health - www.ondaosservatorio.it

Cancer Genetical Risks - www.rigenio.it

Italian School of Senology - www.senologia.it/scuola

SP — cancer prevention measures and initiatives www.spazioprevenzione.it/default.asp

SIS – Italian Senologic Society - www.societaitalianasenologia.it

National Guidelines System - www.pnlg.it/

UGI - Cancer Parent Organisation - www.ugi-torino.it

VITA DI DONNA – non-profit association for the protection of women's health - www.vitadidonna.it

#### Lithuania

### Legal protection for the worker in case of disability and oncological conditions

Lithuanian labour legislation provides general rules applied to disabled or ill workers, but no specific protection regarding women workers with oncological diseases. Besides, special work protection is provided only when person has legal status of "disabled" worker. On 28 November 1991, that is to say before the entry into force of the 1992 Constitution, the government passed Act no. I-2044 (Law on Social Integration of People with disabilities), aimed at promoting the integration of people with disabilities into society. This law applies to all individuals who have a permanent or a total incapacity to work. There are three degrees of disability, depending on "the seriousness of the physical or mental disability, the extent to which it affects the individual and relational sphere, the enjoyment of his/her rights, and the performance of his/her duties". The law prohibits employers discrimination against individuals with disabilities in job procedures, and provides that an enterprise with more than 50 workers has to hire at least one disabled person (otherwise, the employer is subject to an increase in monthly contributions). Enterprises that hire people with disabilities are also granted a state subsidy, which is used to buy the necessary facilities allowing them to carry out their task properly. The Panel of experts that has to determine the percentage of invalidity is also legally bound to specify the working conditions that have to be provided for the disabled worker.

In the 1990s, Lithuania faces profound political, economic and social changes; within a very short period of time, the most important labour laws are adopted, aimed at creating ad-hoc health, insurance, and retirement systems for people with disabilities. The new Law on Social Integration of the Disabled enters into force on 1 July 2005. To implement the provisions of the new Law and ensure high-quality assessment of the level of capacity for work and disability level, the Disability and Capacity for Work Service under the Ministry of Social Security and Labour is established (the Service).

The Service decides on matters concerning:

- the level, cause, time of appearance and period of disability;
- the level, cause, time of appearance and period of capacity for work;
- the need for professional rehabilitation services for individuals under 18 who are (were) covered by state social insurance and individuals over 18;

- the nature and conditions for work of the disabled;
- general initial determination of special needs of the disabled.

From 1 July 2005, the disabled people over 18 until they reach the age for the old-age pension are awarded the capacity for work level instead of the disability group (children under 18 are awarded the disability level). The capacity for work level is set at the interval of 5 percentage points, i.e.:

if the person is recognised as having 0-25% of the capacity for work - he is deemed to be incapable for work;

in cases of 30–55% of the capacity - as partially capable;

in cases of 60–100% of the capacity - as capable for work.

With regard to the health system, the Ministry of Health plays a leading role, as it is responsible for the functioning of several services at local and regional level. It is important to point out, however, that the difference between "primary" and "special" care, which had been in existence until 1996 is no longer valid, especially in smaller medical facilities. The social integration system for the disabled comprises provision of medical, professional and social rehabilitation services, provision for special needs using special assistance tools, support to employment of the disabled, social assistance, award and payment of pensions and benefits of the State Social Insurance Fund, award and payment of benefits of the Compulsory Health Insurance Fund, provision of education services, ensuring equal opportunities to participate in cultural, sports and other areas of public life.

### Protection and specific rights at work

Employment and working conditions of disabled persons are set in the above mentioned Law on the Social Integration of Disabled, the Labour Code<sup>31</sup>, the Law on Occupational safety and health, other legal acts.

Specific rights that disabled persons may enjoy:

1. Disabled persons persons who have or may have additional difficulties in finding work due loss of functional capacity may be provided additional guarantees when being admitted to work.

The Labour Code of the Republic of Lithuania. Approved by Law No. IX-926 of 4 June 2002.

- 2. An employee shall be entitled to terminate a non-term employment contract, as well as a fixed-term employment contract prior to its expiry by giving his employer notice thereof at least three working days in advance before the day of submitting of the application, where his request to terminate the employment contract is justified by the employee's illness or disability restricting proper performance of work
- 3. An employment contract with employees, who are disabled, may be terminated on the initiative of an employer without any fault on the part of an employee only in extraordinary cases where the retention of an employee would substantially violate the interests of the employer. Disabled workers must be given notice of dismissal from work at least four months in advance.
- 4. Part daily working time or part weekly working time shall be set on request of a disabled person according to the conclusions issued by the Disability and Capacity for Work Service (the Service) under the Ministry of Social Security and Labour.
- 5. Disabled persons may be assigned to do overtime work only with their consent. Moreover, disabled persons may be assigned to overtime work provided that this is not forbidden by the conclusions of the Service.
- 6. The minimum annual 35-calendar-day leave shall be granted to disabled persons<sup>32</sup>. Unpaid leave shall be provided at the disabled employer's request for up to 30 calendar days per year. Additional facilities are also provided for the relatives who look after the disabled person (part-time working, work at home, flexible working time).

# The Labour Code provides:

It is prohibited to give notice of the termination of an employment contract and to dismiss from work (on the initiative of an employer without any fault on the part of an employee) an employee during the period of temporary disability (temporary disability according to the Lithuanian legislation means the period of illness (sickness). Employees, who have temporarily lost their functional capacity for reasons retain their position and duties if they are absent from work due to temporary loss of functional capacity for not more than 120 successive days or for not more than 140 days within the last 12 months.

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<sup>&</sup>lt;sup>32</sup> The standart minimum annual leave is a period of 28 calendar days.

Employees who are likely to be exposed to occupational risk factors must undergo a preentry medical examination and periodic medical examinations in the course of employment, according to the medical examination schedule for employees approved in the enterprise. Employees who are exposed to occupational hazards at work and who use dangerous carcinogenic substances in the course of their work shall undergo a medical examination upon employment; and periodic medical examinations in the course of employment and upon changing their work or workplace. Compulsory medical examinations shall take place during working time; the employer shall pay employees their average wage for the working time spent undergoing medical examination. An employee, who has refused to undergo a medical examination in due time, shall be suspended from work without paying him any wage. Such a refusal is treated as gross breach of duties.

The employee, who according to the conclusions of the Disability and Capacity for Work Service or health care institution may not perform the agreed work (hold position) due to his health status, as it poses danger to his health or his work may be dangerous to others, must be transferred, with his consent, to another job suitable for his health and, if possible, in line with his qualification.

#### Social insurance

Certain types of Social Assistance Benefits (provided to people who have reached retirement age but who are not entitled to a supplementary income; to the parents who have looked after a disabled child for at least 15 years, disabled children and other categories of persons) have been introduced. The national insurance body, *SODRA* (State Social Insurance Fund Board), is in charge of collecting contributions and paying for services. The Ministry of Labour and Social Security is at the head of a three-party organization (which includes representatives of social partners and members selected by governmental organizations) that monitors the activity of this Fund.

These Social Assistance Benefits provide financial support to disabled persons (or persons with disabled children) and guaranty minimum incomes.

Individuals covered by the sickness and maternity social insurance during the period of illness are entitled to receive the sickness benefit if due to the illness they lose their

income from work. The benefit is granted if before the day on which temporary incapacity for work was established, the insured has the social insurance period of at least 3 months in the last 12 months or 6 months in the last 24 months. The sickness benefit for the first 2 calendar days of sickness overlapping with the work schedule of an employee (except for the benefit for nursing a family member) is covered by the employer. The sickness benefit covered by the employer may not be lower than 80% and higher than 100% of the average salary of the beneficiary. Starting from the third calendar day of incapacity for work, the sickness benefit equal to 85% of the reimbursed salary is paid from the State Social Insurance Fund Budget. Sickness benefit is paid until the recovery or the day of establishment of the capacity for work.

# Specific Legal Protection for people with cancer

Starting in 1993, the Ministry of Labour and Social Security launched a wide-ranging research campaign, to study occupational diseases, paying special attention to oncological pathologies.

The 1993 Provisions on Safety at Work, as well as other provisions, allowed the Public Health State Service to identify and classify occupational diseases (see *www.stat.gov.lt* for statistical data). The Department of Labour is in charge of promoting effective measures to improve working conditions, and of sanctions for employers who break the law.

According to official statistics, 3.5% of cancer deaths are due to exposure to chemical substances in the work place, and 80% of the cancers contracted for this reason might have been prevented, as the risks due to the use of such substances were already known.

#### **Prevention at work**

The duty of the employer is to ensure safety and health of workers at work in all aspects related to work. All measures of safety and health at work shall be financed by the employer himself.

A workstation of each worker and the environment of workstations must satisfy the requirements of this law and other regulations on safety and health at work.

Workstations must be designed in such a way that workers working in them would be protected from possible injuries; their working environment would not contain risk factors harmful or dangerous to health. When designing workstations worker's physical capabilities must be evaluated.

# Protection of workers from exposure to dangerous chemical substances and preparations, as well as biological substances<sup>33</sup>.

If dangerous chemical substances and preparations, as well as biological substances are used in the course of activities of the undertaking (used, produced, packaged, labelled, stored, transported, supplied to other users, their waste is managed), the undertaking shall provide for and implement measures for safeguarding the health of workers. Seeking to safeguard workers from the exposure to dangerous chemical substances and preparations, as well as biological substances, the employer's representative or, upon his instruction, the person authorised by the employer shall:

- 1) undertake measures aiming at replacing dangerous chemical substances and preparations with not dangerous or less dangerous ones,
- 2) undertake all necessary measures aimed at safeguarding workers from the exposure to dangerous chemical substances and preparations, as well as biological substances;
- 3) organise work in such a way that the number of workers exposed or likely to be exposed to dangerous chemical substances and preparations, as well as biological substances is kept as low as possible;
- 4) use such work equipment, work methods and production technologies which would ensure that dangerous chemical substances and preparations, as well as biological substances would not harm workers' heath;
- 5) draw up plans for preventative measures and rescue work in the event of accidents during which workers, other persons, and the environment may be exposed to dangerous chemical substances and preparations, as well as biological substances.

<sup>&</sup>lt;sup>33</sup> Law on safety and health at work. Approved by Law No. IX-1672 of 1 July 2003.

When using dangerous chemical substances and preparations, as well as biological substances, the limit values of their concentration in the atmosphere of the working environment must not be exceeded.

All workers must be informed about the effect on their health of specific dangerous chemical substances and preparations, as well as biological substances used the undertaking. The workers, whose activities (work) involve dangerous substances and preparations, as well as biological substances, must be instructed and trained in the safe work with the said specific substances and preparations.

# In particular way: protection of workers from the risks related to exposure to carcinogens at work

In the case of any activity likely to involve a risk of exposure to carcinogens, the nature, degree and duration of workers' exposure must be determined in order to make it possible to assess any risk to the workers' health or safety and to lay down the measures to be taken. Limit values of carcinogens are established by Health Ministry of the Republic of Lithuania.

Employer's requirements in this area are set in the Order of the Health Minister on the protection of workers from the risks related to exposure to carcinogens at work and extending it to mutagens.<sup>34</sup>

Actually the Order repeats\_Council Directive 90/394/EEC of 28 June 1990 on the protection of workers from the risks related to exposure to carcinogens at work, as last amended by Directive 1999/38/EC word-by-word.

#### **Encountering occupational disease**

Occupational diseases are classified according to the time of manifestation and the symptoms of a disease:

1) Chronic occupational disease: a health disorder of a worker caused by one or more hazardous factors within a certain time period.

<sup>&</sup>lt;sup>34</sup> Approved by Order No 97/406 of 24 July 2001.

Acute occupational disease: an acute health disorder of a worker caused by a short-term (single or repeated during the working day) exposure to a dangerous factor (factors) in the working environment having an acute effect.

A person who or contracts an acute occupational disease, must, if he is in the position to do so, immediately report this to the head of the subdivision, the employer's representative, the safety and health at work service of the undertaking. All undertakings shall apply a uniform and obligatory procedure for the investigation occupational diseases.

A doctor who suspects that a person may be suffering from a chronic occupational disease must within three days report to the employer, the State Labour Inspectorate and the territorial institutions of the State public health care service thereon in writing. A suspected occupational disease shall be diagnosed for a worker who is or was employed in the undertaking by a doctor who has a licence to engage in these activities.

- c) The causes of the occupational disease shall be investigated by the commission for the investigation of occupational disease, which shall also diagnose the disease as an occupational disease. The commission shall consist of the labour inspector (acting as commission chairman), a representative of the territorial institution of the State public health care service in the county and the doctor who suspected the occupational disease. Employer's representative and workers' representative with specific responsibility for the safety and health of workers shall take part in the investigation. The chairman of the commission may enlist the appropriate experts and specialist to assist during the investigation. The employer shall provide the required conditions and furnish the information required for the investigation.
- d) Disputes relating to the diagnosing of occupational diseases shall be settled by the Central Occupational Medicine Experts Commission. Decisions of the Central Occupational Medicine Experts Commission may be appealed against to the court.

# **Social Insurance of Occupational Diseases and Benefits**

According the Law on Social Insurance of Occupational Accidents and Occupational Diseases<sup>35</sup> "Occupational disease" means an acute or chronic health disorder of the

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<sup>&</sup>lt;sup>35</sup> Law No VIII-1509 of 23 December 1999.

employee caused by one or more hazardous and/or dangerous factors in the working environment deemed an occupational disease in accordance with the established procedure.

The Law provides several types of benefits:

Individuals covered by the relevant type of social insurance are entitled to receive the occupational disease benefit if they temporarily become incapable for work and lose their income from work as a result of occupational disease. The insured become entitled to the benefit irrespective of the duration of state social insurance (no insurance period is required).

Lump-sum and periodic compensations for incapacity for work are paid to the insured individuals when due occupational disease they lose at least 30% of their capacity for work.

Compensations are the following:

- a) in case of loss of up to 20% (inclusive) of the capacity for work: 10% of the reimbursed salary for 24 months used to calculate a lump-sum compensation;
- b) in case of loss of 21–29% (inclusive) of the capacity for work: 20% of the reimbursed salary for 24 months used to calculate a lump-sum compensation.

If an open-ended incapacity for work is established, the insured receives a triple lumpsum compensation for incapacity for work.

The periodic compensation for incapacity for work is paid to the insured individuals when due to accident at work or occupational disease they lose at least 30% (inclusive) and more of their capacity for work.

Information provided above is linked to special guarantees to the workers with disability level. Persons who do not have disability recognized but suffer from frequent illness of oncological type may enjoy other special rights. But it should be noted that these right are referred to all sick workers. Thus, workers with oncological diseases do not have special exclusive guarantees.

# National Best Practices (overview)

# For people with cancer

Since 1957, all cases of tumors in Lithuania have been reported in a special register. Researchers from the University of Vilnius update this register regularly, on the basis of the data collected by the National Institute of Oncology (more than 50% of all cancer patients come here to receive medical treatment). Their main task is to report the number of deaths, to describe the impact of the disease on local population, to verify the type of treatment the patients undergo, and their quality of life after recovery (see, www.loc.lt, and www.leidykla.vu.lt/netleid). It is also important to point out that Association for Palliative Care has made a valid contribution to the treatment of this disease since the 1990s.

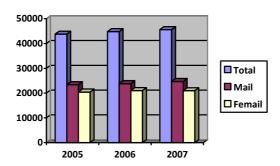
In Lithuania there are several public organizations that unite persons with oncological diseases and represent their interests. These organizations are established under grounds of separate oncological diseases, e.g.: Association of the Red Ribbon - women with breast cancer; Association of Persons with Prostate Cancer. Such organizations mainly deal with medical, psychological and family life aspects.

#### For women with breast cancer

A study conducted by the Faculty of Medicine of the University of Kaunas (www.elsevier.com/locate/rhm) has shown that there are marked social inequalities among women in terms of health care. In particular, rural women and women with a low level of education are at a distinct disadvantage. Therefore, in September 2008, in order to promote the prevention of oncological pathologies affecting women, and to improve the legal protection for women with cancer, the Ministry of Health has presented a plan that involves several non-governmental organisations. In addition, EU Structural Funds have been used to finance several projects, aimed at improving the national health service, reducing for instance waiting times for special medical examinations in public facilities (especially when dealing with cervical and breast cancer). As for hospitals, they are trying to sensitize local authorities about the creation of a national information network, in order to monitor the cases of breast cancer with a genetic component.

# Statistics

# **Mortality rate** (number of death)<sup>36</sup>



# Causes of death (in percents)

Mail	2005	2006	2007
Bloodstream diseases	45,9	45,2	44,5
Malignant tumour	19	19,4	19,2
External reasons	18,5	17,2	16,5
Digestive diseases	4,6	5,8	6,6
Respiratory diseases	5,2	5,2	5,7
Other			
Femail	2005	2006	2007
Bloodstream diseases	64,1	64,5	63,6
Malignant tumour	17,7	16,8	16,9
External reasons	6,1	5,9	5,6
Digestive diseases	3,9	4,6	5,2
Respiratory diseases	2,5		2,6
Other			

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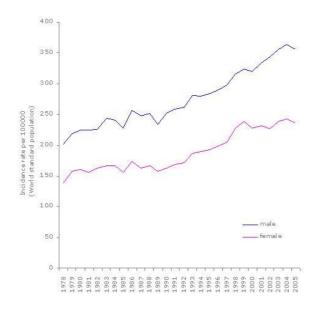
 $<sup>^{36}</sup>$  Statistical date is provided using statistical sources from special publication "Lithuanian Health in Numbers 2007", drafted by R. Gaidelyte, V. Ciceniene.

# Morbidity: Consist of malignant tumour

(firstly diagnosed diseases)

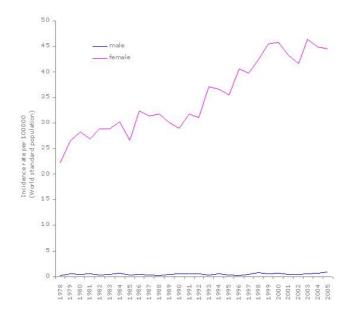
Mail	2005	2006	2007
Prostate	24,3	36,2	40,0
Lungs	15,8	12,9	11,7
Derma	9,2	8,3	8,1
Bladder , kidney	9,4	7,5	6,9
Intestine	9,0	7,9	6,8
Femail	2005	2006	2007
Breast	16,8	19,0	18,6
Derma	16,2	17,7	17,0
Ovarian, uterus	11,9	12,0	12,9
Intestine	9,5	9,1	8,9
Cervix	6,3	6,9	6,7

# **Cancer statistics** (all cancer sites)<sup>37</sup>



<sup>&</sup>lt;sup>37</sup> Lithuanian Cancer Registry. Cancer Registration Department of Institute of Oncology, Vilnius University.

# **Breast cancer statistics**<sup>38</sup>



# Further information

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<sup>&</sup>lt;sup>38</sup> Lithuanian Cancer Registry. Cancer Registration Department of Institute of Oncology, Vilnius University.

#### The Netherlands

Legal protection for the worker in case of disability and oncological conditions

In the Netherlands, legal protection for people with disabilities has undergone profound changes over the last ten years. This is due to the fact that during the 1990s, this country had the lowest rate of unemployment in Europe, even though the number of people with disabilities was considerable. This led the government to assume that there was a close connection between these two factors. In almost all cases, the national insurance system, as well as the social security scheme, is privatized, and in 2005, the Dutch Parliament approved the WIA, Wet werk en inkomen naararbeidsvermogen (see <a href="https://www.watson.org/wyatt.com/europe/netherlands/research/publicaties/pdf/WIA enpensioen ENG.pdf">https://www.watson.org/wyatt.com/europe/netherlands/research/publicaties/pdf/WIA enpensioen ENG.pdf</a>), that applies to workers who fell ill after 1 January 2004 and who have paid insurance contributions for at least two years. However, the <a href="https://www.watson.org/wyatt.com/europe/netherlands/research/publicaties/pdf/WIA enpensioen ENG.pdf">wyatt.com/europe/netherlands/research/publicaties/pdf/WIA enpensioen ENG.pdf</a>), that applies to workers who fell ill after 1 January 2004 and who have paid insurance contributions for at least two years. However, the <a href="https://www.watson.org/wyatt.com/europe/netherlands/research/publicaties/pdf/WIA enpensioen ENG.pdf">wyatt.com/europe/netherlands/research/publicaties/pdf/WIA enpensioen ENG.pdf</a>), that applies to workers who fell ill after 1 January 2004 and who have paid insurance contributions for at least two years. However, the <a href="https://www.watson.org/wyatt.com/europe/netherlands/research/publicaties/pdf/WIA enpensioen ENG.pdf">wyatt.com/europe/netherlands/research/publicaties/pdf/WIA enpensioen ENG.pdf</a>), that applies to workers who fell ill after 1 January 2004 and who have paid insurance contributions for at least two years. However, the <a href="https://www.watson.org/wyatt.com/wyatt.com/energen/wyatt.com/wyatt.com/wyatt.com/wyatt.com/wyatt.c

WIA applies to people having a total long-standing disability (including workers with 80% disability who are already entitled to the *IVA* benefit) or a partial long-standing disability (who receive a benefit known as *WGA*), provided that the degree of disability is greater than 35%. Disability is defined as a total or a partial inability to work. A different definition is given to short periods of sickness, as workers are considered unable to work only if they cannot carry out their normal tasks In any case, in the Netherlands, the cause of the infirmity resulting in the disability is not relevant, because the only aspect that is taken into consideration is the reduced capacity to work. There are several degrees of disability, and they do not depend on the health status of disabled workers, but on the type of task they carry out, and their medical condition.

The *UWV* (a semi-privatized national insurance body, see *www.q-go.nl/34442/Default.aspx*) assesses the degree of disability, and the benefit is paid on the basis of the previous salary. In the event of partial disability, however, the benefit is paid according to reduced capacity to work. In any case, the employee and the employer have to cooperate to facilitate the worker's return to work, even on a partial basis.

The same applies to short-term disability (Previously, sick leave was granted for a maximum of 52 weeks. Since the WIA entered into force, it can be granted for 104 weeks). This policy has been very effective. In fact, in 2003 the number of individuals classified as disabled was 100,000, while in 2006 it was just 18,000. In addition, a major increase in the number of workers returning to work has been reported, especially 18 months after the onset of the medical condition.

# Administrative procedures related to legal protection

The drastic reduction in the number of people registered as disabled has been accompanied by a prevention campaign against industrial injuries and diseases, by effective measures aimed at facilitating their return to work, and by a national plan for equal opportunities (the 2003 *Equal Treatment Act*). In this regard, the Ministry of Work and Social Affairs has set up a National Committee for the occupational integration of people with disabilities. The Committee has been charged with the task of looking for enterprises that are outstanding in terms of *Disability Management*, in order to reward and promote them as a role model.

The November 2003 *Peer Review meeting* considered the Dutch system as an example of best practices.

#### National Best Practices (overview)

### For people with cancer

In 2007, the Netherlands published the Plan Against Cancer, to reduce the death rate and to improve people's quality of life during and after the disease.

In 2007, the Amsterdam-based *Academic Medical Centre* completed a study on the difficulties faced by people with disabilities when they attempt to return to work. It provides statistical data focusing on the time they need to reintegrate into the working environment, explaining how to facilitate such reintegration.

The Dutch Cancer Society plays an active role in supporting the disabled workers and the research, by the promotion of information campaigns and the funding of information centers (www.onderzoekinformatie.nl/en/oi/nod/organisatie/ORG1238857).

#### For women with breast cancer

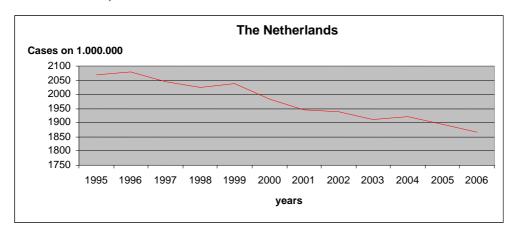
The *Katholièke Universitèit* of Leuven is completing a scientific research on this issue, focusing the attention on the role of the family of the employers, of social welfare and on how they can support women with breast cancer.

## **Statistics**

Analysis of the processed 2006 Eurostat data. Mortality for cancer (*standardized data considering 1.000.000 cases*)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
Olanda	2068	2079	2046	2023	2039	1985	1947	1939	1910	1920	1895	1865
%	0,207%	0,208%	0,205%	0,202%	0,204%	0,199%	0,195%	0,194%	0,191%	0,192%	0,190%	0,187%
							-	-	-		-	-
Variation		0,001%	-0,003%	-0,002%	0,002%	-0,005%	0,004%	0,001%	0,003%	0,001%	0,003%	0,003%

2006 Eurostat data progress chart. Mortality for cancer (*standardized data considering* 1.000.000 cases)



# **Further Information**

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## **Portugal**

## Legal protection for the worker in case of disability and oncological conditions

The cancer mortality rate in Portugal is among the lowest in Europe, even though this disease is the second most common cause of death in the country. In 2002, 6,008 women were admitted to hospital suffering from breast cancer, 8,050 from colon cancer, and 1,058 from cervical cancer (see Appendix no. 1). This led to the institutionalization of public hospitals. Regulatory Decree no. 6/2001 of 5 May contains the list and the index of occupational diseases (*Decreto Regulamentar n°6/2001: aprova a lista das doenças profissionais e o respetivo índice codificado*). According to it, diseases classed as "occupational" occur as a result of a work activity, resulting in a disability or the worker's death (an ad-hoc list of these diseases is provided).

# National List of Disabilities caused by industrial injuries and occupational diseases (Tabela Nacional de Incapacidade por Acidentes de Trabalho e Doenças Profissionais)

The list was included in Decree no. 341 of 30 September 1993. Chapter XVI explains that the identification of occupational diseases (and, more specifically, cancer) is based on the strong relationship between occupational hazards and the working environment (a cause and effect relationship).

The diagnosis of cancer should be made considering the individual's medical and professional background, and confirmed by additional examinations, such as smear tests, histology, and immunology.

The identification of carcinogenic agents is made taking into account statistics and epidemiological data. The list of the factors that are likely to cause cancer should also include additional information, such as physiopathology.

From a medico-legal point of view, the agents classified as "carcinogenic" are those appearing in the above-mentioned list. As we have seen, the diagnosis of cancer is made considering the individual's medical and professional background, and confirmed by additional examinations, such as smear test, histology, and immunology. For this reason, in Portugal, people with cancer resulting from the exposure to agents classed as *carcinogenic* by law, are required to prove that the disease was caused by this exposure. Only in this case is it possible to speak of "occupational cancer".

Carcinogenic substances are included in the following decrees:

- Decree no. 479/85 of 13 November;
- Decree no. 273/89 of 12 August;
- Decree no. 284/89 of 24 August;
- Decree no. 348/89 of 12 October.

In part 3 of Chapter XVI, num. 9, entitled "Guidelines for a medical evaluation" (*Guião para exame pericial*), breast, cervical, and ovarian cancer (points h, g, and i, respectively), are classed as diseases caused by the working activity, but not necessarily as occupational diseases. In fact, in this last case, the cause and effect relationship has to be proven, in order to classify people with this condition on the basis of Provision no. 2127 (chapter XXV, no. 2).

Part 4 of the same chapter contains the table of disabilities (*Tabela de incapacidades*), and explains that each case is evaluated on the basis of general criteria and levels of severity, also considering carcinogenic and co-carcinogenic factors.

In this connection, general directives are provided, for example:

- 1) in the event of a benign tumour, the side effects of the treatment have to be evaluated, as well as the lesion to part of the body concerned. It is important in this case to consult the ad hoc section of the table, where several levels of severity are reported;
- 2) in the event of chronic illnesses (e.g. malignant tumour), it is the same as for point 1;

3) in the event of malignant tumours or metastasis seriously affecting the patients' quality of life, the degree of disability can be increased to 60%;

4) the degree of disability for people with a malignant tumour with low life expectancy (due to the failure of medical treatment) ranges from 80 and 100 percent;

5) the degree of disability, in the event of cancer reactivation with generalized metastasis, and malignant tumours with low life expectancy, is always 100%;

6) the degree of disability will be multiplied by 1.5 if, in the event of point five, the patient is not self-sufficient and the disease affects his/her life seriously.

Regulation on legal protection for workers who are exposed to carcinogens or mutagens at the workplace

(Regula a protecção dos trabalhadores contra os riscos ligados à exposição a agentes cancerígenos ou mutagénicos durante o trabalho)

This provision is included in Decree no. 301/2000 of 18 November, and it implements Directive 90/394/CEE, amended by 97/42/CEE and 99/38/CE. They deal with the extension of the list of mutagens, also adopting limit value for occupational exposure to a number of chemicals (e.g. benzene and hardwood). In this connection, the definition of "carcinogens" has also been modified, including new substances that are dangerous for workers' health, in case of prolonged exposure.

The decree does not provide special protection for women, nor for women workers with cancer (whether caused by prolonged exposure to chemicals or not). It only provides that it is mandatory for the employer to reduce as much as possible the use of carcinogens and mutagens, replacing them with safer substances, in order to improve the health and safety of workers at the workplace.

#### National Health Plan 2004 - 2010

The National Health Plan includes a set of principles regulating the activity of the

institutions within the Ministry of Health, as well as that of private facilities which deal with public health issues. It aims at promoting the prevention of the diseases in the period 2004 - 2010.

The plan also provides important statistics. It points out, for instance, that in Portugal, in the period 2000 - 2001, life expectancy for both sexes was 76.9 years (which is lower than the EU average of 78.2 years). More specifically, male life expectancy was 73.5 (EU average 75.2), while the corresponding figure for women was 80.3 years (EU average 81.2).

With regard to 2001, circulatory diseases and malignant tumours were the leading causes of death in the country, especially among young people. Cancer-related death rates are higher among men than women.

Comparing national statistics with those of EU countries with the lowest cancer mortality, it might be possible to reduce untimely death rates by 38% for men, and by 10% for women. Breast cancer is the most common cause of death among women (see Appendices 2 and 3). It should be noted, however, that in Portugal mortality has decreased lately (13.5 cases per 100,000 inhabitants in 1998).

Colon cancer is the third most common cause of death among men and the second among women, and mortality for this pathology has increased.

With regard to cervical cancer, death rates have fallen, especially among young women, thanks to the promotion of smear tests.

According to the National Health Plan projections, by 2010, 60% of national cancer cases will be detected, cancer death rates among people under the age of 65 will decrease by 30%, and survival rates for cancer patients will comply with the EU average (10 years).

As for working conditions, increasing attention is paid to the adoption and promotion of effective measures relating to health issues. In this connection, a Health Promotion and Protection National Program has been set up, consisting of five basic intervention strategies. The program aims at putting into practice the principles contained in the National Prevention Plan on health and safety at work, working conditions and industrial injuries, as established by 2001 Economic and Social Council.

According to the Ministry of Health, the national screening program will focus on breast, cervical, and colon cancer.

Table VIII - Priority targets for oncology diseases

Indicator	Present situation	Projection for 2010	Target for 2010
Female breast cancer			
Screening rate	N.A.	_	60% of target population
Rate of standardized mortality from breast cancer before 65 years / 100,000 women 1	14.3	13.5	10
% of survival at 5 years <sup>2</sup>	71.9	N.A.	75

A determined effort will be also made to establish a set of rules regulating scientific research and the provision of medical treatment, in order to promote a rational approach to the disease.

In this connection, public health has to be safeguarded, providing practical information on the issue, and also promoting a healthy lifestyle.

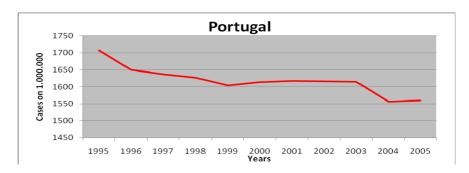
This is the reason why the government set up the *National Program for Integrated Intervention in Health Determinants Related to Lifestyles*, which deals with transmittable and non-transmittable disease, such as AIDS, tuberculosis, arterial hypertension, ischemic heart diseases, and several types of cancer (lung, breast, stomach, colon, and cervical cancer).

#### **Statistics**

Analysis of the processed 2006 Eurostat data. Mortality for cancer (standardized data considering 1.000.000 cases)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
Portugal	1707	1650	1636	1627	1604	1613	1617	1616	1615	1556	1560	
%	0,171%	0,165%	0,164%	0,163%	0,160%	0,161%	0,162%	0,162%	0,162%	0,156%	0,156%	
										-		
		-0,006%	-0,001%	-0,001%	-0,002%	0,001%	0,000%	0,000%	0,000%	0,006%	0,000%	

2006 Eurostat data progress chart. Mortality for cancer (standardized data considering 1.000.000 cases)



# **Further Information**

Breast cancer cases (GDH: 174): Admissions to hospital), in the region of Salud in 1998 and 2002, broken down by city and average cost of hospitalization (in Euros).

Cancro da mama (GDH: 174): número de episódios de internamento ), por Região de Saúde de residência e de internamento e custo médio/ episódio de internamento (em euros), em 1998 e 2002

	Por residência dos internados		Por região de	internamento	Custo médio /episódio d internamento €		
	1998	2002	1998	2002	1998	2002	
Norte	1129	1507	1293	1655	2 742,11	2 745,99	
Centro	1253	1692	1538	1633	3 240,21	3 144,81	
LVTejo	2122	2327	2003	2362	3 096,01	2 791,43	
Alentejo	240	277	167	188	2 847,72	2 922,47	
Algarve	168	202	130	170	2 638,96	2 879,13	
Outras	191	23					
Ignorado	28	0					
Total	5131	6008	5131	6008	3 019,32	2 880,46	

Fonte: DGS - DSIA - DEST e IGIF

Number of deaths and breast cancer death rate in 2001 among women (ICD-9:113), broken down by age and sex (out a total of 100,000 inhabitants)

Óbitos e taxas de mortalidade por cancro da mama feminina (CID-9:113), por idade e o sexo, no País, (Por 100000 hab) (< 1ano por 100000 nados vivos), 2001

IDADES	ÓBITOS M	TAXA M
<l< td=""><td>0</td><td>0,0</td></l<>	0	0,0
01-04	0	0,0
05-14	0	0,0
15-24	0	0,0
25-34	20	2,6
35-44	100	13,2
45-54	258	37,5
55-64	305	51,4
65-74	406	73,6
75 <b>E</b> >	564	130,8
Total	1653	31,0

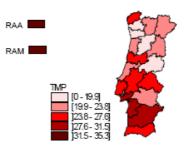


Figura 5- Taxa de mortalidade padronizada (por 100 000 hab.) por tumor maligno da mama feminina

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#### Romania

Legal protection for the worker in case of disability and oncological conditions

In connection with its accession to the European Union on 1 January 2007, Romania has made a determined effort to meet European standards in terms of legal protection for people with disabilities. In particular, in 2006, the government introduced a series of measures on the basis of specific European Union directives. Their implementation, however, is being called into question, reflecting a lack of real commitment on the part of stockholders, union representatives and politicians.

Up until 2002, as a result of the health care restructuring following the overthrow of the regime in 1989, the national health system covered only 3% of medical expenses. Full medical cover was provided only in the event of certain diseases, such as tuberculosis and cancer.

Romania has 21 million inhabitants, and the number of occupational health officers / company medical officers is somewhere around 350 (consider, for instance, that in France they are approximately 7000). In addition, general practitioners with some competence in occupational medicine are only 2000 (source: Occupational Physician – A Romanian occupational physician's perspective - www.physician.ro, December 2007). In general, this professional figure is a account for practitioners who have a private agreement with employers. They do not have a fixed working time, even though the number of patients to be treated can be considerable. Only large enterprises employ a medical officer to look after their employees on an exclusive basis. In some cases, they are given responsibility by the government for verifying workers' health and safety.

The law provides that workers classified as being at high risk should undergo medical examinations each year. In small and medium-sized enterprises, however, this does not happen, and job applicants are required to undergo medical examinations only at the

initial time of being employed. Medical officers can also help to evaluate occupational risk, even though it is not within their province.

In the event of sickness or injury, the law provides also that the worker maintains his/her position, but the employer can also employ another worker during his/her absence, to carry out the same task. In any case, however, it is possible to apply for sickness benefit regardless of type of disease, length of sickness as long as the employer has paid the mandatory health insurance taxes for the employee.

# National Best Practices (overview)

## For people with cancer

Cancer is the second leading cause of death in Romania, and two-thirds of cases are diagnosed only after it has entered the terminal stage (data: 2002). In formal terms, the 1980 Cancer Prevention and Control National Programme provides people with cancer with several means to combat the disease, such as preventive measures, early diagnosis and effective medical treatment. However, the government has been deficient in the provision of basic palliative care, as provided for in the 2002 WHO directives for developing countries. For this reason, non-governmental palliative care organisations, such as Brasov-based Casa Sperantei Hospice, have rapidly developed. The Casa Sperantei Hospice works in cooperation with a UK Hospice, providing training courses on palliative care. It is expected to develop into a centre of excellence for medical research, supporting the National Resource and Training Center in the training of experts in oncological diseases. Furthermore, since the end of 2000, it has been acknowledged as one of the five most important Regional Resource and Training Centers in South Eastern Europe, not to mention the fact it is partially funded by New York-based Open Society Institute, and it also cooperates with the United States National Hospice and Palliative Care Organization (source: Daniela Mosoiu, MD Hospice Casa Sperantei and National Association for Palliative Care, Brasov, Romania, Romania 2002: Cancer Pain and Palliative Care - Vol. 24 No. 2, August 2002, Journal of Pain and Symptom Management).

The Romanian Cancer League (Liga Româna de Cancer) is a non-profit organisation that has launched several initiatives to combat cancer:

- "smoking and cancer" is an "aggressive" anti-smoking campaign addressed to young people, which consists of a special screening program and different approaches to the disease, on the basis of the mortality risk, the patients' age, and their medical test (www.romaniancancerleague.org/en/program-smokingandcancer.php);
- "support children with cancer" (www.romaniancancerleague.org/en/program-supportchildrenwithcancer.php);
- "save your health" is a programme which refers to the thirteen-point code included in the report "Nutrition and the prevention of cancer: a global perspective", released by the American Institute of Cancer on the basis of more than 4,500 scientific studies (www.romaniancancerleague.org/en/program-saveyourhealth.php);
- "count on us" (www.romaniancancerleague.org/en/program-countonus.php): this programme provides support service to people with cancer, and this kind of medical assistance is extremely important in the event of early discharge from hospital

Main long-term objectives are:

- 1 to provide sick people and their families with necessary information on oncological conditions;
- 2 -to provide home care service;
- 3 to provide financial support;
- 4 to provide patients and health personnel with transport service;
- 5 to provide the doctors specialising in other disciplines and health personnel with a training course on oncological pathologies;
- 6 to provide palliative care for terminally ill patients;

7 – to purchase efficient apparatuses for CAT (computer axial tomography), radiotherapy and tumour marker detection, in order to provide better diagnosis and medical treatment.

Association of People with cancer in Romania (Asociatia Oncologic Rom) supports people with cancer in their return to work, helping them to acquire new skills. It cooperates with another European organization, EUROPAUOMO, which, on similar lines to EUROPADONNA, is at the forefront in combating prostate cancer, promoting a manifesto aimed at safeguarding people with oncological disease.

#### For women with breast cancer

In Romania, especially in rural areas, only a small number of women receive cancer screening, mainly because of ignorance and fear of breast cancer. The vast majority of women prefer to ignore the problem, or even not to undergo medical examinations. According to the data reported on the website **Global Iniziative for breast cance awareness (www.globalkomen.org)**, today in Romania there a few apparatuses for mammography. Susan G. Komen's Global Initiative for Breast Cancer Awareness (www.globalkomen.org - Global Komen is a US organisation founded in 1982, and the programme is carried out by the Institute of International Education West Coast Center (IIE), which involves Romania, Brazil, Costa Rica, Jordan, Mexico, Ukraine and the United Arab Emirates. The main goal of the programme is to create a dynamic global network of experts with a high level of competence in oncological pathologies, serving as a reference point for women with breast cancer. In this connection, future stakeholders need to receive adequate training, in order to reinforce national policies on the issue, enabling private individuals and organisations to launch prevention and information campaigns.

To facilitate their education, a special training system, known as the Course of the Cure has been developed. Patented by Susan G. Komen, it consists of five modules and it can be used in multicultural contexts. The main partner of the project is SECS (Society for Education on Contraception and Sexuality, Bucarest).

There are other organisations that support the initiative:

- the American International Health Alliance (AIHA), which funded a conference on

breast cancer in Bucharest, in October 2002;

- Common Destiny: in September 2007, the president of this organisation attended

Hungary's Susan G. Kolmen For the Cure, and she was also sent as a delegate to the

international summit "Ignite the Promise: Global Advovate Summit". At the summit,

there were 50 representatives from all over the world, and the discussion regarded breast

cancer, global health system, and effective measures for early diagnosis and medical

treatment.

The Susan G. Komen for The Cure US version of the website provides a very detailed

guide on breast cancer. See:

http://cms.komen.org/komen/About

BreastCancer/TheABCsofBreastCancerGuide/index.htm

http://ww5.komen.org/

The Romanian Cancer League (Liga Româna de Cancer) has launched a specific

programme for women with breast cancer, "Save Women"

www.romaniancancerleague.org/en/program-savewomen.php

The programme consists of several points, and aims at:

reducing breast (and genital) cancer incidence and mortality, as well as the cost of

medical treatment;

- training general practitioners and gynecologists, involving them in the

programme;

involving Bucharest and Cluj-Napoca-based oncological institutes, and university

medical centers;

- creating a center for breast and genital cancer prevention and early diagnosis,

which cooperates with the league itself, supporting sick women with low income;

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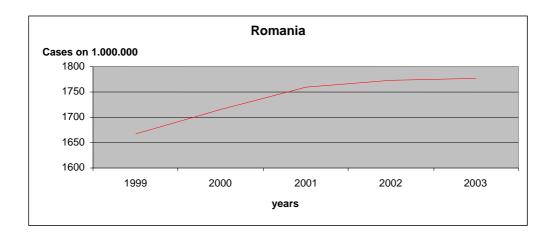
- treating patients with precancerous lesions;
- providing support after therapy and facilitating reintegration into the social and professional environment;
- collecting funds to support the main activities.

## **Statistics**

Analysis of the processed 2006 Eurostat data. Mortality for cancer (standardised data considering 1.000.000 cases)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
Romania					1668	1716	1760	1774	1777			
%					0,167%	0,172%	0,176%	0,177%	0,178%			
Variation						0,005%	0,004%	0,001%	0,000%			

2006 Eurostat data progress chart. Mortality for cancer (*standardised data considering* 1.000.000 cases)



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# **Spain**

# Legal protection for the worker in case of disability and oncological conditions

Royal Decree no. 1971 on people with disabilities, dealing with the "recognition, evaluation, and assessment of the degree of disability (*minusvalia*)", was passed on 23 December 1999. Depending on the tasks the disabled person can carry out, the provision provides several types and degrees of disability (*discapacidad*):

- no disability,
- slight,
- moderate,
- serious, and
- very serious disability.

The same applies to people with cancer, pursuant to chapter IX of the Decree.

The Spanish Institute for Migration and Social Services, *IMSERSO* (*Instituto de Migraciones y Servicios Sociales*), which operates under the supervision of the Ministry of Labour and Immigration, is in charge of carefully evaluating the *minusvalía* (disability status), on the basis of the above-mentioned classification. The *minusválido*, that is the disabled person, is entitled to a series of benefits, provided that his/her degree of disability is greater than or equal to 33%.

For example, enterprises employing more than 50 workers have to hire at least one disabled worker (which is equal to 2% of the employees). Furthermore, relatives who look after disabled persons who are unable to work are granted special leave of absence. Pursuant to *Ley* 39/1999 on the integration between private and working life, which is included in the Statute of Workers' Rights, they are entitled to a 20% to 50% reduction in their daily working hours, and the salary is paid *pro rata*. The same applies (art. 37 par. 5) to relatives up to the second degree of kinship, who look after an unemployed person classified as not self-sufficient (due to age, sickness or injury). In this latter case,

up to one year's sick leave (included in the calculation of seniority, and which can be extended, if provided by the applicable collective agreement) is granted to the relative, who is also entitled to maintain his/her employment. Even in the case of prolonged sick leave (more than one year) the employee cannot be dismissed (if discriminatory conduct is proven, dismissal is classified as unfair) but is reassigned to another occupation with comparable tasks.

With regard to permanent disability, a series of benefits are provided, depending on whether it is classified as "total" or "partial". In the first case, a disability allowance is provided to those who are no longer able to work (they are also entitled to invalidity benefit provided by national insurance *SOVI*, *Seguro Obligatorio de Vejez and Invalidez*). The same applies to workers with a partial and permanent disability (with a reduced capacity to work that is more than 33%), but in this case the seriousness of the disease and the number of years the individual has been on welfare (*Seguridad Social*) are also taken into consideration.

## Specific Legal Protection for people with cancer

There is no specific provision for people with cancer, as they are on an equal footing with people with disabilities (they are classified as having a temporary incapacity to work, incapacidad temporal laboral). For this reason, the Instituto Nacional de la Seguridad Social, which is the National Institute for Social Insurance, provides them with sickness benefit ("de incapacidad temporal" Royal Decree no. 1976 of 24 July 1982) for a maximum of one year or less, in the case of a return to health. After this time, they are certified as permanently disabled (permanente).

## Specific Legal Protection for women with cancer

On 1 December 2006, the Council of Ministers passed the *Plan de acciòn 2007 para las mujeres con discapacidad*, aimed at combating discrimination against women and people with disabilities. According to the provision, people discriminated against on the basis of a medical condition or gender (or for both of them), are at a distinct disadvantage, and therefore need to be protected. For this reason, it promotes practical measures, involving

non-discrimination policies, and promoting equal opportunities, the right to be self-sufficient and to participate in social life.

## National Best Practices (overview

### For people with cancer and with disabilities

In Spain, special attention is paid to people with disabilities. In this connection, on 30 January 2004 the *Comisión de Protección Patrimonial de las personas con discapacidad* (Commission for the protection of people with disabilities) was set up. It is an external collective body acting in consultation with the Ministry of Labour and Immigration. It consists of members of the government and representatives of people with different kinds of disabilities. The Commission has a section on the Ministry of Labour and Immigration website, which provides information on how to protect disabled people from discrimination.

Furthermore, Spain has always invested heavily in effective measures against cancer (the Strategy against Cancer). This year, for instance, 39 million euros have been spent by the country in information campaigns, cancer prevention programmes and continuing education for medical personnel, on the basis of the agreements made with the autonomous communities (regional government).

In addition, since 1999, further research has been conducted on occupational diseases, providing useful data and national best practices (2006 Strategy, *Estrategia en cancer del Sistema Nacional de Salud*, for instance, was intended to promote these measures).

### For women with breast cancer

According to official statistics, breast cancer is the leading cause of cancer death among women in Spain (16,000 new cases are diagnosed every year), even though the country has the one of the highest survival rates in Europe (75%, five years after the day of the diagnosis). From this point of view, the region of Navarre has a leading position. Here, due an effective mammography screening programme, the death rate has fallen by 8%

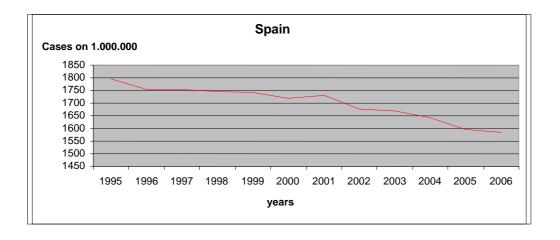
every year, since 1995 (the national average is 2%). Belatedly, (Madrid and the Canaries started in 1999) other autonomous communities have launched the same programme, leading to the conclusion that Spain is focusing more on prevention than effective legal protection.

### **Statistics**

Analysis of the processed 2006 Eurostat data. Mortality for cancer (*standardised data considering 1.000.000 cases*)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
Spain	1798	1755	1752	1745	1743	1720	1730	1677	1671	1642	1597	1583
%	0,180%	0,176%	0,175%	0,175%	0,174%	0,172%	0,173%	0,168%	0,167%	0,164%	0,160%	0,158%
								-	-	-	-	-
Variation		-0,004%	0,000%	-0,001%	0,000%	-0,002%	0,001%	0,005%	0,001%	0,003%	0,005%	0,001%

2006 Eurostat data progress chart. Mortality for cancer (*standardised data considering* 1.000.000 cases)



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### Sweden

## Legal protection for the worker in case of disability and oncological conditions

In Sweden people with oncological conditions have the same legal protection as disable people.

The main law in the field of employment is **Act on law environment** (**arbetsmiljölagen** - **AML**),

adopted by the Parliament in 1978 and later modified. It is applicable also to the working students, soldiers, prisoners and self-employed. The act defines the external framework of the discipline of employment conditions. The Swedish authority on labour environment – the national council of health and safety was charged by the government to prepare the detailed norms. In the Code of the norms

(AFS) general recommendations are published. The act contemplates that the employer must ensure that the work place of which he is responsible has a duly organised rehabilitation programme and foresees possible changes of professional profiles of the employees (cap. 3, sez. 2a): the employer is the main responsible for the disable workers. In case of the absence for more than 4 consecutive weeks or frequent short – term absences the employee must start the rehabilitation procedure in collaboration with the local social service (försäkringskassan), in order to return to work as soon as possible. This activities should constitute the integral part of the enterprise strategy and the employer must present documental evidence of the activities performed; he is subject to the control by the competent bodies. In any case "employers and employees should cooperate in order to create good social environment" (cap. 3, sez. 1). Other important laws are the law on the protection of environment

(miljöbalken), law on working hours (arbetstidslagen), law on equal opportunities of men and women (jämställdhetslagen). There is no obligation under the law to create enterprise sanitary services (företagshälsovård), but some important enterprises do so. The services

normally include the medical doctor, nurse, physiotherapist, the expert of industrial hygiene, and sometimes psychologist. One of the technical duties of the industrial service is to adapt the workplace to the needs of people who are working there. The medical functions include the rehabilitation. From the socio-psychological point of view the services must deal with the problems of stress, harassment/bulling (see infra) and work organisation.

Trade unions appoint their representatives responsible for security and have a considerable influence over the organisation of work places.

From 2001 the Swedish government has been working on the strategy to promote healthy work place drafting all the fragmented norms under the unique action plan consisting of 3 pillars:

- Management of social security issues on the work place
- Return to work in case of disease:
- Research

In 2002 the Government defined a national target for improving health in the workplace: "Absence from working life due to illness shall, compared with 2002, be halved by 2008. First-time activity and sickness benefit payments are to be reduced at the same time. Allowance is to be made for demographic developments during the period."

National control body is the Swedish authority for work environment (AV) www.av.se/inenglish/index.aspx. Its objective is to reduce the impact of the disease and work related incidents and to promote healthy working environment. It drafts norms and is responsible for the statistics of diseases and work-related incidents (ISA). There are 10 working environment inspectorates dependent of this body.

In 1993 the national health and safety council adopted the provisions relative to the measures to adopt against the psychological persecution in working ambits (valid from March 1994) or against "repetitive reprehensible or openly hostile actions against single workers in offensive manner influencing their estrangement from the community of other employees of the same work place". Also in this case the employer is the main

responsible to create optimal working conditions. The provisions contain the preventive recommendations also by means of the employee or their representatives participation. These provisions represent the first case of "normation" of mobbing.

### Administrative procedures related to legal protection

 Administrative practice corresponding to each of 3 types of the above mentioned norms:

The council of Stockholm county (www.sll.se/sll/templates/NormalPage.aspx?id=19) ensures the needs of almost 2 millions of citizen also in terms of sanity (prevention and access to treatment). According to this law in each county council there is a consultation committee for the patients where the citizens can address for information purposes or to present claims.

### National Best Practices (overview)

## For people with cancer

The FAS – Forksningsrådet för Arbetsliv och Socialvetenskap (Swedish council for working life and social research - www.fas.se/default\_\_\_\_206.aspx) was created in 2001 by merger of the Swedish council for working life and Swedish council of social research. It is proposed to rise the awareness of the matters relating to the working life promoting basic research, applying international cooperation, in particular Euroepan, and disseminating this scientific knowledge.

National institute of working life was one of the best research and training centres and in was closed 1 July 2007.

In 2001 the Värö Bruk, the enterprise situated 60 km on the South of Gothenburg, was elected the most healthy enterprise in the year of the national institute of public health. The enterprise promotes employee participation, health work environment, prevention measures and majour personal responsibility as for as it regards long-term physical welfare also by means of participation at the triennial plan Work and health (AHA) of

Karolinska Institute, which proposes to reduce the absences for disease. The programme includes the theoretic part and sport events.

At www.cancersamtal.nu/ there is a forum for discussion, mailing list and chat dedicated to the people with oncological conditions (in Swedish).

As for mobbing, of which cancer patients may be victims (cfr. supra), more information can be found at the web site followed in Sweden by German professor Heinz Leymann, www.leymann.se/.

#### For women with breast cancer

The Swedish association against cancer (BRO - www.bro.org.se/english.asp) is a main organisation involved in this programme. It has a representative for the national guidelines within the national council for health and safety at work and for national programme for treatment of breast cancer. It unites 33 territorial associations and has 10.200 members. The president, Ingrid Kössler, is also a president of EUROPADONNA. In particular, BRO is involved in mammography screening which following the recommendations of the national council, should be extended for the people in age 40-74.

The BRO established the award for excellence in results and the treatments, scientific treatment and progresses and tried to attract the attention of mass media to this problem. Recently it has obtained success in campaign of rose ribbon which attracted other partners; € 600.000 were collected.

BRO puts at stake schorlaships and research grants of the Swedish foundation against cancer

(Bröstcancerfonden), and of the Elisabeth Hedins e Falck-Löfdahl foundations.

The list of almost all the associations against cancer with contact information can be found at in Swedish at BRO web site: www.bro.org.se.

This is a summary of the new rules.

Time limitation of sickness benefit

You can receive ordinary sickness benefit for at most 364 days during a 450-day period (15 months). This period is called the time frame. After the 364 days, you can apply for extended sickness benefit. If you are very seriously ill (Breast Cancer is not included in this group), you can apply for continued sickness benefit.

The time frame has been introduced to prevent persons from receiving sickness benefit for a longer period than 364 days by temporarily declaring themselves fit and then requesting sickness benefit again. The time frame is 450 days (15 months) immediately preceding the day for which you request sickness benefit. Days when you have received three-quarters, a half or a quarter sickness benefit are counted as a whole day with sickness benefit. Days when you have received preventive sickness benefit, compensation for additional expenses for work travel, rehabilitation allowance and extended sickness benefit are also counted as sickness benefit days.

### **Extended sickness benefit**

You can receive extended sickness benefit for at most 550 days (approximately one and a half years.)

Extended sickness benefit gives you around 75 per cent of your earnings. It is thus lower than ordinary sickness benefit, which gives you around 80 per cent. This is the case as long as your annual income does not exceed SEK 307,500 (307,500 Swedish kronor). Higher income does not entitle you to higher sickness benefit. If you are unemployed, there is moreover a ceiling, which means that your sickness benefit can be at most SEK 486 kronor per day.

You must apply for extended sickness benefit. Försäkringskassan will contact you when you can receive ordinary sickness benefit for at most another 30 days.

#### **Continued sickness benefit**

If you have a very serious illness, you can also apply to continue to receive around 80 per cent in sickness benefit. Examples of such serious illnesses are certain tumour diseases, neurological diseases such as ALS or when waiting for transplantation of a vital organ.

There is no time limit for how long continued sickness benefit can be paid. The compensation is the same as during the first 364 days.

## Assessment of work capacity and entitlement to sickness benefit

During the first 90 days that you are on sick leave, you are entitled to sickness benefit if you cannot perform your ordinary work. After 90 days, you are only entitled to sickness benefit if you cannot perform any work at all for your employer. After 180 days, you are only entitled to sickness benefit if you cannot perform any work at all on the regular labour market. This way of assessing entitlement to sickness benefit is called the **rehabilitation chain.** The rehabilitation chain only applies in full for those in employment. If you are self-employed, Försäkringskassan will assess your work capacity in relation to your normal work tasks until the 180th day. After that, your work capacity will be assessed in relation to the whole regular labour market. If you are unemployed, your work capacity will be assessed in relation to the whole regular labour market from the start of the sickness period.

### Stricter requirements for sickness compensation and activity compensation

From 1 July 2008, the requirements for receiving sickness compensation – i.e. sickness compensation which is not time-limited – are also being changed. If you have sickness compensation today, you will retain your compensation until further notice. This change in the law accordingly does not apply to you.

If you are aged between 30 and 64 and your work capacity is reduced due to illness or another reduction of the physical or mental capacity to perform, you can receive sickness compensation. To obtain sickness compensation, work capacity must be permanently reduced, i.e. for the foreseeable future. Permanently reduced work capacity must be due to chronic illnesses and injuries where it is considered that medical or working-life focused rehabilitation cannot lead to a restoration of any work capacity or that existing work capacity cannot be improved. Work capacity must then be reduced by at least a quarter. Furthermore, all possibilities for a return to work must have been considered, in all work available on the whole labour market. This also includes employment with wage subsidies and other similar work. This means that, unlike previously, work capacity is to be considered in relation to a broader labour market. When assessing work capacity, consideration will no longer be taken to special reasons such as age, residential

circumstances, education or previous activity.

### New rules for entitlement to activity compensation

If you are aged between 19 and 29 and your work capacity is reduced due to illness or another reduction of the physical or mental performance capacity you can receive activity compensation. To obtain activity compensation, work capacity must be reduced by at least a quarter for at least a year. Furthermore, all possibilities for a return to work must have been considered, in all work available on the whole labour market.

### How sickness insurance works

### Sick pay

If you are employed and fall ill, you must report sick to your employer. If you are employed for at least a month or have worked for fourteen days without a break, you are entitled to sick pay from your employer for the first 14 days of your illness. No payment is made for the first day (the "waiting period"). If you are still ill after 14 days, your employer will notify the Swedish Social Insurance Agency (Försäkringskassan) of your illness. When you are well again, you must provide your employer with written assurance stating that you have been ill and specifying the extent of your absence from work.

### Sickness benefit

If you are not entitled to sick pay, you may be able to get sickness benefit from the Swedish Social Insurance Agency. In this case you must notify the Swedish Social Insurance Agency that you are ill. You may also be entitled to sickness benefit when you have been ill for 14 days and are no longer receiving sick pay from your employer. The Swedish Social Insurance Agency assesses your entitlement to sickness benefit.

## A long period of illness

If you are ill for more than seven days, you will normally be expected to produce a sick note from the doctor in order to continue receiving sick pay or sickness benefit.

## If you become unemployed

If you become unemployed, it is important that you register within 3 months from the day your work ceased with the employment office as seeking work. The reason is that when you no longer have income from work, the main rule is that your previously fixed SGI

(the income on which your sickness benefit is based) ceases to apply. In some circumstances, however, it is possible to keep your SGI despite you are not working. This is the case, for instance, when you are unemployed and have registered with the employment office as seeking work.

### Complete or partial incapacity for work

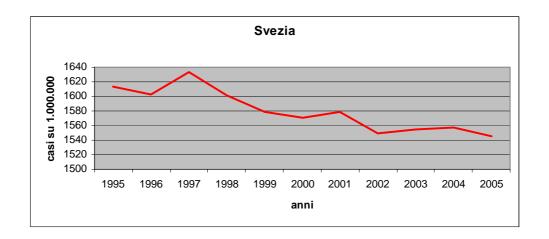
You may draw one-quarter, half, three-quarters or full sickness benefit, depending on the extent to which you are unable to work. The Swedish Social Insurance Agency assesses your entitlement to sickness benefit and decides whether you are able to carry out your work full time or part time, despite your illness. It also decides whether you will be able to return to your regular job after your period of illness comes to an end. If you can go back to work, your disability will be assessed in relation to your normal work. If not, your disability will be assessed in relation to other work that your employer can offer you. If your employer has no other work to offer or if too long a period of rehabilitation is needed, your capacity for work will be assessed in relation to the needs of the labour market as a whole.

### **Statistics**

Analysis of the processed 2006 Eurostat data. Mortality for cancer (standardised data considering 1.000.000 cases)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
Swedish	1613	1603	1633	1601	1579	1571	1579	1549	1555	1557	1546	
%	0,161%	0,160%	0,163%	0,160%	0,158%	0,157%	0,158%	0,155%	0,156%	0,156%	0,155%	
								-			-	
Variation		-0,001%	0,003%	-0,003%	-0,002%	-0,001%	0,001%	0,003%	0,001%	0,000%	0,001%	

**2006** Eurostat data progress chart. Mortality for cancer (standardized data considering 1.000.000 cases)



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# The United Kingdom

Legal protection for the worker in case of disability and oncological conditions

The 1995 **Disability Discrimination Act** classifies cancer as a disability. As a result, people with cancer are protected from any form of discrimination arising from this condition, such as mobbing, unequal treatment in terms of working conditions and so on. Furthermore, according to the law, employers have to provide workers with reasonable accommodation in terms of working opportunities, trying to meet their professional needs also after their recruitment (by changing their working time, by granting sick leave for medical examinations, and by allowing them to opt for teleworking).

Whenever an employee suffers discrimination or unfair dismissal, he/she must report the matter to his/her superiors. In cases in which this is not enough, the employee can file a formal complaint to be dealt with at company level (Grievance Committee). If the employee is not satisfied, he/she can file a complaint to the Employment Tribunal (by filling in an *ad hoc* form) within three months of the alleged violation. The local Citizens Advice Bureau (CAB) can offer free legal advice.

The duration of leave of absence from work is established by the employer, according to the specific company policy.

The Department for Work and Pensions (DWP - www.dwp.gov.uk) provides information on sickness benefits (Statutory Sick Pay -SSP).

### Specific Legal Protection for people with cancer

The Department of Health is currently discussing a five-year plan aimed at promoting cancer prevention and treatment. In this regard, representatives of the coalition known as 'Cancer 52' have been invited to contribute to the consultation. The name 'Cancer 52' refers to the fact they represent a group of people with rare oncological diseases, that have killed more than 50% of people with this specific condition.

### **National Best Practices**

## For people with cancer

In July 2007, on the basis of the 2003 European Commission directives on cancer screening, the UK Cancer Research Institute launched a screening campaign (Screening Matters Campaign) aimed at raising political and public awareness on the issue. The United Kingdom was one of the first European countries to promote national screening for bowel cancer, and the project was funded by charitable institutions. Today, the initiative is well developed, and the next step is to involve four British municipalities. The goal of the body promoting the project is to screen at least three million people over the next five years, to give everyone in the country the opportunity to be screened, and to provide special screening programmes and qualified medical personnel. The website is www.cancercampaigns.org.uk

The private TV network **GMTV** has also set up a hotline, in order to provide information on colon cancer. In this three-minute TV programme, callers can talk to the journalist Lynn Faulds Wood, an expert in symptomatology and the current president of the European network of people with cancer, who herself had cancer 16 years ago. Department of Health provides also a special free phone number.

People Management, a company dealing with human resources, occupation and business, has launched a campaign against cancer (Working through cancer), setting up (www.people an exhaustive section on the issue on its website management.co.uk/pm/sections/news/campaigns/working-through-cancer.htm). The partner of this campaign is Macmillan, and it also involves researchers from the University of Manchester, the Welsh Assembly, the Royal Bank of Scotland, Nationwide and Ford.

This example shows how the protection for people with disabilities might involve not only the enterprise concerned, but other social actors as well. As for Macmillan, (www.macmillan.org.uk/Get Support/Find information/Working through cancer/Worki ng through cancer.aspx), it is a leading organisation that supports people with disabilities outside the enterprise. It aims at providing sick workers with a suitable and pleasant working environment. Here are some examples of its activity: first line managers are strongly supported in their activities and during their absence; the working time and the working place are changed, according to the worker's health; in the case of absence from work due to medical treatment, the company provides paid sick leave; a gradual return to work is provided for sick employees; the colleagues who have recovered from cancer act as mentors; sick workers are provided with external advice on the matter; a special information telephone line (known as Cancer Line) has been set up; terminally ill workers are given careful consideration; the Employee Assistance Programme provides specialist advice; there are specific agreements in terms of sickness benefits, while good value medical and life insurance is offered; in the case of recruitment and career advancement, a determined effort is made to prevent discriminatory conduct; training and information are provided to those who are indirectly affected by the disease (Macmillan Management Guidance on Cancer in the Workplace and Cancer Guide) and the issue is widely discussed.

- Materials provided by Macmillan on how to support sick worker's families is available at:

www.macmillan.org.uk/Documents/Support\_Material/Get\_support/Working\_through\_cancer/Carers\_Policy.pdf.

The **BT** (a leading telecommunication company) launched an information campaign against cancer, after noticing that a number of employees fell ill with oncological pathologies.

According to a survey carried out in the UK by the CIPD (Chartered Institute of Personnel and Development), only a small percentage of employers have adopted specific measures to deal with cases of cancer or serious disease, and to monitor such cases in their own business.

For women with breast cancer

The above-mentioned screening campaign also involves breast cancer. In this regard, **The** 

Breast Cancer Campaign (www.breastcancercampaign.org), involves 62 UK scientists

who provide a significant contribution to research. Furthermore, an online bulletin on

related parliamentary initiatives is published periodically.

The main campaign activities are:

- Science For Life (www.breastcancercampaign.org/whatwedo/science for life), that

deals with scientific and medical research;

- Getting Better care for people with breast cancer, an organisation that is part of the

Cancer Campaigning Group (www.cancercampaigninggroup.org.uk)

involving 40 voluntary organisations and charitable institutions. In Scotland, this

organisation also supports a national plan of action.

See: www.breastcancercampaign.org/whatwedo/better care/;

- Breast screening; The Screening Matters Campaign has been launched to boost the NHS

Breast Screening Programme.

See: www.breastcancercampaign.org/whatwedo/breastscreening.

As regards this Programme, the social network Facebook has been involved, allowing its

users to make a small donation to the research (at least £1.50), and providing those who

contribute with a special sign (Pink Ribbon) on their personal web page. Please consult:

www.breastcancercampaign.org/shop/facebook/

http://apps.facebook.com/breastcancercampaign/

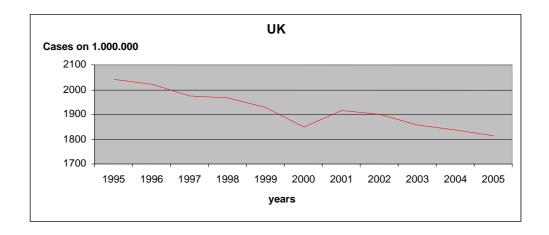
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## **Statistics**

Analysis of the processed 2006 Eurostat data. Mortality for cancer (*standardized data considering 1.000.000 cases*)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
UK	2041	2020	1973	1966	1927	1850	1914	1901	1856	1838	1815	
%	0,204%	0,202%	0,197%	0,197%	0,193%	0,185%	0,191%	0,190%	0,186%	0,184%	0,182%	
								-	-	-	-	
Variation		-0,002%	-0,005%	-0,001%	-0,004%	-0,008%	0,006%	0,001%	0,004%	0,002%	0,002%	

**2006** Eurostat data progress chart. Mortality for cancer (standardized data considering 1.000.000 cases)



## Further information

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## Chapter 4

### **Employment and oncological conditions**

Tindara Addabbo, Marina Bettoni, Arja Leppänen and Giulia Rossi

### 4.1. Introduction

The importance of a continuous active life in making a positive impact on illness and the recovery of people with cancer has been widely assessed in the literature.<sup>39</sup>

In this Chapter we present the results of applied research performed in two countries (Sweden and Italy) that are characterized by a different incidence of cancer amongst employees. According to data referred to in Crepaldi (2008, p.16), Sweden is characterized by a lower incidence of cancer among male workers than Italy and by a comparable incidence in female workers (in both countries the incidence is lower than the average for the EU27). Widening the analysis to long-standing illness and health problems, Sweden shows a much higher degree of employment integration than Italy (Crepaldi, 2008, p.17).

There are methodological differences in the design of the surveys in the two countries: in Italy the questionnaire was distributed to employees in a public and in a private firm, whereas in Sweden the questionnaire was released on the internet, it was publicized in newsletters, newspapers, magazines and through links from all organizations working for cancer-patients, with the sponsorship of Roche, Sweden.

In this Chapter we will also exploit the wealth of observations and variables of the National Institute of Resarch Institute Multipurpose Survey on Health Conditions to assess the probability of employment of people affected by cancer (Section 4.1). We then present the tools used for the survey and its design (Section 4.2), the institutions that took

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<sup>&</sup>lt;sup>39</sup> A good survey on the positive effect of returning to work for people who have had cancer is Crepaldi C. (ed.) (2008) *Cancer and in general long-term illnesses at workplaces*, European Parliament Policy Department Economic and Scientific Policy, Irs.

part in the survey (section 4.3), the composition of the sample and the characteristics of employees affected by cancer (section 4.4).

# 4.2. The employment situation of people with cancer in Italy

We can use the Italian National Institute Multipurpose Survey data to assess the rate of employment of people with cancer (or who have had cancer) by gender and level of education and to get more information on the type of work that they are doing.

The ISTAT (Italian National Statistical Institute) multipurpose survey on health conditions and access to health services was administered between October 2004 and September 2005 on a sample of 60,000 households (140,000 individuals).<sup>40</sup>

Table 1 - Employment rates of people from 15 to 64 years old who have / have had cancer

	M	F	Total	gender gap
affected by cancer	50.68	34.57	39.84	16.11
not affected	71.98	46.77	59.43	25.21
gap in employm.	21.3	12.2	19.59	9.1
total	71.78	46.53	59.14	25.25

**Source**: our data processning of ISTAT multipurpose survey On health and access to health services 2004-2005

The employment rate of those who did not have cancer was on average 59% (72% for men and 47% for women), whereas the employment rates of those who had or have cancer wass 40% (51% for men and 35% for women). The gender gap in employment rates is lower among people who had or have cancer and the gap in employment rates by gender and cancer is higher for men (whose employment rates decreases by 21% from

<sup>&</sup>lt;sup>40</sup> Istat (2008) Nota metodologica, www.istat.it/dati/dataset/20080131 00/notametodologica.pdf

those who did not have and those who had/have cancer) than amongswomen (whose employment rate decreases by 12%).

Employment rates increase with the level of education for both groups of the population. However, the gap with regard to employment is relevant at different levels of education, with the highest degree of disadvantage for men with no education or primary school education (the employment rate for men in this group was almost 30% lower if they had cancer) and the lowest degree of disadvantage for women with secondary education.

Table 2 - Employment rates men and women (15-64) by level of education And whether they had/have cancer

	affec	ted by ca	ancer	not affe	ected by ca	gap not aff- aff		
	M	F	gap	M	F	gap	M	F
no or								
primary	30%	12%	18%	59%	21%	38%	29%	9%
secondary								
school	52%	32%	20%	69%	38%	31%	16%	5%
high school	57%	50%	7%	76%	58%	19%	20%	8%
degree or post	68%	60%	9%	86%	74%	12%	18%	15%
n.obs.	417	826		41440	41963			

**Source**: our data processing of ISTAT multipurpose survey on health and access to health services 2004-2005

Amont employed people the distribution by type of job shows that workers who had/have cancer are overrepresented with regard to other workers in white-collar positions and are underrepresented with regard to others in blue-collar positions consistently with what has been found also by other studies on the difficulties of returning to work for those in blue-collar positions:

Long-standing illnesses seem to have stronger adverse social and economic effects on

manual workers as, for example, manual jobs are less flexible and heavier, and teleworking

is not possible. Consequently, manual workers have a higher incidence of disability: it is

obviously easier for white collar-jobs to return to work, whereas jobs presupposing

heavy physical activities can be very difficult for cancer patients to go back to. This also

applies if the job involves piecework. (Crepaldi, 2008, p.v).

Table 3 - Employment position of workers not affected / affected by cancer

	not aff.	affected	gap
manager	2.31	4.22	1.91
high skilled	5.41	8.44	3.03
white-collar	31.88	40.86	8.98
blue-collar	34.26	20.89	-13.37
apprentice	1.38	0	-1.38
homeworking	0.42	0.41	-0.01
entrepreneur	4.32	6.26	1.94
professional	5.61	3.73	-1.88
self-employed	12.14	13.02	0.88
socio coop.	0.57	0.67	0.1
home ass.	1.68	1.49	-0.19

Source: our processing of ISTAT multipurpose survey on health and access to Health services 2004-2005

The analysis on Italian microdata on individuals and oncological conditions shows a different employment probability according to their state of health, level of education and gender with a lower presence of individuals with oncological conditions in blue-collar positions.

The aim of the following Sections of this chapter is to analyse in greater depth the changes taking place inside the workplace and the degree of knowledge about employees' rights in cases in which employees have an oncological condition. The data were collected by administering a questionnaire the structure and aims of which are described in the following section.

## 4.3. The questionnaire

This section presents the survey carried out to explore the situation of workers with oncological conditions in specific workplaces.<sup>41</sup> The aim of this survey is to gain an understanding of barriers and protection in specific workplaces but also of the perceptions of workers about this issue. Without such an understanding it is difficult to design and develop appropriate and transferable interventions and approaches. The decision to carry out a questionnaire-based survey is related to the many advantages this type of survey can give in collecting information.

The response to the questionnaire by the workers was sufficient to allow statistically significant elaboration of data also when analysing multiple-choice questions. Moreover, standardized questions make measurement more precise by providing standard definitions for the participants while allowing space for additional comments.

Four key issues were considered when the questionnaire was designed: respondents' attitude, the nature of the questions, the cost of conducting the survey and the suitability of the survey for the purposes of the research.

The first point concerns the possible reaction of people when they are asked to provide information on such a sensitive issue. This means that the first priority was the protection of participants' privacy and so the questionnaire was constructed so as to be completed and evaluated anonymously. In compliane with the Italian Law, it was prefaced by a

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<sup>&</sup>lt;sup>41</sup> The questionnaires used for the two surveys is to be found in the appendix to this Chapter.

Privacy Statement to ensure that the data were used only for the purpose of the specific survey.

In the questionnaire the majority of questions are closed, that take the form of multiplechoice questions and that make it possible to have a questionnaire that is quick to answer and easy to code.

With regard to the costs the survey might entail, the questionnaire was administered in electronic form. The choice of an electronic questionnaire made it possible to reach a large number of workers, especially in institutions and firms located in various parts of the country. Moreover, this method reduces data transmission times, in addition to the potentially quicker response time. However, the composition of the sample of workers who replied to the survey can be affected by the required capability to reply to an electronic questionnaire. In order to deal with this issue, hard copies of the questionnaire were distributed to the Italian firms for workers who did not have internet access.

The questionnaire is divided into three sections: the first part concerning personal data, the second concerning employment status and the last one concerning oncological conditions of the person filling in the questionnaire, and the worker's knowledge of her rights as well as information on the changes occurring at work. In this general framework, each session was adapted depending of the country involved because of the different experiences and different provisions concerning the protection of workers with an oncological condition. But comparability across countries was maintained.

In the first part personal data are collected. This section gathers information relating to age, place of residence, sex, marital status, level of educational achievement, number of children, living conditions, family members in need of assistance. These variables provide information on the demographic and social condition of the employees and can be used to analyse the data collected in the other sections of the survey.

The second part of the questionnaire examines employees' working condition. Information on the occupational status and area of work are collected together with information on the type of contract. This information on employment is relevant to test differences in the protection of workers in different employment conditions. Eight types of contracts were identified, in addition to the chance to specify other forms: open-ended full-time contract, open-ended part-time contract, fixed-term full-time contract, fixed-term part-time contract, contract of collaboration, temporary agency work contract, associate employment. The questionnaire also collects information on past work experience and on social insurance contributions.

The third part provides a reliable and valid frame and assessment of the situation of workers with an oncological condition in different workplaces. Many important aspects are examined. Smoking is considered one of the main causes of cancer affection and the health risks caused by cigarette smoking are not only limited to smokers. Whether the participant is or has been a smoker and whether legal provisions on smoking are respected in the workplace are two important issues in this analysis. Moreover giving up smoking has major health benefits for men and women of all ages and, for this reason, also the status of having been a smoker is analysed.

The next questions concern the workers' awareness of the legal provisions concerning the protection of workers with an oncological condition. Here the respondents can give an answer on their knowledge about different legislative provisions, making it possible to see whether some legislative interventions are better known than others. Moreover, there are three specific questions in this part of the questionnaire that concern information and communication about the rights of workers with oncological conditions in the specific workplace. This type of information is of central importance for the aim of the survey because it makes possible an assessment of the actions that different institutions adopt and of where there is lack of information.

The second part of the last section of the questionnaire concerns only those workers who have or have had an oncological condition. The questions in this part, concerning more

personal and intimate questions, were designed with particular attention to ensure the dignity and privacy of the respondents. All these questions aim to explore to what extent and how the condition changed employment conditions and personal relationships in the workplace. Four questions concern the right to change a full-time contract to a part-time one, and to change back to full-time at a later date.

Finally eight questions concern the problems faced after the return to work, in particular with regard to the reintegration of employees who have had cancer. Respondents are asked to evaluate their current working conditions, after their return to the workplace, in comparison with the situation before the first oncological diagnosis. Working conditions are evaluated in terms of working hours, occupational position, career prospects, relations with colleagues, relations with management, remuneration and job satisfaction (excluding and including remuneration). The questionnaire ends with a space for further comments.

The microdata collected through the questionnaire make it possible to process the information in various ways.

First of all, the analysis regards the entire sample of employees for each work context considered. In particular the employment status is analysed by gender, employment grade, type of contract, age, marital status, presence of children, mean tenure and state of health.

Subsequently, the attention is focused on those workers who have or have had cancer and on their employment status.

The family composition of workers with cancer (whether they live alone or whether they have care responsibility) is analysed with particular attention since in general, welfare systems only partially respond to the needs of people living alone or having care responsibilities, and this might have important consequences on their employment. In addition to the medical treatment relating to the oncological condition, there might be difficulties in reconciling working time with care responsibilities. The ageing of the demographic profile in recent decades goes hand in hand with the increase in the absolute

number of older persons suffering from disabilities and chronic diseases who need care, and this trend is expected to continue in the coming decades. Moreover, this is an aspect that affects women in particular because in general in the European Union, although the rates vary across countries, two-thirds of carers are women.

The research methodology used mainly quantitative methods in order to seek a high degree of precision and representativeness across various types of workers, with a different occupational status and working in different fields. In addition, the study adopted a gender-focused approach to the issue, as a means of addressing women's concerns more holistically and effectively. It utilizes gender analysis, which is the tool for analysing the specific nature of gender differences and assessing gender differences and inequalities in personal and working conditions. On the basis of the information obtained from gender analysis, appropriate interventions and strategies can be identified to improve women's status, in particular in the presence of oncological conditions.

### 4.4. The institutions taking part in the survey

The questionnaire was administered in three distinct settings, that were very different in terms of their nature and structure. The three settings were an Italian public institution, the Milan City Council, a multinational private firm, Roche (Italy), and individuals contacted by means of an on-line questionnaire in Sweden. This session provides a brief description of these institutions and how they participated in the survey.

## 4.4.1. Milan City Council

Milan is the second largest city in Italy and it is the capital of the Lombardy region, with a territorial area of 182 sq. km and a population of around 1.3 million in 2008<sup>42</sup>. Milan is a good example of a dynamic and diversified economy. Milan City Council is the public institution that provides many of the basic civic functions. It has around 18,000 employees and it provides services in all parts of the city. At the beginning the work was

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<sup>&</sup>lt;sup>42</sup> Source: National Institute of Statistics (Istat)

preceded by a meeting with the central divisions that report to the municipal departments. The meeting was held with the officials in charge of the city administration, who were then able to carry forward the project, after taking advantage of the expertise of the labour law specialists taking part in the project. In this way they were able to gain indepth insight into the design and implementation of an effective information campaign for the employees of the city council with regard to the provisions for workers with cancer.

One of the aims of the research project was to enable workers to acquire detailed information, particularly in the organisations taking part in the various phases of the project. This meeting held for the purposes of training was followed by further meetings for an evaluation of the most effective methods to adopt for the information campaign compatible with the right to privacy of the employees.

Milan City Council was more than willing to take part in the survey, providing the opportunity to test the questionnaire on a large sample of workers, with considerable benefits, in terms of number of collected data, for the outcome of the survey. In its role as an employer the Milan City Council continuously communicates all the legislative measures and different options provided under collective bargaining to employees with disabilities or health problems, and this category includes employees with oncological conditions.

It was underlined that Milan City Council as a public institution grants the right to modify individual employment contracts, changing from a full-time contract to a part-time one. This is a right of the individual worker, that has only recently been extended to public employees: originally, the Biagi Act did not apply to the public sector. This information is circulated by means of written and electronic internal communications and it is posted online, on the intranet website, in the document on sick leave / leave of absence.

Moreover, the Human Resources Department organises periodical meetings with staff managers of each central division in order to update them about various issues on human resources management and to carry out an in-depth examination of the situation of workers with particular disabilities. For the most serious cases, when there is no prospect of a return to work or of remaining in the workplace, the Human Resources Department supports those employees in bringing the contract to an end and in the procedures to obtain a disability pension.

On 20 October 2008 Milan City Council, Adapt, Europa Donna and the Marco Biagi Foundation organized a workshop on "Promoting new measures for the protection of workers with oncological conditions" in Milan, in support of this survey. The workshop was opened by the Italian Ministry of Health, Labor, and Social Policy, Mr. Maurizio Sacconi (Appendix 1), who explained the importance of developing new measures for the protection of these workers, for the elimination of discrimination and harassment in the labour market. He underlined the interest of political parties in this issue also at a national level when he stated that: "Politics has a key role in dealing with labour law and health issues, and it has to provide effective measures especially in terms of legal protection for people with oncological conditions".

Milan City Council was represented by two town councillors, Mr. Andrea Mascaretti and Mr. Gianpaolo Landi di Chiavenna, respectively Milan city councillors for Labour and Employment and for Health. The workshop included presentations by Prof. Alessandra Servidori, Mr. Dario Francolino, Head of Communications and Public Affairs at Roche S.p.A., Ms. Patrizia Ravaioli, director of LILT, the Italian League against Cancer and representative of Europa Donna Italy, Dr. Francesco De Lorenzo, president of the Italian Federation of Oncological Voluntary Associations, Ms. Maria Rosa Strada of the Italian Society of Oncology, and Ms. Arja Leppänen, representing Europa Donna Sweden.

The experience of Milan City Council highlighted many procedural and administrative difficulties, mainly connected to the nature of the public institution. Four central divisions – Labour and Employment, Health, Human Resources, Communication – were directly

involved in the survey, in addition to the council in its role as an employer. The Milan City Council Statistics Office collaborated in the design of the questions which might identify the respondents. In Milan City Council there are some officials, especially in the top management, who might be easily identified due to their specific circumstances, if the questionnaire failed to take account of the need to safeguard the privacy rights of all the employees taking part.

Milan City Council also collaborated in presenting the aim of the survey to the employees, through two different types of communications. A mail was sent to all the municipal employees, inviting them to fill the questionnaire, which was available on an external link. An additional notice was posted on the intranet web site. Staff managers were asked to distribute a paper version of the questionnaire among those employees who do not have access to a personal computer and/or to an internet connection.

The Communication Office made a significant contribution to dealing with all the aspects related to privacy rights. The assistance of the city council was fundamental for the purposes of contacting the employees and adapting the questionnaire according to the characteristics and procedural requirements of the institution.

Milan City Council is the only public institution taking part in this survey and this experience should be a pilot study in order to involve other public institutions. The comparison between public and private firms can cast light on various issues in the debate, allowing for some significant improvements.

### 4.4.2. Roche Italy

Roche is a multinational company that plays a pioneering role in healthcare. As an innovator of products and services for the early detection, prevention, diagnosis and treatment of diseases, it contributes on a broad range of fronts to improving people's health and quality of life<sup>43</sup>. The headquarters of the company are in Basle, Switzerland, and it is one of the leading groups in the world operating in the pharmaceutical and

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<sup>&</sup>lt;sup>43</sup> More information at www.roche.it

diagnostic sector. Roche is the leading company in the world for in vitro diagnostics and in pharmaceutical products for oncology and transplants, it is one of the leading groups in the virology sector and it is active in other significant areas of treatment such as auto-immune and inflammatory disorders, metabolic disorders, and diseases of the central nervous system. In Italy it is the number one company in the hospital sector and in oncology. Due to its leading role in oncology, the contribution of the company to the research project was particularly significant. The Roche network made it possible to disseminate the research findings also among other companies. As regards Roche Italia, it has been active on the Italian market since 1897 and as of September 2008 had a total of 1,213 employees in the Pharmaceutical Division, including the company offices in Monza and the establishment in Segrate (province of Milan) and around 520 employees in the Diagnostics Division.

Roche played a key role from the beginning of the project with a well designed information campaign and the distribution of the questionnaire to its employees. An organisational meeting was held at the start of the campaign between the Head of Human Resources, Internal Communications Specialist, and the Head of Communication & Public Affairs.

In the framework of the information campaign there were three main tasks:

- an analysis of the normative provisions
- discussions between the Human Resources Division and social worker
- the design of information material.

The analysis of the normative provisions was based on information materials produced by Adapt and other bodies (including meetings organised by the trade unions on this issue) and made available to the social worker. A selection was made of the most important measures relating to employment, with an outline of the available legal provisions, enabling each individual worker to obtain more detailed information about key issues. The materials were designed using a formal register without adopting "bureaucratic" language. The campaign was supported by the management of Roche Italia, the trade

unions active in the company, and the Sodalitas Foundation.

In order to make the questionnaire available online, joint action was taken with the IT department and the Legal and Corporate Affairs department concerning all aspects relating to privacy and data processing.

The internal information campaign consisted of:

- the distribution by email to all the company employees of information concerning existing measures protecting workers with an oncological condition;
- further information on the company intranet;
- notices on the information columns inside the company;
- an article in the company journal;
- the administration of the questionnaire online, including a privacy disclaimer;
- the distribution of hard copies of the questionnaire for employees without Internet access.

The campaign was implemented both at the Monza headquarters and at the establishment in Segrate. In Segrate, hard copies of the questionnaire were distributed due to the fact that not all the employees have access to Internet or familiarity with computers.

### 4.4.3. The Swedish Breast Cancer Association

The Swedish Breast Cancer Association (BRO) is a non-political, non-religious and non-profit organization consisting of 33 breast cancer societies (BCF) from all over Sweden. The association is active internationally as a member of Europa Donna and Reach to Recovery International. It was founded in 1982 and has around 10,200 members.

BRO works actively for the rights of women, aged 40-74 years, to have access to mammograms, regardless of where they live, and for the rights of patients with breast cancer to have access to high quality diagnostics, treatment, care and rehabilitation, regardless of where they live.

BRO works for the rights of breast cancer patients to receive treatment for lymph oedema under the established health care agreements. Lymph oedema is a common complication

that can occur after surgicery or radiation therapy.

The questionnaire on "Promoting new measures for the protection of women workers with oncological conditions by means of social dialogue and company-level collective bargaining" was distributed in collaboration with Roche, Sweden. It was an electronic questionnaire and linked to the homepages for several member-organizations for people affected by cancer, to Roche Sweden, newspapers, magazines and generally to all institutions connected to cancer. The survey was publicised by articles in newsletters, advertisements in newspapers and a press release was also sent about this survey.

The time-period for the survey was three weeks in the autumn of 2008. Unlike the Italian surveys that took as a sample employees working in a given institution or firm, the Swedish sample consisted only of people with oncological conditions.

### 4.5. The sample

This section shows the general characteristics of the various samples analysed in order to give an overview of the workers participating in the survey. In Section 4.4.1 we describe the sample of the Milan City Council, in Section 4.4.2 the sample of Roche Italy and in Section 4.4.3 we describe the Swedish case. The survey and the methodologies used were described in detail in Section 4.2 above.

### 4.5.1. The sample of employees working for Milan City Council

The questionnaire was made available for employees of Milan City Council for a total of 20 days in the autumn of 2008. During this period 3.4% of the Milan City Council employees took part in the survey and 619 questionnaires were collected. Of these, 75.3% complied with the privacy statement and could therefore be used for analysis. Among the employees taking part in the questionnaire, 31.12% were men while 68.88% were women, this might be related to the fact that, in general, in the public sector women are over-represented in the occupational structure.

Figure 1 shows the composition of employees taking part in the survey by gender and age group. The highest participation was registered among men and women aged 35-44 and 45-55 years old, while it is lower in the younger and older age groups.

45,26 11,64 Total 5 37,93 **25-34** ■ 35-44 Female 39,06 10,94 45 **45-54** □ over 55 13,19 Male **5,5** 35,42 45,83 20% 40% 60% 80% 100%

Figure 1 – Composition of employees by gender and age group

**Source**: our processing of data from Milan City Council survey.

In terms of employment grade, the majority of employees were white-collar employees (88.18% of the men and 92.46% of the women), while in the higher positions the percentage of men was higher than the percentage of women. In fact, only 5.96% of the women were employed in a high-level white-collar position and 1.57% as managers, compared, respectively, with only 8.33% and 3.47% of men.

Table 4 – Composition of employees by gender and employment grade

	Men	Women	Total
White collar	88.19	92.48	91.14
High level white collar	8.33	5.96	6.7
Manager	3.47	1.57	2.16
Total	100	100	100

Source: Our processing of data from Milan City Council survey.

Of the employees taking part to the survey, the majority worked on an open-ended full-time contract, which is fairly typical of hiring in the public administration. As shown in Figure 2, open-ended full-time contracts were more widespread among men than among women, and open-ended part-time contracts more common among female employees. Amongst women 80% had an open-ended full-time contract, while 18% had an open-ended part-time contract; the percentage of other types of contracts, such as fixed-term full-time and part-time contracts and contracts of collaboration was very low. Among men, 94% had an open-ended full-time contract and only 3.45% had an open-ended part-time contract.

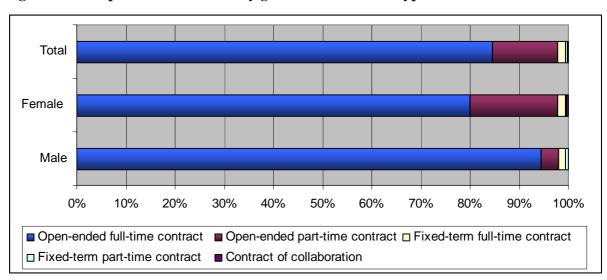


Figure 2 – Composition of workers by gender and contract type

**Source**: our processing of data from Milan City Council survey.

With regard to the marital status of the employees taking part in the survey, the majority were married or cohabiting, as shown in Figure 3. Among women, 66% were married or cohabiting, while 18% were single and 15% separated or divorced. Among men, 59.31% were married or cohabiting, 31.03% were single and 9.66% separated or divorced.

Table 5 shows the composition of female employees by marital status and age groups. The largest proportion of single women was in the 25-34 age group and this percentage decreases with age. The highest percentage of separated or divorced women was among

those aged 45-54 (19.44%) and among those aged over 55 (17.14%). Moreover 63.55% of women had children, compared to 57.93% of men.

Among women with children, 81.86% were married or cohabiting, while 15.20% were separated or divorced; the same percentages are lower among men, with 80.95% married or cohabiting and 13.10% separated or divorced. However 5.95% of men with children were single, compared to 1.96% of women.

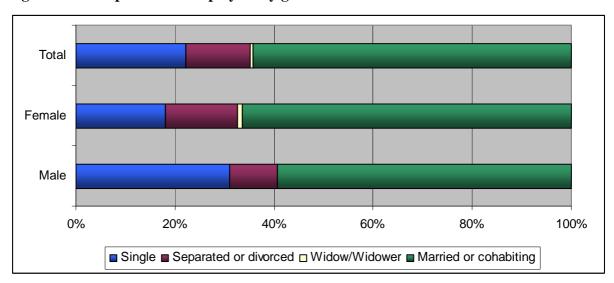


Figure 3 – Composition of employees by gender and marital status

**Source**: our processing of data from Milan City Council survey.

Table 5 – Composition of women employees by age and marital status

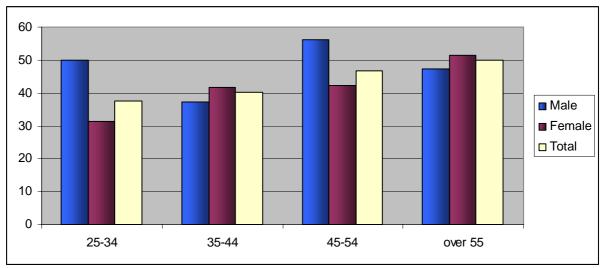
	25-34	35-44	45-54	over 55	Total
Single	62.5	16	16.67	8.57	17.81
Separated or divorced	0	10.4	19.44	17.14	14.69
Widow/Widower	0	0.8	0	5.71	0.94
Married or cohabiting	37.5	72.8	63.89	68.57	66.56
Total	100	100	100	100	100

**Source**: our processing of data from Milan City Council survey.

Figure 4 shows the composition of employees with older people or people who need assistance in their family. The percentage of carers was calculated for each age group in order to avoid distortion due to the different size of the groups, which would otherwise result in a skewed sample. As we can clearly see in Figure 4, in general the percentage of carers increases with age, with the sole exception of men aged 45-54 and those aged 25-34: in these cases respectively 56.1% and 50% had a relative in need of assistance, while among the other age groups this percentage was lower.

It was found that 51.4% of women aged over 55 were in this situation, and the share decreases among the younger groups: the percentage was 31.2%, among those aged 25-34, 41.6% among those aged 35-44, and 42.4% among those aged 45-54.

Figure 4 – Employees who have in their family older people or people who need assistance: distribution by gender and age group



**Source**: our elaborations on data from Milan City Council survey.

### **4.5.2. Roche** – **Italy**

The questionnaire was made available for the employees of Roche Italy for a total of four weeks in November 2008. During this period we collected 252 questionnaires and 97% of

them were found to be valid in terms of acceptance of the privacy statement. Around 14% of the employees took part in the survey.

Among the employees taking part 64% were male, reflecting the over-representation of male employees in the firm. Figure 5 shows the composition of the sample of employees by gender and age group. The largest participation among men was among those aged 45-54 (72%), while among women participation was more equally distributed among the age groups: 22% of the female employees taking part were aged 25-34, 48% were aged 35-44, 29% were aged 45-54 and only 1% were over 55. Among men 5% were aged 25-34, 19% aged 35-44 and 4% were over the age of 55.

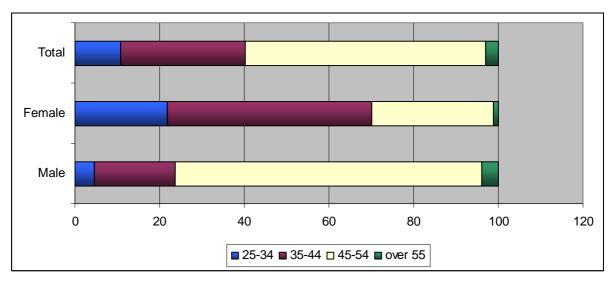


Figure 5 – Composition of employees by gender and age group

**Source**: our processing of data from Roche Italy survey.

In terms of employment grade, the majority of participants were employed as white-collar workers (72.4% of males and 79.1% of females), while among high-level white-collar workers the percentage of men was higher than that of women. In fact, 17.4% of women were employed as high-level white-collar workers and 2.3% as managers, compared, respectively, with 22.4% and around 2% of men. Finally, just 3.3% of men were employed as blue-collar workers, compared to 1.2% of women.

Table 6 – Composition of employees by gender and employment grade

	Male	Female	Total
Blue collar	3.29	1.16	2.52
White collar	72.37	79.07	74.79
High level			
white collar	22.37	17.44	20.59
Manager	1.97	2.33	2.1
Total	100	100	100

**Source**: our elaborations on data from Roche Italy survey.

Among all the employees taking part, the large majority were working on an open-ended full-time contract: 97% of respondents had been hired an open-ended full-time contract, while 1% had an open-ended part-time contract. The employees with a part-time contract were all women, amounting to 2.3% of all women taking part in the survey. Just 2% of the women had a fixed-term full-time contract and 2% a fixed-term part-time contract, while 99% of men worked on an open-ended full-time contract.

The majority of the employees taking part were married or cohabiting, as shown in Figure 6. Among women, 69% were married or cohabiting, while 18% were single and 12% separated or divorced, whereas among men, 89% were married or cohabiting, 7% were single and 4% separated or divorced.

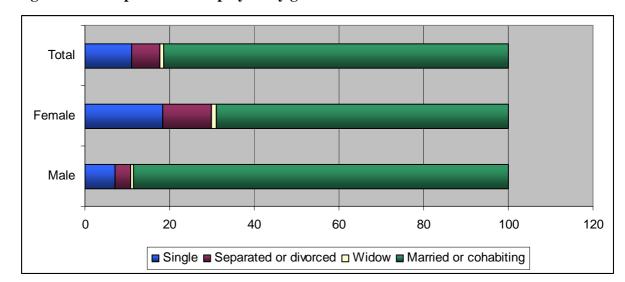


Figure 6 – Composition of employees by gender and marital status

**Source**: our elaborations on data from Roche Italy survey.

27% of employees declared to have in their family older people or people who need assistance. Amongst men 32.1 stated to be in this situation, while amongst women 18.4%. Figure 7 shows the share of employees who have in their family older people or people who need assistance, calculated on the total of participating employees for each age group. Among male employees the share of carers increases with the age: carers are 14.3% of those aged 25-34, 23.3% of those aged 35-44, 34.4% of those aged 45-54 and 50% of those aged over 55.

The situation is indeed different among female employees: here the highest share of carers is among those aged 35-44 (21.4%), while it is 16% among those aged 45-54 and 15.8% among the youngest age group. No one, among those aged over 55, declared to have in their family people in need of assistance.

60 40 30 20 10 25-34

35-44

45-54

over 55

Figure 7 – Employees who have in their family older people or people who need assistance: distribution by gender and age group

Source: our processing of data from Roche Italy survey.

Among the questionnaire respondents, 3.3% stated that they are or have been affected by an oncological condition: 8 respondents out of 244 questionnaires. Among them, 5 were women and 3 were men. Affected women account for around 6% of the female workers taking part in the survey, while affected men account for around 2% of the total male workers.

The limited size of the sample does not allow us to use the findings to generalize the responses. However the responses may be used to cast light on the amount of information on the rights and the legislative provisions in the Roche context and this is the issue analysed in Section 4.6.

## 4.5.3 The Swedish Study

The questionnaire was distributed by the Swedish Breast Cancer Association (BRO), in collaboration with Roche Sweden. It was made available for a period of 22 days during the autumn of 2008 and a total of 714 responses were received.

Among the employees who took part in the survey, 12.4% were up to the age of 40, 69.3% were aged 41-65, while 18.3% were aged over 65. The majority of participants (25.2%) were living in Stockholm and 18.8% in Skåne, while the other participants were living in other counties: the distribution of county of residence is shown below in Table 7. The results show that 89.5% of participants were born in Sweden, with the remaining 10.5% from other countries.

Table 7 – Place of residence of participants in the Swedish Survey

	Percentage	Count
Blekinge	1.9%	12
Dalarna	1.6%	10
Gotland	0.8%	5
Gävleborg	2.1%	13
Halland	4.6%	29
Jämtland	1.3%	8
Jönköping	2.2%	14
Kalmar	1.8%	11
Kronoberg	3%	19
Norrbotten	2.6%	16
Skåne	18.8%	117
Stockholm	25.2%	157
Sörmland	4.5%	28
Uppsala	2.9%	18
Värmland	1.9%	12
Västerbotten	2.2%	14
Västernorrland	4.6%	29
Västmanland	2.4%	15
Västra Götaland	11.9%	74
Örebro	1%	6
Östergötland	2.2%	14
Don't know	0.5%	3
	Respondents	624
	No response	28

Source: Our processing of Swedish survey data

The distribution by gender of employees shows a greater participation of female employees: in fact 85.7% of participants were female and only 14.3% male. Of the participants, 74.9% were married, while 10.3% were single and 11.8% separated or divorced. Moreover, 3% were widowed.

Concerning the family composition, a significant proportion of the participants (44.8%) had two children, 15.1% had one child, and 26.1% three children or more, while 14% had no children. 67.9% stated that the youngest child was aged over 18, while only 6.3% had a child younger than six.

Table 8 shows the composition of respondents by level of education. A significant proportion (43%) had a university/college level degree. 58.6% of them were in employment, 6.4% were unemployed, 5% self-employed and 26.8% retired. 2.4% of respondents were studying. Among those in employment, the majority (75.5%) had an open-ended full-time contract, while 18.1% had an open-ended part-time contract. The composition of participants by type of contract is shown in Table 9.

Table 8 – Composition of participants by level of education

	Percentage	Coun
		t
Six-year elementary schooling	2.1%	13
Nine-year compulsory schooling	7.3%	46
High school	21.7%	136
Vocational training	18.2%	114
University/College	43%	269
Bachelor's/Master's degree or other higher qualification	7.7%	48
	Respondents	626
	No response	26

**Source**: Our processing of Swedish survey data.

Table 9 – Composition of participants by type of contract

	Percentage	Count
Full-time permanent employment	75.5%	275
Part-time permanent employment	18.1%	66
Full-time temporary employment	2.2%	8
Part-time temporary employment	2.2%	8
Other, describe below	1.9%	7
	Respondents	364
	No response	3

**Source**: Our processing of Swedish survey data.

With regard to seniority, 75.1% had been working in their workplace for more than five years, 19.9% for a period from one to five years, while only 4.9% had been employed in the current workplace for less than one year.

## 4.6. Characteristics of cancer affected employees

## 4.6.1. Milan City Council

Figure 8 shows the composition of employees affected by cancer by gender and age groups. These shares were calculated by gender and age out of the total of employees taking part for each age group. As stated in the previous Section, in our sample oncological conditions seem to be more common among women than among men.

In general the percentage of affected employees increases with age among women, while the opposite appears to be the case for men. Among women aged over 55, 45.7% have or had an oncological condition, compared to 22.9% among those aged 45-54, 12% among those aged 35-44 and 12.5% among those aged 25-34. Among men aged over 55, 5.3% had or had had an oncological condition, 6.1% among those aged 45-54, 9.8% among those aged 35-44 and 12.5% among those aged 25-34.

50 45 40 35 30 Male 25 ■ Female 20 □ Total 15 10 5 0 25-34 35-44 45-54 over 55

Figure 8 – Composition of workers affected by oncological condition by gender and age group

With regard to employment grade, 16.6% of white-collar workers had or had been affected by an oncological condition. Among high-level white-collar workers 19.4% were in this situation, while none of the managers reported an oncological condition.

Some significant issues relate to the contract type distribution among the workers. As shown below in Figure 9, the situation is quite different by gender. While all the affected men were working on an open-ended full-time contract, 18.18% of the affected women had an open-ended part-time contract, 1.52% had a contract of collaboration and the remaining 80.3% had an open-ended full-time contract. Also in this specific case, part-time contracts are still more common among women. In the sample there seems does not seem to be a significant relationship between the type of contract and the probability of being affected by an oncological condition. Among female employees with an open-ended part-time contract, the incidence of cancer was 21.5%, and this was just a little lower among female employees with an open-ended full-time contract. Among men with an open-ended full-time contract the incidence of cancer was around 8%.

Total

Female

0% 20% 40% 60% 80% 100%

Open-ended full-time contract Open-ended part-time contract Collaboration

Figure 9 – Composition of employees affected by oncological condition by gender and contract type

In oncological cases, it is important to consider the marital status and the family composition of the affected workers. This allows us to make some conjectures about the living conditions, in particular in terms of the potential economic and moral support the family unit is supposed to give or with respect to the unpaid work that the person with cancer provides or needs to provide.

Figure 10 shows the composition of affected workers by gender and marital status. In the Milan City Council sample the majority (76.62%) of affected workers were married or cohabiting, while 9.09% were single and 12.99% separated or divorced. Among women 78.79% were married or cohabiting, 15.15% separated or divorced and only 4.55% single. The situation was slightly different among men, with 63.64% married or cohabiting and 36.36% single.

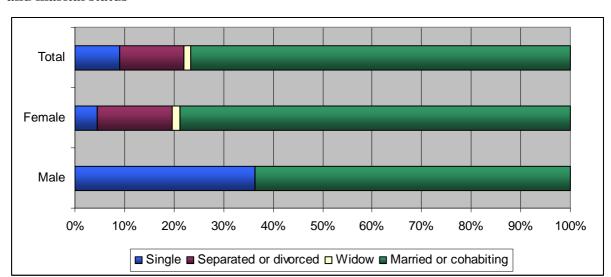


Figure 10 – Composition of workers affected by oncological conditions by gender and marital status

Almost 70% of affected women had children but this was lower among affected men (63.6%). Table 10 shows the family composition by gender for employees affected by and not affected by cancer. Among women with cancer, the percentage living with children was higher than among those not affected. The questionnaire does not allow to disaggregate by the age of the children due to the high number of missing responses about the number and age of children, so it is not possible to calculate the number of affected lone mothers with children who need assistance and lone mothers living with grown up children. 26% of women affected by cancer lived with their partner and children, 23.4% only with their partner and 9.1% alone. The percentage of women living with their parents was lower among those affected than among those not affected, and the percentage of female employees living with their parents was significantly lower than that of male employees.

Among male employees affected by cancer the highest shares were living with their partner or with their children and these percentages were higher than for employees not affected.

Table 10. Composition of family unit as a percentage of the number of employees not affected or affected, disaggregated by gender

	Not Affected		Affected		
	Male	Female	Male	Female	Total
Alone	23.1	11.3	12.5	9.1	14.2
With my parents	8.8	5.2	12.5	2.6	5.9
With my partner and					
children	14.7	24.8	0	26	21.7
With my partner	31.1	24.2	37.5	23.4	26.2
With my children	22.3	34.9	37.5	38.9	32

The responses show that, 41% of affected women reported that they have to take care of people in need of assistance in their family, while none of the affected men had to do so,

Table 11 shows the percentage of carers by gender and cancer affection.

Table 11 – Percentage of carers by gender and oncological condition

	Not Affected		Affected	
	Male	Female	Male	Female
People in need of assistance in the family	51.49	42.75	0	40.91
No one in need of assistance in the family	48.51	57.25	100	59.09

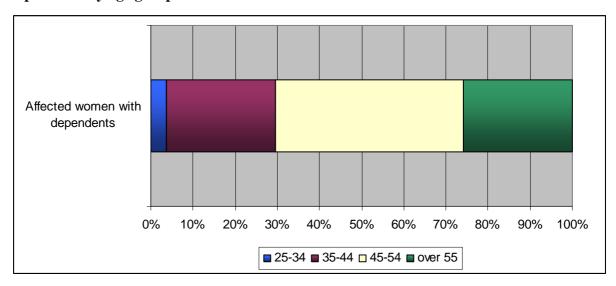
Figure 11 shows the composition by age group of female affected carers. The largest percentage of them were aged 45-54 (44%), but it is quite a widespread condition also among women aged 35-44 and over 55 (both 26%). When asked if they had problems

relating to responsibilities in the family in supporting other dependents during the treatment period, 38% answered positively.

They were asked how they solved this problem (by replying to a multiple-choice question): of those who answered that they had problems 60% solved them by sharing responsibilities with their partner, 64% with the help of other family members, and 36% with the help from friends. None answered that they benefited from help from public services.

The evidence collected on employees affected by oncological conditions regarding caring responsibilities highlights the need for attention, in the design of public policies, to the needs of a wider range of family members, including relatives receiving care from the person with cancer.

Figure 11 – Composition of women affected by an oncological condition with dependents by age group



**Source**: our processing of data from Milan City Council survey.

Among the affected employees, 54% were affected by breast cancer and 19.5% of these employees were aged 35-44, 51.2% were aged 45-54 and 29.3% aged over 55. These figures show, in the sample of analysis, a significant incidence of oncological conditions also in the younger age groups, while the largest percentage concerns women aged 45-51.

Among the whitecollar workers in the sample, 22.8% of the women were affected by an oncological condition while, among high-level white-collar women workers 31.6% were in this situation.

Regarding the contract type, the large majority of women with a cancer had an open-ended full-time contract (72%), but a significant proportion had an open-ended part-time contract (26%). Only 2% had a contract of collaboration.

Administrator

Officer

0% 20% 40% 60% 80% 100%

Open-ended full-time contract Open-ended part-time contract Contract of collaboration

Figure 12 – Composition of breast cancer affected women by employment grade and type of contract

**Source**: our processing of data from Milan City Council survey.

Among workers affected by an oncological condition, 23% were smokers, 51% were non-smokers and 26% were former smokers. Smoking seems to be more common among affected men than women: in fact 45% of affected men were smokers, versus 19.7% of women, and the shares of non-smokers and former smokers were 36.4% and 18% compared, respectively, to 53% and 27% among women.

In terms of tenure at the Milan City Council, among affected employees the large majority had been employed for more than five years, while around 20% had been working for a between one and five years. The percentage of employees working for more than five years increased among those not affected, with only 9.7% of male and 7.84% of female respondents in this group working for a shorter period.

#### 4.6.2. Sweden

The Swedish questionnaire received 714 responses and 628 of them were from people affected with cancer. The respondents lived in Stockholm 25.2% (157), Skåne 18.8% (117), Västra Götaland 11.9% (74) and the rest of the country. The majority 95.5% (595) had lived in Sweden for five years or longer and 89.5% (562) had been born in Sweden. The marital status of respondents was: married or living with a partner 74.9%, single

The marital status of respondents was: married or living with a partner 74.9%, single 10.3%, separated or divorced 11.6%, and widowed 3%.

With regard to the gender distribution of the respondents affected of cancer 85.7% (538) were women and 14.3% (90) men. Only 18.8 % were diagnosed before 2000 and 18.3% were aged 65 years or older. This means that the majority diagnosed after 2000 and they were younger than 65. In fact 69.3 % were 41-65 years old, and 78 of these respondents were 40 or younger (12.4%).

The survey showed that 14% (88) did not have children. This may reflect the relatively young age of respondents. Amongst them 44.8% had two children, 26.1% had three children or more and 15.1% had one child. Among the people with children 67.9% answered that the children were 18 years or older. This means that 32.1 % of the children were younger than 18 years and principally lived with the person affected by cancer.

The persons affected by cancer had different types of pathology, but the biggest group 62.2% (390) had breast cancer. The other groups were lung cancer 7.7% (48), cancer of the blood, including leukaemia 5.1% (32), prostate cancer 5.1% (32), brain tumour 4.6% (29) and gynaecological cancer 5.4%(34). Responses were given from many different smaller groups but the groups listed were the largest.

The survey showed that 48 of the questionnaire respondents were affected by lung cancer and among them 14.6% were smokers, 60.4% ex-smokers and 25% non-smokers. The total figures for smoking were: 38.9% ex-smokers, 9.7% smokers and 51.4% non-smokers.

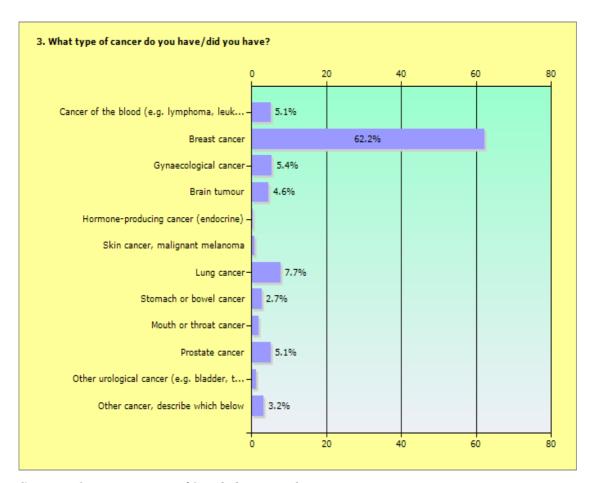


Figure 13 – Composition of respondents by type of cancer

Source: Our processing of Swedish survey data

Employees who took part in the survey and were affected by cancer show on average a high level of education: University/College (43%), high school (21.7%), vocational training (18.2%), Bachelor's/Masters degree (7.7%), nine years of schooling (7.3%) and six years of elementary schooling (2.1%).

Persons in employment or self-employed were 63.3 % and of these 75.5% were full-time permanent employees, 18,1% part-time permanent employees and 4.4% in temporary employment. The remaining 1.9% answered that they had another form of employment, per hour, per day etc.

## 4.7. Rights, information and services

## 4.7.1. The situation in the Italian organisations

In the employment relationship an important issue is related to the amount of information workers have about their rights in terms of protection in case of oncological conditions, and consequently about the specific legal provisions in force<sup>44</sup>. Education and information can play a fundamental role when the worker has to deal with the disease and also when she returns to work after treatment.

Since January 2005, Italian legislation has banned smoking in the workplace. Among the employees of Milan City Council, 85% report that the legal provisions on smoking are respected in the workplace and this percentage was slightly higher (87%) among those workers affected by an oncological condition.

Five specific legal provisions were identified in order to assess the level of information among workers on the protection of workers with cancer:

- Act No. 18/1980 concerning the right to benefits for the entire period of chemo or radiotherapy
- Act No. 104/1992 concerning the right to sick leave for medical treatment and the right to choose a work place nearest to the worker's home
- Collective agreement for local authority workers 14/09/2000 concerning the exclusion from the calculation of the leave of absence of the days of hospital treatment, day-hospital and medical treatment
- Decree No. 276/2003 concerning the right to change the labour contract from full-time to part-time

<sup>&</sup>lt;sup>44</sup> Tiraboschi M. (2008), Labour law for the people: how to protect employees suffering from oncological conditions and breast cancer, Adapt Bulletin - Special Edition Newsletter No. 6

- Act No. 80/2006 stating that, in the case of the oncological condition, the medical panel of the local health authority is required to carry out a disability assessment within 15 days of the date of application

In the Milan City Council sample it is possible to see that the different legal provisions are not equally known among employees. The best known provision is Act No. 104/1992 which is known by 65.2% of the employees taking part in the survey. Some 35.2% are familiar with Act No. 276/2003 while 33.7% are familiar with the collective agreement for local authority workers 14/09/2000. Only 23% of the employees were found to be informed about Act No 18/1980 and Act No 80/2006.

The level of awareness increases when considering only employees affected by cancer. In this case, 79.2% of affected employees are aware of Act No. 104/1992, 50.6% of the collective agreement for local authority workers 14/09/2000, 45.5% of Act No. 276/2003, 33.8% of Act No 80/2006 and 23.4% of Act No 18/1980.

With the sole exception of Act No 18/1980, there do not seem to be any significant differences in the level of information in terms of gender. Among women, 19.9% are aware of Act No 18/1980, 65.4% of Act No. 104/1992, 34.6% of the collective agreement for local authority workers 14/09/2000, 35.8% are aware of Act No. 276/2003 and 22.4% of Act No 80/2006. Among men, 23.4% are aware of Act No 18/1980, 64.8% are aware of Act No. 104/1992, 31.7% are aware of the collective agreement for local authority workers 14/09/2000, 33.8% of Act No. 276/2003 and 24.1% of Act No 80/2006.

Table 12 shows the levels of information in relation to the level of educational achievement.

 $\label{lem:constraint} \begin{tabular}{ll} Table 12-Knowledge~(\%)~of~specific~legal~provisions~by~cancer~affection~in~Milan~City~Council~sample \end{tabular}$ 

		Employees affected by
	All employees	cancer
Act No. 18/1980	23	23.4
Act No.104/1992	65.2	79.2
CCNL Enti Locali		
14/09/2000	33.7	50.6
Act No. 276/2003	35.2	45.5
Act No. 80/2006	23	33.8

 $\label{thm:constraint} \begin{tabular}{ll} Table~13-Knowledge~(\%)~of~specific~legal~provisions~by~level~of~educational~achievement~\\ \end{tabular}$ 

			High		
			School		
			Diploma		
	Middle	High	(at least		Postgraduate
	School	School	five years)	Degree	education
Act No. 18/1980	25	27.8	16	24.5	25
Act No.104/1992	77.3	71.1	55.6	75.5	75
CCNL Enti					
Locali					
14/09/2000	41	37.3	30.7	37.2	20
Act No. 276/2003	38.6	45.8	31.1	35.1	30
Act No. 80/2006	29.5	26.5	21.3	20.2	25

Source: Our processing of data from Milan City Council survey

The situation changes when we consider the Roche Italy sample, especially among employees affected by cancer. However, because of the much smaller sample of Roche Italy, the sample size might affect the results and, in any case, the two samples are not comparable. Also in this case the best known provision is Act No. 104/1992, which is known by 37.8% of all employees taking part in the survey, Act No. 18/1980 is known by 25.2%, while the collective agreement for local authority workers 14/09/2000 is known by 18.29%, Act No. 276/2003 by 25.61% and Act No 80/2006 by 15.85%. Among employees affected by cancer the level of knowledge increases only in relation to Act No. 18/1980, which is known by 37.5% of those with an oncological condition. In the other cases, the share decreases and it is important to note that none of the affected employees is aware of the provisions of Act No. 276/2003 and Act No 80/2006.

Table 14 –Knowledge (%) of specific legal provisions by state of health in the Roche Italy sample

		Employees affected by
	All employees	cancer
Act No. 18/1980	25.2	37.5
Act No.104/1992	37.8	25
Collective Agreement for		
Local Authority Workers		
14/09/2000	18.29	12.5
Act No. 276/2003	25.61	
Act No. 80/2006	15.85	

**Source**: Our processing of data from Roche Italy survey

Table 15 shows the level of information among affected employees of Milan City Council by employment grade. It seems there is a higher level of specific legal knowledge among high-level white-collar workers with regard to Act No. 18/1980 and Act No. 104/1992, while for the other legal provisions it is higher among white-collar workers.

Table 15 – Knowledge (%) of specific legal provisions by employment grade among employees affected by cancer in Milan City Council

	White collars	High-level white-collars
Act No. 18/1980	22.9	33.4
Act No.104/1992	78.6	83.4
Collective Agreement for		
Local Authority Workers		
14/09/2000	51.4	50
Act No. 276/2003	48.6	16.7
Act No. 80/2006	35.7	16.7

The limited sample of Roche Italy does not allow us to disaggregate the findings on the level of awareness of the legal provisions by employment grade.

Table 16 shows the level of awareness of the legal provisions in the sample of affected employees of Milan City Council by mean tenure. The table shows that the various legal provisions are better known among employees who have been working for the city council for a shorter period (between one and five years), than among those working there for more than five years. Moreover, the gap is higher with regard to the more recent legal provisions.

Table 16 – Knowledge (%) of specific legal provisions by mean tenure with Milan City Council

	Between one and five	
	years	More than five years
Act No. 18/1980	6.2	3.4
Act No.104/1992	28.6	11.3
Collective Agreement for		
Local Authority Workers		
14/09/2000	14.3	7.7
Act No. 276/2003	20.5	6
Act No. 80/2006	12.2	4.8

As a result of the limited size of the sample and the fact that, in the case of Roche Italy, all the employees with an oncological condition have been working for the company for more than five years, the mean tenure cannot be considered to be a significant variable. For both men and women the main sources of information on the rights of employees affected by cancer are friends and the company, followed by associations and, for women, relatives, whereas only a smallpercentage of these employees were informed about their rights by trade unions.

**Table 17 – Source of information on rights** 

Variable	M	F	T
Source of information on rights			
company	0.27	0.23	0.23
association	0.18	0.12	0.13
unions	0.09	0.06	0.06
friends	0.27	0.24	0.25
relatives	0.00	0.12	0.10
none	11	66	77

**Source**: Our processing of data from Milan City Council survey

Among the employees 12% think that information provided by the company on the rights of employees with cancer is clear and effective, 66% think that it is not effective (74% among those who had cancer). With regard to the application of the norms, 34% report that the norms to protect employees affected by cancer are applied in the institution they work in, however 50% did not give a reply on this matter (38% if they had cancer and 52% not affected by cancer).

Among the employees 94% continued to work after the diagnosis of cancer (91% for men and 94% for women) and 90% of them worked for the employer in the survey. Among those who informed their employer about their condition 40% of men and 65% of women stated that the employer had paid attention to their needs.

With regard to the type of services used during the period of illness and treatment, the psychological support service was used on average by 22% of employees affected by cancer (23% of women and 18% of men) and the period of illness and treatment 18% made contact with associations with no differentiation by gender.

## 4.8. Changes in the labour market condition of those affected by cancer

# 4.8.1. Milan City Council

All the men who had cancer continued in the same type of employment tasks afterwards, whereas 79% of women did. Most of them continued on the same type of contract (90% of men and 87% of women). Only a small percentage of those who opted to change from full-time work to part-time (10% of men and 11% of women) later returned to full-time (no men and 14% of women). The main reason for not changing back from part-time to a full-time work for women was that this type of contract was more suited to the current needs of the household (50%) or to personal needs (33%), while men preferred the part-time contract due to greater flexibility. However, the number of responses obtained does not allow us to perform further analyses to disaggregate the data on those who do not return to their previous full-time job. This could be further analysed in a wider survey.

The survey allows us to measure the change in working conditions after the person who is or was affected by cancer returned to work. In this regard our analysis by gender shows

that on average the conditions that have worsened are related to career prospects and income (the latter especially for men) while the relationship with colleagues in a range from 1 to 10 on average was rated 7 without gender differences.

Table 18 – Change in working conditions after interruption connected to cancer (answer to question: Is the situation with regards to the following conditions deteriorated (1) or improved (10)?)

	M		F		<b>M</b> +	F
Change in	mean	s.d.	mean	s.d.	mean	s.d.
Work schedule	5.4	2.1	5.8	2.0	5.8	2.0
Job task	5.7	1.3	5.2	2.3	5.3	2.2
Career	4.0	2.7	4.4	2.4	4.3	2.5
Rel with colleagues	6.9	2.7	6.9	2.2	6.9	2.3
Rel with principal	5.5	2.5	6.2	2.2	6.1	2.3
Income	4.4	2.4	5.3	1.7	5.2	1.8
Job satisfaction (non	6.2	2.3	5.5	2.6	5.6	2.6
wage)						
n.obs.	10		62		72	

**Source**: Our processing of data from Milan City Council survey

Employees evaluated the research conducted positively and with regard to policies to improve the situation of employees with cancer and their families they gave greater importance to prevention, followed by attention to working time, the grace period, and the calculation of days in hospital.

Table 19– What should be the priorities to improve the situation of workers with cancer and their families?

(1= top priority)

Affected by cancer	No	Yes	Total	
prevention	2.4	2.2	2.4	
time	4.4	4.6	4.4	
grace period	4.7	4.7	4.7	
calculation of days in hospital	4.9	5.1	4.9	
paid sick leave	5.0	5.0	5.0	
flexibility	5.4	5.5	5.4	
care of worker's family	5.7	5.5	5.6	
social security	6.3	6.4	6.3	
social agreements	6.3	6.1	6.2	

Source: Our processing of data from Milan City Council survey

## 4.8.2 Changes in labour market condition of workers affected by cancer: Sweden

The majority of workers in the survey (75.1%) had worked at the same workplace for more than five years, 88.2% were in employment when the cancer was diagnosed, 88.6% still work for the same employer and 70.1% still do the same work as they did before they were diagnosed. In addition 98.8% told their employers about their condition, and of these 64.8% were allowed to go to medical appointments during working hours.

However, this means that 35.2% were not allowed to go to medical appointments during working hours. In considering this group and comparing the terms of employment it may be seen that people with full-time permanent and temporary employment are allowed to go to medical appointments during working hours, but 54.1% of those in part-time permanent employment were not entitled to go to medical appointments during working hours.

With regard to the question about changing to part-time employment because of their condition, 34% work or worked full time, 20.7% changed to part-time because of their condition and 11.6% worked part-time and continued to do so. In addition, 33.7% were on full-time sick leave. After the sickness and treatment period, 82.4% of the respondents that they changed to part-time did not revert to full-time. Of these 33.3% said that they now work part-time and 66.7% stated that there are other reasons why they have not returned to full-time working, including the following:

- Still on sick leave
- I don't feel well. Tired.
- I am not ready with my treatments.
- I have a small child, and I am too tired to work full-time
- I have pain in my whole body and I am too tired to work full-time
- Not able to work full-time, too tired, can not handle stress
- I have many side effects after the treatment and medication
- I can't do my work anymore, because of my operation and side effects from treatment and medication.
- My employer and I must find a work solution for me. I can't do my ordinary work.
- Part-time retirement
- I don't have energy and health to work full-time.
- My employer does not have suitable work for me

When it comes to conditions of employment compared to the period before the diagnosis with cancer, the overall response was that the conditions had not changed much. Career opportunities and income deterioriated due to different working conditions. Men reported that their career opportunities were not so good as before and women reported earning lower wages than before. The conditions that had changed for the better were relations with workmates/colleagues and also job satisfaction.

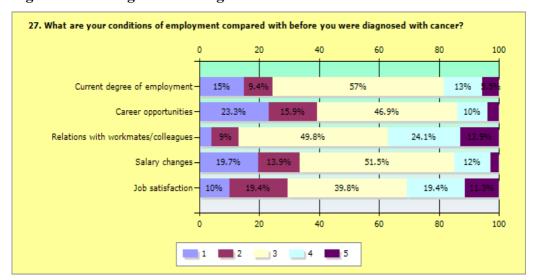


Figure 14 – Changes in working conditions

Source: Our elaboration of Swedish survey data

With regard to job security for workers diagnosed with cancer, 37.2% answered that in their opinion it was inadequate, 22.5 % answered that they did not know, and 40.3% found it good.

In the light of their experience as a cancer patient, 48.6% pointed to the need to change social security procedures, 49.7% considered it important to be able to adjust working hours during treatment, 50.3% considered it important to be able to adjust working hours after the completion of treatment and 16.8% wrote other comments. All the other comments asked for greater understanding for persons affected by cancer who need protection in work situations. Many people have side effects after treatment such as tiredness, fatigue, physical disabilities, not to forget the psychological change and concern about an illness that can lead to death. This needs greater understanding and support from employers. Many companies provide the temporary interruption of the employment contract for a reasonable period (known as the grace period), considering it like any other legitimate absence from work.

In a European dimension where there are such big differences between the countries, it should be recommended to have common guidelines for the EU countries concerning the working situation for persons affected by cancer. For this reason, the code of good

practice and "the charter of rights" for the worker affected by oncological conditions, which have been taken into consideration by the European Parliament, are of great importance.

# 4.8.2.1. Assessment of work capacity and entitlement to sickness benefit according to new sickness insurance rules from 1 July 2008

There are three stages in the period of sick leave in Sweden. During the first 90 days on sick leave, workers are entitled to sickness benefit if they cannot perform their normal functions. After 90 days, they are only entitled to sickness benefit if they cannot perform any work at all for their employer. After 180 days, they are only entitled to sickness benefit if they cannot perform any work at all on the regular labour market. This way of assessing entitlement to sickness benefit is called the rehabilitation chain. The rehabilitation chain only applies in full for those in employment. For the self-employed, Försäkringskassan will assess their working capacity in relation to their normal tasks until the 180th day. After that, their work capacity will be assessed in relation to the regular labour market as a whole. If they are unemployed, their work capacity will be assessed in relation to the regular labour market as a whole from the start of the sickness period.

# 4.8.2.2. Complete or partial incapacity for work

Workers may draw one-quarter, half, three-quarters or full sickness benefit, depending on the extent to which they are unable to work. The Swedish Social Insurance Agency assesses entitlement to sickness benefit and decides whether workers are able to carry out their work full-time or part-time, despite the effects of the illness. It also decides whether workers are able to return to their regular work after the period of sick leave comes to an end. If the worker can go back to work, the disability will be assessed in relation to his/her normal work. If not, the disability will be assessed in relation to other work that the employer can offer. If the employer has no other work to offer or if too long a period of rehabilitation is needed, the worker's capacity for work will be assessed in relation to the needs of the labour market as a whole.

According to the survey findings, many oncological patients suffer in financial, psychological and social terms under the new Swedish laws, that do not deal adequately with the difficult working situation of workers who have, or have had, an oncological condition. Considering the profound psychological implications of a condition such as cancer, it is not possible to draw the same conclusions for all individuals with this condition. However, there is clearly a need for legal provisions that can protect workers with cancer in their employment relations.

### 4.9. Conclusions

The importance of work in helping people to recover from cancer and long-term illness has been widely acknowledged. The present study has analysed two countries, Italy and Sweden, in which workers have a different chance of returning to work after long-term illness (including cancer).<sup>45</sup>

The respondents to the survey provide information on the changes in employment conditions and on the problems faced in daily life, as well on their perception of the ability of the employer to respond to their condition and to grant them their rights. The survey did not take account of workers who did not continue working, and there is a need to be aware of this selection problem in the interpretation of the results. It was not possible to extend this project to examine a sample of workers who affected by cancer but were not able to return to the labour market in order to identify the problems they encountered, but this is a strand of research that would be worth pursuing.

Another problem to be further investigated is the role of new technologies in increasing the probability that employees who have had cancer continue working. The two countries analysed reveal a different level of dissemination of teleworking, a type of work that has been found to help enhance the employment prospects of employees with long-term illness (Crepaldi, 2008) Moreover the number of observations is not sufficiently high to be able to ascertain how the return to work and current working conditions were affected in the Italian case by the type of work and employment contract. According to Crepaldi

<sup>&</sup>lt;sup>45</sup> Crepaldi (2008) shows the differences in the rates of return to work among European countries.

(2008) workers with a lower level of education tend to return to work sooner and to opt for part-time work less often, but this may be related to their limited access to longer sick leave and their income needs.

Another point to be investigated in greater depth is the social protection of those in the family who are taking care of employees affected by cancer. As found by other researchers, carers are mainly women and they may have limited access to leave and different rights to paid leave, depending on the type of job. In the case of Milan City Council, considering those who informed their employer about their condition, 40% of men and 65% of women stated that they received due attention from the employer. There is room to improve on this parameter, that can be regarded as an indicator of how much the employer supports the workers in the critical phase. The literature shows that a more supportive environment is positively associated with the probability that workers who have had cancer will return to work. In this regard the improvement, in the Italian and the Swedish case, with regard to relations with colleagues is a positive factor to produce a supportive environment in the workplace.

A more effective dissemination of information in the firm on the measures to protect employees who have had cancer is needed in order to produce a more supportive environment, and this can also improve the assessment of the capacity of the worker to continue to play a productive role in the firm. Still with reference to the Italian case study, there is a limited use to psychological support services and also limited contact with cancer associations.

Most of the workers affected by cancer in the Italian case did not change their type of work or type of employment contract. Only a small percentage opted for part-time working in Italy but a significant number of them continued in part-time work afterwards, due to its compatibility with personal and family needs.

<sup>&</sup>lt;sup>46</sup> Crepaldi (2008).

With regard to the changes occurring in working conditions after employees return to work, a worsening of career perspectives and a decline in earnings (especially among men) is a significant factor in both countries. This is in line with previous research and is worthy of attention since it can be an indicator of discrimination. More attention should be paid in working conditions surveys to the impact of the period of sick leave on career prospects and earnings amongst employees. Further analysis should be done on the effect of training and lifelong learning on continuity of employment and working conditions. Most employees in Italy, regardless their state of health, indicated that the most important policy to be implemented in order to improve the situation of workers affected by cancer and their families is prevention, followed by attention to working time arrangements, the grace period and calculation of days in hospital. A more effective programme of screening and prevention can help to detect cancer earlier. leading to a swifter recovery and a faster return to active life.

Finally, with regard to the Swedish case, the questionnaire findings highlighted the importance of improving social security procedures, and the importance of adjusting working hours during and after treatment, and of a higher level of protection in the workplace.

<sup>&</sup>lt;sup>47</sup> Crepaldi (2008) shows a positive link between retention rate and training.

### Chapter 5

Some practical proposals to support workers with oncological conditions. The Code of Good Practice.

Alessandra Servidori

# **5.1.** Some practical proposals to support workers (both women and men) with oncological conditions.

In addition to medical care, workers with cancer need protection, from a legal and financial point of view. This is why the legal system has to provide effective measures to allow these individuals to live with dignity, despite their condition. In addition, the person (whether considered sick or disabled) has to become acquainted with the rights provided by the law, in order to facilitate their application. It is also important to develop new programmes and laws, to meet the needs of people with a serious medical condition, especially those with cancer. The only way to do this is by putting pressure on the Government and Parliament, and working together with associations, because this synergy will help both sick people and society to deal with issues relating to permanent or temporary disabilities. In addition, measures such as the prompt assignment of benefits, the entitlement to sick leave, as well as community awareness of the issue, help people with serious health problems to overcome difficulties in everyday life. Such measures can be effective only if supported by active co-operation between institutional actors and the social partners. It is important to improve and standardise this institutional co-operation between the State and the Regions, and develop it at a national, regional and territorial level. In this regard, provincial administrations can play a key role, because they have the task of implementing labour policies and developing local vocational training programmes, that are fundamental to achieving effective integration among health services.

We therefore need to promote collective bargaining agreements, concluded between the social partners, as a way to encourage application protocols. In this way, we can promote the inclusion of those who are in a weaker position in the labour market, as well as

placing greater value on the role of workers with a medical condition.

In this connection, close cooperation between both public and private services and the voluntary sector is important. In accordance with the most recent European recommendations, the development of new forms of safety-net measures, aimed at combining flexibility and security, requires substantial financial resources. There is also a need to consider policies to encourage the social partners and joint bodies to contribute to disability benefits.

In Italy, there are many people affected by cancer. Official statistics give us misleading information on the number of workers forced to leave their jobs (by means of 'voluntary' resignation or involuntary dismissal) after having been diagnosed with a tumour. Employment is one of the biggest issues for cancer patients. In addition, they need to be fully informed about their rights and duties during sick leave for surgery, subsequent treatment (radiotherapy and chemotherapy), or depression. Some of the most serious issues relating to the worker's absence and subsequent return to work include the following: the grace period may not cover the entire period of absence; the worker may be assigned a new task, due to his or her condition; the employer may be prejudiced against the worker, and in some cases this leads to the termination of the employment contract. Therefore, it is fundamental to encourage institutional initiatives, aimed at providing legal, psychological, social and physiological support, during and after the period of treatment, and intended to raise awareness of the issue on the part of the employer and the public. Clearly, the Constitution is one of the main instruments for safeguarding the right to work and health care. Some of the key Constitutional provisions are as follows: Italy is a Republic, founded on work (Article 1); it is the duty of the Republic to remove those obstacles of an economic and social nature that, by limiting the freedom and the equality of the citizens, impede the full development of the individual and the effective participation of all workers in political, economic and social life (Article 3 (2)); the Republic recognises the right of all citizens to work and promotes the conditions that will make this right effective (Article 4); all citizens are equal in terms of social dignity and are equal before the law, without distinction as to their personal or

social condition (Article 3 (1)); health is a fundamental right of the individual and a public good (Article 32); workers have the right to be provided with adequate means for their requirements in the case of accident, illness, disability and old age, and involuntary unemployment (Article 38). As we can see, the Italian legal system includes many provisions offering protection for workers who are unable to work, because of an illness. A close reading of Article 2110 of the Civil Code helps us to understand the main consequences of sickness on the employment relationship.

Workers who are absent due to sickness or injury are entitled to receive their salary or an equivalent amount (the employer will disburse the sickness benefits, deducting the sum paid by national insurance). In addition, the employer cannot dismiss the worker, who continues to accrue seniority during this period. These rights, however, are of limited duration. The law and the collective agreements provide a time limit for maintaining the employment position (the "grace period"). If still unable to work, the worker will not be dismissed automatically at the end of the grace period. The employer who intends to terminate the contract in entitled to dismiss the worker in compliance with the rules regulating individual redundancy. The grace period, then, is a legal instrument that protects the sick worker, allowing him or her to continue in employment, without overlooking the enterprise's requirements. At the end of the time limit for maintaining the employment position, if the worker cannot be reinstated, because of his/her state of health, the social security scheme will provide assistance and protection. This, however, should be avoided, as workers receiving treatment for cancer should have the opportunity to continue in employment, even in the case of a long absence from work.

With regard to this matter, Article 46 of the Legislative Decree No. 276/2003 of Biagi reform modifies the regulation of part-time employment. For the first time in Italy, workers with cancer have the right to modify their employment contract, changing from full-time to part-time work. In fact, Article 12-bis, Legislative Decree No. 61/2000, gives private-sector workers with an oncological condition (affecting their capacity to work, also because of life-saving treatment) the opportunity to change their employment contract. Recently, Article 44 of Act No. 274/2007 granted this right to workers in the

public sector: they had initially been excluded as the negotiating body, ARAN, did not support the Biagi Act. In both the public and the private sector, however, the worker has the right to return to full-time employment.

This provision is aimed at reconciling the needs of the employer with the needs of the worker receiving treatment. Wherever possible, the worker can ask to be assigned to alternative tasks, more compatible with his or her state of health and reduced working capacity. In this regard, it is important to point out that the assignment to alternative tasks is not a recognised right for the sick worker (unless specified in the contract), even though some collective agreements provide it. As a result, it is important to examine the terms of collective agreement applied by the employer. Pursuant to Act No. 104/1992 (Article 33), when a local health authority certifies a disability or a poor state of health, due to oncological conditions, the worker is entitled to paid sick leave. As an alternative, workers are entitled to continuous or intermittent leave of two hours a day, or three days a month. They also have the right to choose the workplace that is closest to their home, and cannot be transferred without their consent. In addition, they can take up to 30 days' paid sick leave for medical treatment every year (Article 10, Legislative Decree No. 509/1988), if the degree of disability is at least 50%.

In most cases, collective bargaining provides more favourable protective measures for workers, according to the severity of the condition. As a result, it is important to verify the existence of these provisions in the collective agreement applied by the employer. Collective bargaining is a useful means to prevent the dismissal of workers at the end of the grace period, and to facilitate the return to work. It may provide for a range of measures, such as an adjustment of working hours or an assignment to more suitable tasks, to allow the worker to receive medical treatment.

The following provisions of national collective agreements are significant in this respect: one recent agreement provides that the grace period is to be extended to three months for workers with up to 10 years' seniority (this period has to be extended to six months for those with longer seniority) "in the case of serious oncological conditions, disabling ictus

or multiple sclerosis, vital organ transplantation and full-blown AIDS". In the collective agreement for the rail industry, the grace period for these conditions is tripled (12 months' sick leave, Article 26 (6), and 30 months for oncological conditions, Article 26 (8)). In the electricians' collective agreement, there has been a considerable extension of the grace period, and hospitalisation is not included, facilitating the maintenance of employment. In many public-sector agreements, sick leave for day hospital and life-saving treatment, such as chemotherapy and dialysis, are not calculated as part of the grace period (Public Health, Revenue Authorities, Non-economic Public Bodies Collective Agreement).

With regard to remuneration during the grace period, most collective agreements make provision for the entire amount for a certain period (usually at the beginning, but it depends on the agreements and length of service), after which it is reduced by 50% (Paper, Footwear Manufacturers, Chemists, Graphic Designers, Metalworkers Collective Agreement). The collective agreement for non-economic public bodies, for instance, provides that bodies have to promote the adoption of working time, to meet the needs of individuals taking time off for medical treatment and examinations (Article 21). The same applies to the Revenue Authorities and Ministerial Collective Agreement. At the end of the grace period, some agreements give the worker who is still unable to work the opportunity to request further leave, in order to avoid dismissal. If a certified medical condition still persists, some collective agreements (Food-producing Cooperatives Collective Agreement, Food Industry Collective Agreement) allow the worker to request sick leave for up to eight months, before the end of the grace period. In other cases (collective agreements of regional and local authorities), once the medical condition has been ascertained, the worker can be assigned to more suitable tasks in the same employment grade, after the grace period. If this is not possible (as a result of the medical condition), the worker may be assigned with his/her consent, to other tasks in a lower employment grade. In the case of the Paper Manufacturers Collective Agreement (Article 18), the worker who is unable to perform the same duties as before will be assigned to lower level tasks, and his/her retribution reduced in proportion to the new task.

In order to provide more protection for all workers with an oncological condition, a significant change could be the adoption of a code/protocol, supported by employers' associations, associations such as the Italian Association against Cancer (LILT) and by trade unions. It is also important to understand and acknowledge the role of the family of the worker with a medical condition.

As a result, the implementation of a protocol of agreement at a local level, and of an experimental kind, is fundamental, especially if local authorities adopt new policies, aimed at giving workers with a medical condition the opportunity to choose their working conditions. We also need to consider the role of the worker within the family. In addition to work, women workers in the age groups with the highest risk of breast cancer often have to look after their children and their elderly parents.

The main points of the protocol should be:

- to adopt a Charter of the Rights for people with cancer;
- to carry out a survey of existing legislation and examine its application;
- to experiment with the distribution of vouchers, in order to inform employment service personnel about new ways of reintegration into the labour market;
- to experiment with incentives for enterprises that include protective measures in the employment contract, and additional leave for medical treatment for workers with an oncological condition;
- to take socially responsible companies, in the sense of employers that work to meet the needs of workers with a medical condition (for instance, by adopting more flexible working time), as a model;
- to increase the number of part-time workers, access-to-work contracts, and more flexible contracts, pursuant to Legislative Decree no. 276/2003 and Act no. 274/2007, in order to reconcile working time, personal life and medical treatment;
- to calculate increased contributions during the work period.

The legal measures to be used include:

- framework agreements between the two sides of industry for continuity of employment and the return of workers with an oncological condition to employment;
- measures to raise awareness on the part of management, and human resources
  departments, of Corporate Social Responsibility; creating a link between social
  responsibility and economic return of employers providing protection measures
  (business case studies); providing information about the measures used to support
  workers with a medical condition;
- the adoption of a Code of Good Practice, concerning company strategy, activity, behaviour and problem-solving, by companies adopting a Corporate Social Responsibility approach;
- the granting of benefits to companies that adopt a Code of Good Practice. For instance, they might be exempted from paying tax on productive activities (IRAP) of workers with cancer.

Employers might also benefit from a specific contribution system, for workers absent for medical treatment and convalescence. In addition, these companies could be assigned extra points in competitive biddings.

The family of the worker with a medical condition plays a major role in dealing with this situation. We strongly believe that workers with a medical condition have the right to assistance from a member of the family, especially during critical periods. The person taking care of the relative with a medical condition has the right to carry out this task full-time or part-time, reconciling it with employment. This should be free choice, that can be modified at any time.

Family and social solidarity should develop in a complementary manner. This means that workers with a medical condition have to be supported not only by their relatives, but also by local, regional, and national authorities, that have to recognize and safeguard their social rights. A practical example could be the granting of supplementary sick benefit,

provided by local health authorities.

The support of the relative who takes care of the worker with a medical condition should have a legal and economic recognition, because in some cases this support replaces and supplements government intervention, and the local welfare services.

In this regard, the following measures should be taken into consideration:

- employment: planning of working time, sick leave and holidays, measures for the
  maintenance and the return to work after a period of absence, provision of
  medical, social, and pension assistance;
- *full accessibility*: accessibility to services (transport, accommodation, education, communication, etc.), by means of an economic integration;
- disability support allowance: disability support allowances should be paid after recognizing the status of the relative taking care of a non-self-sufficient worker (recognition of care services);
- recognition of care services: relatives should be granted recognition as carers.

Quality of life. The quality of life of the worker with cancer and those providing assistance are interdependent. Therefore, it is necessary to develop measures (precautionary measures against medical conditions, fatigue, stress, overwork, breakdown, etc.) that allow the relative to meet the non-self-sufficient worker's needs. Such support must be provided by qualified authorized services.

*Right to respite care*. This is a fundamental right, and it should provide support and help in an emergency, as well as substitutes and high-quality reception centers, covering the entire period of the relative's absence (due to holidays, rest periods, health problems).

*Information/Education*. Relatives caring for a non-self-sufficient worker with a medical condition have the right to be informed about his/her rights and duties, and access to all information they need to facilitate and improve their task. Public authorities, together with other representatives (non-governmental organisations, trade unions, social partners and employers' representatives) need to provide an effective information system.

Evaluation. The evaluation process has to be continuous, involving the workers with

cancer, their relatives, and public authorities:

- evaluation of the patient and the relative's needs;
- constant evaluation of services: public authorities have to verify the accomplishment and the quality of the relative's duties, also providing necessary advice:
- evaluation of the quality of assistance, in order to make changes where necessary.

To sum up, we believe that much can be done to improve the quality of life and the expectations of workers with oncological conditions. This is in line with the thinking of Prof. Marco Biagi, who dedicated his life to the study of labour law, and who taught us that "Today, it is important to analyse the employment conditions of workers (both men and women) and their protection in labour market, especially in Italy, in order to improve them from a juridical point of view".

### 5.2. Safeguarding workers with cancer

The 2008 project *Promoting new measures for the protection of women workers with oncological conditions by means of social dialogue and company-level collective bargaining* included a series of initiatives promoting awareness-raising and information campaigns on this issue, aimed at company management and human resources departments. The aim of these initiatives was to devise effective strategies for the protection of women workers with oncological conditions. The final proposal of the Code of Good Practice was preceded by a series of initiatives and meetings. The most important step was the presentation to President Giorgio Napolitano on 8 July of *The Manifesto for the Rights of Workers with Cancer*, drafted by Lilt (Italian Association against Cancer) in cooperation with Adapt, the Marco Biagi Foundation and Europa Donna, as a draft version of the code.

The document was signed by all political parties and many citizens (see www.legatumori.it, The Manifesto for the Rights of Workers with Cancer). The Manifesto makes the case for legislative and collective bargaining provisions upholding the

principle of equality and the right to health care, and consists of seven points aimed at improving the legal protection for workers with cancer.

In particular, the Manifesto promotes employment conditions that allow the worker to receive treatment, by making arrangements for adapting working hours by modifying the business organisation. This is particularly important for those who need diagnostic tests and follow-up treatment. It also highlights the importance of new arrangements, more compatible with the worker's state of health and reduced working activity, even by way of derogation from the existing law.

With regard to the grace period for oncological conditions, disabling ictus or multiple sclerosis, vital organ transplantation and full-blown AIDS, the Manifesto proposes that it should be extended, according to the worker's length of service. Furthermore, day hospital and life-saving treatment, such as chemotherapy and hemodialysis, should not be included in the calculation of the grace period, and remuneration should be reconsidered. Most collective agreements make provision for the worker to receive full pay for a certain period (this period may vary, depending on the length of service) after which it is usually reduced by 50%. At the end of the grace period, it is fundamental to give the worker the opportunity to take further leave. Moreover, once the medical condition has been ascertained, the worker should be assigned to more suitable tasks in the same employment grade.

The draft Code of Good Practice intended as a memorandum of understanding between the social partners is intended to help workers with an oncological condition, especially women workers with breast cancer, to return to work, providing them with part-time or flexible work, and safeguarding their career prospects. The draft Code of Good Practice provides for information about preventive measures and strategies, such as the right to sick leave for diagnostic tests and medical examinations, in order to prevent and combat cancer.

The project also included experimental activities, such as the implementation of the Code by means of networks (colleagues, partners, and collaborators). Our main objective was to consult a wide range of experts and professionals, with considerable and diverse experience in the field, in order to gather information for the definition of a draft Code of Good Practice attracting widespread support to be sent to the European Commission in January 2009. The document contains a number of suggestions about the strategies to be used both by employers and the employee coming to terms with the oncological condition.

The main legal source used in drafting the code is the Resolution of the European Parliament of 10 April 2008 on *Combating Cancer in the enlarged European Union*<sup>48</sup>, which urges the Commission "to draft a Charter for the protection of workers with oncological conditions and chronic diseases at the workplace, according to which enterprises should allow them to maintain their position during the medical treatment, and to facilitate their reinstatement" (point 35).

This phase of the project was implemented mainly in Italy and in Sweden, in the hope that the number of organisations and individuals involved would increase in a subsequent phase. It was intended to collect as many comments and experiences as possible, starting from the Adapt network, which has always been acutely aware of the issue, as well as the Europa Donna Forum.

The Manifesto for the Rights of Workers with Cancer, the Draft Code of Good Practice, and the Adapt Dossier <sup>49</sup> were drafted in cooperation with Adapt, Marco Biagi Foundation, and Europa Donna. They put into practice European guidelines aimed at improving existing legislation providing protection for workers with cancer. In this connection, considerable attention is paid to the following points, which are considered to be essential:

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<sup>&</sup>lt;sup>48</sup> P6\_TA-PROV(2008)0121 Resolution, in www.fmb.unimore.it, A-Z Index, *Patologie Oncologiche e Lavoro*.

Available at www.fmb.unimore.it, English version of the website.

- the extension of the grace period, which is insufficient to meet workers' needs at the moment;
- the safeguarding of employment for workers with cancer, also by the adoption of more flexible contracts, such as part-time work;
- the promotion of a number of initiatives to facilitate the return to work after the completion of medical treatment.

#### 5.3. Draft Code of Good Practice

- This company acknowledges that workers who have or have had an oncological condition are vulnerable at an emotional level, since they need to safeguard their employment and receive medical treatment at the same time (surgical operations and life-saving treatment). The company therefore recognises their right to change from a full-time to a part-time employment contract in this difficult phase, providing them with the opportunity to return to a full-time contract after their recovery.
- 2) This company undertakes to inform its employees about existing measures that provide them with legal protection in the case of oncological conditions affecting them or their relatives, who might need medical assistance due to their condition. It also undertakes to inform them about any supplementary measures amending existing legislative provisions.
- 3) Employees with an oncological condition are granted the right to be reassigned to more suitable tasks, taking account of their state of health or reduced working capacity.
- 4) Employees of the company with an oncological condition are also granted an extension of the grace period, on the basis of their length of service, in the event of serious illness, disabling stroke and multiple sclerosis, full-blown AIDS, and serious illness requiring life-saving treatment (e.g. chemotherapy), the terms of which have to be agreed with the human resources department.
- 5) This company shall provide the sick worker with remuneration during the grace period (the length of which shall depend on the employment contract and years of

- service), showing its effort to meet individual needs. Most collective agreements make provision for the entire amount for a certain period (usually in the early stages), after which it is reduced by 50%.
- 6) In order to allow workers to continue in or return to employment, in the calculation of sick leave this company does not consider time off taken for day hospital treatment, life-saving treatment (chemotherapy and haemodialysis), and time spent in hospital during the grace period.
- 7) This company undertakes to arrange more suitable working hours and to seek a solution for organisational and management issues, on the basis of the worker's specific needs (medical treatment, tests, etc.).
- 8) This company also allows the worker to request additional leave of absence. At the end of the time limit for maintaining the employment contract, the company will arrange for workers certified as fit to work to be reassigned to more suitable tasks in the same employment grade, in cases in which they are unable to continue in their previous position.
- 9) This company undertakes to develop ad-hoc initiatives aimed at devising effective means to strike a balance between working time and personal life, in order to safeguard the well-being of the worker and his/her family, by means of flexible work organisation and service networks.
- 10) This company recognises the right of the worker to health education, in the sense not just of information about illness, but also of training and rehabilitation following a change in their state of health.
- 11) This company recognises and protects the right of the sick workers's relatives (partner, parent, or child) or cohabitant to take care of them during medical treatment, offering more flexible working hours, to help them provide assistance.

## 5.4. Survey of good practices

The following questions were submitted to the Adapt and Europa Donna network to give all those involved the opportunity to share not only their views about oncological conditions, but also information on good practices and examples in the world of work of effective measures linked to this issue.

- 1 In your company, has there ever been a case of a worker with oncological conditions? If so, what kinds of measures were adopted to support him/her?
- 2 Does the applicable collective agreement implement provisions for workers with this specific condition? Does your company have specific regulations dealing with the issue?
- 3 Are you aware of specific preventive measures (good practices) adopted by your company concerning the rights of workers and their relatives in the event of oncological conditions? If so, can you describe them?
- 4 Do you agree with the draft Code of Good Practice? Do you wish to make any comments or express an opinion, also considering your personal experience?

The responses to the survey (that continue to arrive at the Adapt research centre) are of undoubted interest but perhaps it is important to underline that the proposed Code of Good Practice was drafted with the intention of submitting it to the European Commission as a memorandum of understanding to protect workers with cancer, to be signed on a voluntary basis by employers and the social partner organisations.

This aspect was not always fully appreciated, perhaps due to the fact that the message was not sufficiently clear, above all in the case of employers who are slightly diffident and do not fully understand that this is a voluntary decision, albeit an important one.

The large number of companies expressing their agreement with our proposal show that an initiative that is widely supported and considered to be useful can be disseminated more rapidly if it has support from above. In this sense the Code of Good Practice is intended to identify good practices in a framework of Corporate Social Responsibility and to put forward models and actions that have been put to the test in experimental projects, to be developed in the workplace and informal relations between the social partners. Our objective is to seek further support for measures strengthening the rights of workers with an oncological condition, regardless of whether they are women or men.

This initiative can be carried forward on the basis of widespread consensus, making use of social and labour law expertise in applying the European charter of rights in the workplace. At the same time there is a need to be aware that adopting measures without monitoring their implementation is of little practical value.

The aim of our proposal is to a gain widespread support for the values underlying the research and the good practices outlined in it. For this reason, a key feature of the research was to engage in an exchange of ideas with the social partners, employers, the institutions and all those concerned with these issues.

# 5.5. The contribution of employers and the social partners to the drafting of the Code

The research project on "Promoting new measures for the protection of women workers with oncological conditions by means of social dialogue and company-level collective bargaining" that was launched in March 2008, with a European dimension but based in Italy, gave rise to numerous initiatives and valuable contributions, that it is intended to outline in the following

The extremely positive response to the project may be seen from the active involvement and the contribution of all the interested parties: companies, trade unions, institutions, sectoral associations and individual workers. Most of the documents collected as part of the project were Italian, also due to the difficulty encountered by some of the partners involved in fully appreciating the research project (see Chapter 1, Introduction).

Returning to the analysis of the comments received, it may be noted that the responses sent by email express a high level appreciation of the draft Code of Good Practice and of the research project as a whole, due to the fact that it fills a significant gap in existing provisions and information on the protection of workers with an oncological condition.

In addition to mentioning this widespread support for the contents of the Code of Good Practice, it is important to provide an overview of the main findings of the project.

1) One extremely important factor, as noted many times in different phases of the research project and as underlined in various publications that were produced and the conferences that were organised as part of the project, is the importance of information in relation to the rights granted and measures adopted in favour of workers with an oncological condition. It was reported by numerous authoritative sources that employers, workers with cancer, and trade union officials are not informed about the measures laid down in the legislation in force. As a result, many complications and unfair decisions take place due to ignorance, rather than inefficiency or, even worse, an attempt to circumvent the law. Some commentators have defined this situation in terms of a "cultural deficit and lack of ability to deal with these situations" in the enterprise and the trade unions: there is a lack of awareness of the particular nature of the condition of people affected by an oncological condition.

Dealing with this lack of information (especially in Italy) is one of the main aims of our work: in the presence of such a widespread phenomenon, it is our intention to work closely with our partner organisations and with the social partners who have offered us their support; to produce and disseminate new publications; and to organise other conferences aimed at labour market operators and the public at large.

At present, by way of example of the type of action that can be taken, a blog has been set up as part of the website and the hard copy of the financial newspaper *Il Sole 24 Ore* in order to disseminate information about this initiative. This channel is particularly well suited to this purpose since *Il Sole 24 Ore* is a highly respected quality newspaper read by many labour market operators and human resources managers. In addition, members of the Adapt research team, including Prof. Michele Tiraboschi and Prof. Alessandra Servidori, were recently invited to take part in radio broadcasts on the radio station, Radio 24, to discuss issues concerning workers with oncological conditions.

- 2) Even when knowledge about the legal provisions is made available, according to a number of experts contributing to the project, the existing norms appear to be insufficient to safeguard the continuity of employment of the workers affected. In particular, a number of amendments and modifications were suggested, and these were translated into practical proposals in the draft Code of Good Practice, as summarised below:
- a) the implementation of arrangements such as teleworking and flexible working hours to respond to the needs of workers who have (or have had) cancer, by means of provisions in national agreements and company-level;
- b) in legislative terms, some of the experts suggested granting workers with cancer the same status as the category of working mothers, which would mean enabling workers with cancer to maintain their employment position for the time required to overcome their disability, as initially proposed in Act no. 53/2000;
- c) a significant number of the comments underline the need not just to safeguard the worker with cancer but also to provide support for the family providing assistance: this type of assistance is fundamental for the purposes of making a full recovery. In this connection a proposal was made to enable the worker to opt for job sharing, where necessary with another family member in search of employment, in order to allow the family to maintain the same level of income in spite of the need to provide assistance for the worker recovering from cancer;
- d) various comments, in particular those sent in by labour law scholars and employers, point to the need for further training for labour market operators, human resources managers and worker representatives in relation to this topic. It was therefore proposed to include the right to health education in the Code of Good Practice (starting from the principle of the right to education) and to promote education and training programmes for all those concerned;

e) a further point for consideration is that of dismissals, particularly in companies with fewer than 16 employees. In these firms the termination of employment contracts is regulated by Act no. 108/1990 on individual dismissals (with the payment of compensation for dismissal but no right to reinstatement). This may have a detrimental effect in the case of a worker who has opted for part-time working, since the compensation for dismissal received by the employee is considerably reduced in the event of termination: as a result the worker with cancer will actually be paid less.

We now turn to the concluding remarks.

An examination of the comments submitted to us suggests that a misunderstanding may have arisen. The Code of Practice was drafted with the intention of presenting a draft protocol to the European Commission to safeguard the rights of workers (both men and women) with cancer, to be adopted on a voluntary basis by employers and the social partner organisations. This fact was not always fully appreciated, perhaps because the message was not clearly stated, especially by the social partners who at times are rather diffident and do not fully understand the voluntary nature of the proposal. It is not intended to implement the Code by means of legislation, and this point should be very clearly stated. It is important to underline this point because many of the comments received, at times in favour, at times taking a critical stance, focused on the possibility of enacting legal provisions relating to this matter.

The numerous employers who have welcomed our proposals, on the other hand, have informed us of their full support and of the fact that they consider the Code of Good Practice to be a useful instrument, and that it is more likely to be widely disseminated if it is supported by top management. The Code of Good Practice is intended to contribute to Corporate Social Responsibility, and to put forward models and actions that have been tried and tested, to be implemented in industrial relations with the participation of the social partners. Our objective is to gain support to promote the rights of workers with an oncological condition. For these workers it is important to achieve a consensus and an

understanding of the provisions laid down by labour law and by voluntary agreements can drive this initiative forward.

Our objective is not to introduce norms and regulations that are then not applied, as is often the case, but to gain widespread support for the values and the practices laid down in the Code of Good Practice. For this reason it is essential to maintain contact and continue to exchange ideas with the social partners, employers, institutions, and all thos concerned. For this reason the feedback received during the research project is particularly important, enabling us to continue working in close cooperation with those who have contacted us, in addition to completing the tasks required by the research project that was made possible thanks to the active support of the European Commission, following the recommendations of the European Parliament.

Appendix

#### Appendix 1

# Remarks by Maurizio Sacconi, Minister of Labour and Health at the Conference in Milan hosted by Milan City Council on 20 October 2008

I would like to thank you for inviting me and for promoting this initiative. I also want to express my thanks to town councilor, Mascaretti, who is also a friend of mine, and to the municipality of Milan, whose efforts aimed at integrating people with oncological conditions into the labor market confirmed that this issue is taken into serious consideration. My thanks are also due to Adapt, here represented by my friend Prof. Servidori, the research centre working together with the University of Modena and Reggio Emilia, that was founded by Prof Marco Biagi, and is now run by Michele Tiraboschi, the professor who has been appointed to Biagi's chair and who was his closest collaborator at that time.

I also want to thank the Marco Biagi Foundation, whose creation was made possible by the determination of Marina Biagi, Marco's wife, after the tragic death of her husband. His principles were carried forward by the Italian government, which implemented a reform and funded the setting up of the Foundation, a centre of excellence promoting a series of related initiatives, such as the one we are discussing today.

My thanks are also due to Europa Donna, to my friend Patrizia Ravaioli, who is the representative of LILT, an important private and public body, and to all associations and bodies, more generally, that acted as intermediaries for the partecipation and the integration of workers with serious health problems into labor market.

I am here as a Ministry of Health, Labor, and Social Policy, and therefore I consider this issue from different perspectives. Unlike the past, nowadays there is a holistic approach to health care, because we tend to support the sick person at a general level, not only from a medical point of view. As emphasized in the Green Paper (which laid the foundations for a public consultation on the issue) we aim to develop a social model supporting individuals not only at the onset of the disease, but for lifetime, from their birth to natural death, according to their state of health and the improvement of their medical condition. Therefore, in order to provide older people with an active life, and a

better way of living, and to protect them against any factors affecting their health and wellbeing, it is essential to implement this initiative, promoting meaningful prevention activities and primary care services. We believe (and this is also the key principle contained in the Green Paper) that we have to do everything possible to recognize the individuals' potential, at all stages of their life and under any circumstances, even the worst cases, in order to improve and extend their life.

Policy has a key role in dealing with labor law and health issues, and it has to provide effective measures in this connection, especially in terms of legal protection for people with oncological conditions. Despite having long life expectancy, there are many people, and I include myself in this category, who have faced health problems affecting their professional life. They might have difficulties in carrying out tasks requiring a considerable physical effort, but they are still able to perform other duties. In some cases, they might be forced to accept reduced working hours or reassignment to other duties, resulting from a prejudicial attitude at the workplace. Luckily, individuals with this condition are very likely to recover today, and their life expectancy is now as long as healthy people. In this connection, special thanks go to Dr. De Lorenzo, because he was the person who proposed a very important provision while drafting Biagi Act and delegate decree. This provision refers to the opportunity for sick workers to change the employment contract from full-time to part-time, and at their request, to return to a fulltime contract. This amendment was also extended to the Public Administration (originally, as part of the Biagi Reform, it only applied to the private sector). I wish to express my gratitude to him, because this provision raised public awareness about the issue, even though now we have to focus our attention on collective agreements.

Collective agreements represent the instrument used by the social partners to find the most suitable solution for workers in terms of employment relations. In this connection, the grace period is one of the main issues to be considered, because it should be extended on the basis of the individual's medical needs and state of health. Therefore, collective agreements, as a point of contact between the employer and the worker, should support sick people in participating in the labor market, helping them not to be excluded from it. The principle laid down in the Green Paper is "Good life in an active society". We need to consider the real meaning of the active society. But if we consider birthrates, and data

referring to employment, education, and social mobility, we soon realize that an active society offering many opportunities in terms of social inclusion lays the foundations for good life.

For this reason, I warmly welcome this initiative, and I am also aware of the importance of the provision included in the Biagi Act, which calls for a major commitment on the part of the social partners and the institutions, and on my part. This is the starting point of a project which will give people the opportunity to be more appreciated, and to make them feel useful, whatever their condition is. Thank you.

**Journalist**: Thank you, Minister. This is the last week of consultation on Green Paper. What are your impressions?

**Minister Sacconi**: That's right. This is the end of the consultation period, but there are also a number of initiatives which are still in progress. I was also invited to discuss the issue by other organizations, which are close to the Opposition, such as Foundation Italianieuropei, and AREL, a research centre founded by Beniamino Andreatta and now run by Enrico Letta. I am aware that many trade associations are preparing a number of comments on the Green Paper. For this reason, and although we are working hard, I think we will need a postponement. We thought we could make it in three months. We presented the document at the end of July, but we did not consider the fact that August everybody is on vacation.

We don't want to introduce a set of initiatives serving as a buffer between the old and the new social model. What we want to do is draft a White Paper with widespread support, because a social model (or at least the principles it is based on) belongs to the entire community, not only to the majority. It is important for it to be broadly supported by all categories. Afterwards, the social partners, the institutions, the State, the Regions, the majority and the Opposition can discuss the implementation of this model.

At the end of the consultation, we hope to draft the White Paper as soon as possible (before the end of the year). This new model will focus, for instance, on most of the issues we have discussed today, such as the importance of rehabilitation programs and palliative care service. It aims at restructuring the national health and social security

system, which provides effective service in the North of Italy, but not in the South. I was born in an area where individuals with oncological conditions, even those who are terminally ill, are given significant legal protection, and efficient home assistance, allowing them to remain in their own homes. This is not, however, the case in general. In many areas, special assistance is often lacking, and local services do not provide adequate support, that should also include the contribution of family, volunteers, and pharmacists in the provision of palliative care.

This is a very practical proposal, that should help us to create a safer society. It might be a way to go beyond our sense of insecurity and to build awareness of real health needs, even though we are scared to do it. I feel this fear, for instance, when people do not realize that district general hospitals failing to provide basic medical assistance are useless. I believe it is time to close the hospitals like the one in the region of Calabria providing only twenty beds. It is really time to close them! People have to be aware of the fact these types of facilities do not offer effective service. In order to reform the public health sector, however, it is essential to offer a credible alternative.

This alternative should also involve important measures such as the ones we have discussed today, that is rehabilitation programs for sick workers, their participation in the labor market and so on. Thank you

# Appendix 2

Remarks by Alessandra Servidori, Adapt – Marco Biagi Foundation at the Conference in Milan hosted by Milan City Council on 20 October 2008

I would like to thank the Minister of Labour and Health, Maurizio Sacconi, for being with us here today. The project we are discussing today was launched last year, involving a number of actors who were committed to achieving results in terms of legal protection at a European level: Adapt, Marco Biagi Foundation, the municipality of Milan, LILT and AIRC, represented today by Dr. De Lorenzo, who I met at the beginning of the project, have been at the forefront of this important initiative. We are working hard together to promote this cause and to pursue our aims. Cooperation, integration, and teamwork are the way to move forward from the current idea of social welfare, which has failed to cope with changes in society in terms of social protection, and to deal with related issues. This is why Sacconi's Green Paper is a key document. We started this project last year, together with Prof. Tiraboschi and Marina Biagi, who send their regards as today they are engaged in teaching at the university, and the Marco Biagi Foundation. In meeting employment consultants, legal experts, and those attending this seminar, we told each other: "We must all play our part in the project, making a contribution to the success of this initiative".

My thanks are also due to Rosanna Santonocito and *Il Sole 24 Ore*, the newspaper which strongly supported this initiative and was one of the first to sign the *Manifesto for the Rights of Workers with Cancer*, which was presented to Giorgio Napolitano, President of the Republic, on 8 July 2008. The project was warmly welcomed by the President who expressed his support for its aims. The seven points in the Manifesto deal with many key aspects, as underlined by the Minister in his opening remarks.

It is important to bear in mind that we worked at a national and European level, because Milan is a European city and because Italy plays a fundamental role in the European context. The European Commission has adopted a series of directives on work-life balance, discrimination, and other important matters, which are part of an ongoing (social) welfare reform. This rethinking of welfare policies started with the drafting of the *Libro Unico del Lavoro*, which all those present here today will find to be of interest, because it is an attempt to simplify employment law. In this connection, the Biagi Act succeeded in improving existing legislation. These provisions, which are closely connected to the issue we are discussing today, have been carried forward with determination by the Italian government and the Minister of Labour and Health, Maurizio Sacconi.

It is also important to underline the European dimension of this project. In the Resolution of 10 April 2008 on combating cancer, the European Parliament officially asked the Commission "to adopt, wherever necessary, legal measures, and to encourage and support initiatives aimed at involving a large number of individuals, in order to prevent cancer, by reducing professional and environmental exposure to chemicals, and by promoting a healthy lifestyle and better working conditions". A safe working environment! This is a concept underlined by Councillor Mascaretti. When we talk of corporate social responsibility, it is important to define the parameters that help us to evaluate the quality of people's lives. Employers have to focus on the human being, promoting a series of initiatives in terms of good practices, aimed at supporting disadvantaged people, and people with disabilities and health problems, as stated by the delegate for health. He reminded us that individuals with these conditions, and those who are not self-sufficient more generally, face many problems. This is because sometimes life is different from how we would like it to be. Therefore, in some cases people have to live with a permanent or a temporary disability, or to look after a member of the family who is disabled. For this reason, the disability or condition does not affect only the individual directly concerned. Many of us have had to deal with cancer, and to combat it. Many of us have recovered from it. Many of us have looked after their loved ones until the end. Businesses and employers, and all the institutions involved in the labour market, are also taking into consideration another basic issue, involving families and workers looking after family members with cancer.

For our part, we have urged the European Parliament to draft a charter of rights to safeguard workers affected by cancer and chronic illnesses, on the basis of which enterprises should allow patients to hold on to their job during treatment, facilitating their return to work at a later date.

Meeting the representatives from Roche has been particularly useful. Besides producing medicines, this pharmaceutics industry deals with issues relating to health and safety at work, consulting its employees about their health needs, health legislation and its application, and facilitating consultation between the social partners. At a practical level, it means that social dialogue is important, especially if there is a shared vision between the concerned parties.

People with cancer need more flexible working hours, in order to receive medical treatment. In addition, improvements in life expectancy and a caring community should facilitate their return to work. As a result, the implementation of what is known as corporate social responsibility starts here, in Milan.

This is why the draft Code of Practice should allow workers with an oncological condition, and especially those who need to take time off work to receive life-saving treatment, the right to change their employment contract from full-time to part-time, both horizontal and vertical (according to contractual arrangements). At the request of the workers, and wherever their state of health makes it possible, they should also have the opportunity to return to full-time employment at a later date.

I want to welcome Arja Leppänen, a colleague and friend of mine from Scandinavia. Less than three months ago we were in Brussels, taking part in a convention with the European partners involved in the project.

This initiative will also involve the trade unions. This is because, as the Minister said, in view of a renewal of collective agreements (also in terms of decentralised bargaining),

improvements should be possible in terms of good practices (such as the extension of the grace period).

In the near future we want to set up modular training courses and information campaigns, drawing the attention of the actors involved in the industrial relations to the issue of workers' legal protection. In this connection, Confindustria Vicenza has invited us to a meeting next week, in order to discuss the implementation of the project in the workplace. We are carrying forward this initiative together with the social partners, also by promoting new memoranda of understanding and bilateral agreements, in order to provide sick workers with a high quality health support services. Improving healthcare delivery and setting up new support facilities would be a good starting point. The Region of Tuscany, for example, is giving priority to the provision of wigs for those receiving treatment for cancer.

These are only some of the issues we are discussing, which show how much attention is given to this topic. As I said before, at the end of the current project, we will present the Green Paper, containing, among other things, a draft legislative proposal. We are aware this initiative is ambitious, but we are also aware that many authoritative individuals are involved in the project, which has been carried forward with determination. Also thanks to the political reform process carried forward by the government, we will be able to present the European Union with a programme that I am sure will provide our country with a sense of achievement. The EXPO to be held in Milan in 2015 will prove another opportunity to share ideas and strategies. If all those concerned fulfil their duty, and they all play their part, our goal will be achieved.

## Appendix 3

Remarks by Marie-France Mialon, at the Conference in Modena at the Conference hosted by Marco Biagi Foundation on 19 March 2008

Reflections on the French system of protection of women employees with cancer

# 1. General protection in the case of life-threatening long-term illness

Cancer is included in the list of long-term illnesses: cardiovascular disease, multiple sclerosis, Alzheimer and Parkinson's disease, tuberculosis and all forms of malignant tumour and malignant conditions of the lymph tissue.

There are no separate provisions for men and women, based on the principle of nondiscrimination, and no specific provision for women employees with health problems.

## 2. The non-discrimination principle

The principle of non-discrimination in relation to the state of health is applicable at the time of hiring, during the execution and upon termination of the employment contract. Any act of discrimination may be subject to criminal and civil proceedings and gives rise to employer liability. However, there are exceptions: the employee is required to be in a fit state of health in relation to the tasks he or she is expected to carry out under the terms of the employment contract.

In this connection, it is permitted to specify the physical condition required at the time of hiring for certain positions: for example it is legitimate to require hearing and eyesight tests for drivers and machine operators, at the time of hiring, and to reject applicants who do not meet these requirements. It would not be permitted to decline to hire a woman with cancer, or who has had cancer, in these cases, unless her hearing and eyesight were affected, as shown by the results of the tests.

During the execution of the contract, regular medical examinations are provided for the most hazardous occupations in order to ascertain whether the employee continues to comply with the physical requirements for the job, as in the case of bus and train drivers, and airline pilots.

#### 3. The role of the medical officer

In addition an obligation is laid down for a medical examination to be carried out prior to the return to work of the employee. The medical officer plays an essential role in enabling the two parties to find the best way for the employee to return to work after the period of sick leave. The medical examination consists of two separate assessments that are obligatory regardless of the illness (and the same applies in the case of accidental injury). The medical officer may propose a change in the working conditions: for example, adapting the pattern of working hours, a change to part-time working, an extension of rest breaks based on the state of health of the employee returning to work.

Part-time work on medical grounds (*le mi-temps thérapeutique*) enables the worker to return to work on reduced hours while benefiting from sick pay to make up the rest of his or her income; this is useful in the case of a period of rehabilitation or for adapting to a new job. This arrangement can continue for up to three years, depending on an assessment by the social security institute.

The medical officer can also propose a change of work duties and tasks, more suited to the state of health of the employee. It may also be proposed to change the workplace in order to enable the employee to work closer to home and reduce travelling times. Clearly, there is a need for suitable posts in the company, and for a vacancy for one of these posts. In addition, the proposal is required to be acceptable to the employee, who runs the risk of downgrading and a reduction in income. The employer is required to try to find the most suitable arrangement for the worker's state of health, and needs to safeguard his or her employment prospects. The employer is also required to physically adapt the

workplace, particularly in the case of a permanent disability. All these conditions are not always reconciled and in any case costs may be incurred. The question therefore arises as to whether the employment contract may be terminated.

#### 4. Termination of the contract

The termination of the contract is always the responsibility of the employer, even if the decision depends on the refusal of the employee to accept changes to the execution of the employment contract. The employer is under an obligation to provide evidence that the objective interests of the company oblige him to take this decision: he does not have a suitable post in relation to the state of health of the employee, or the adaptation of the workplace would have too high a cost in relation to the expected productivity of the worker.

A further case to consider is that of the employee who returns from sick leave and due to his state of health continues to take further periods of sick leave: the courts may authorise the dismissal of the employee when the periods of sick leave are so frequent that this disrupts the services that the worker is expected to provide. The employer is under an obligation to show that he has tried everything possible to avoid dismissing the worker (the recourse to overtime by the other workers, temporary work contract or posted worker) and that the objective interest of the enterprise requires production to be carried out in a continuous manner. This case law ruling of 1978 was handed down in the case of a woman with cancer. Since then case law has not developed any further.

The employee who is dismissed is entitled to twice the severance pay that would normally have been paid out. In addition he or she will be entitled to unemployment benefit and to specific support in the search for new employment.

# 5. The social protection system

The system of social protection provides protection for the worker in the event of

sickness; the level of protection is higher in the case of a serious illness on the official list. In brief, in the event of cancer, the social security system covers the entire cost of hospital and outpatient treatment; the patient will only be required to cover the cost of personal services such as the use of the telephone or television in the hospital room, though these charges may be covered by his or her mutual insurance body.

An employee on sick leave receives a daily allowance from the first day of sickness in the event of cancer, as in the case of other serious illnesses. This allowance is increased if there are three dependent children; it is index-linked to the increase in wages of employees in the company if the collective agreement so provides, or at the request of the employee to the insurance body if provided by ministerial decree (in general there is an increase on 1 January of each year).

The daily allowance paid by social security amounts to 50% of the daily wages up to the limit laid down by social security. This may be supplemented by a further allowance under the terms of a collective agreement at sectoral or company level. In this way the employee will be able to draw the full salary, though this entails two medical examinations, one to be carried out by the medical officer of the social security institute, and the other to be carried out by the medical officer appointed by the employer. The unjustified absence of the worker on sick leave from his or her home, and the fact that he or she goes to work, even on an unpaid basis, give rise to the suspension of sick pay and to the obligation to repay the sick pay already received (disputes are heard before the TASS). The tribunals are particularly strict, even in the case of work on an unpaid basis, or in the case of helping out a member of the family.

# **6.** Disability allowance requirements

At the end of a period of three years of long-term illness, the employee who has not managed to return to his company or to take up employment elsewhere may be classified as disabled, and will receive a disability allowance or, depending on the age of the worker, a retirement pension. It is significant that all the periods in which the employee

has received long-term sick pay or a disability allowance are calculated for the purposes of the retirement pension bases on the number of valid quarterly contributions. If the condition has resulted in a serious disability, the employee may take early retirement before reaching the age of 60. When an insured person receiving a disability allowance starts to receive a retirement pension, the pension may be increased by up to 40%, in cases in which assistance is required from another person for day-to-day activities.

In addition to the state pension paid by the social security institute, the individual may receive a supplementary pension paid by the private pensions schemes, which vary depending on the occupation, the employment grade (management staff and engineers, white-collar workers, blue-collar workers) and the contributions paid in by the employer in the course of his or her working life. Each collective agreement has its own method of calculation, but the non-discrimination principle is always applied in favour of the retired worker who does not lose his or her rights in the event of illness. Most collective agreements apply the same rules as the social security institute for the calculation of the contributions periods and include periods of sick leave in the calculation of the retirement pension.

#### Appendix 4

Remarks by Anna Maria Sansoni, at the Workshop in Brussels hosted by Italian Permanent Representation to the European Union on 29 July 2008

Fight against cancer and protection of workers with oncological conditions: the Community framework

One in three Europeans is diagnosed with cancer during their lifetime and one in four Europeans dies from the disease. In 2006 there were nearly 2,3 million new cancer cases and over 1 million cancer deaths within the European Union. Death rates from cancer in the new Member States are higher than in the EU-15. Moreover, the number of Europeans with cancer is set to increase dramatically by 2015 due to the ageing population.

That's why a new guideline has recently emerged at EU level: to make fight against cancer a European priority, to pursue through an overall strategy involving European institutions, Member States, researchers, health officers and, of course, the patients and their families. The new priority has been evident in the program of the German, Portuguese and Slovenian Presidencies of the EU and the first steps have already been discussed during the round-table on cancer included in the "Health Strategies in Europe" meeting in Lisbon in July 2007 and during the conference "The Burden of Cancer - How Can it be Reduced", in Brdo in February 2008, addressing the topics of prevention, screening, cure and research.

What is the current situation in the European Union in terms of fight against cancer? According to the first research done to look at recent trends in European cancer incidence, mortality and survival together, cancer prevention and management is moving in the right direction.

The research is published in a special issue of the European Journal of Cancer (the official journal of ECCO – the European CanCer Organisation) on cancer control and

coincides with the start of work by the European Commission to draw up a new EU Cancer Action Plan and with the idea launched by the European Parliament about an interistitutional EU Cancer Task Force (composed of Members from the Commission, the Council and the European Parliament) which shall meet on a regular basis to collect and exchange best practices for prevention, screening and treatment.

The current EU health policy approach to fight cancer focuses on primary and secondary prevention as well as on information to address lifestyle-related health determinants such as tobacco, alcohol, nutrition and physical activity.

In addition to encouraging people to adopt healthier lifestyles to avoid cancer, the Council of Health Ministers adopted a recommendation on cancer screening in 2003.

Effectively, it appears urgent to focus on prevention and screening, especially considering that an average of only 3% of the OECD countries' total budget for health is spent on prevention as against 97% spent on healthcare and treatment and that big disparities, also from this point of view, divide EU Member States.

Furthermore, the Commission is managing a lot of research programmes and funds to help European research to go ahead (we are going to speak about these programmes and funds later on) and preparing a Communication on cancer (which will be adopted later this year).

The Commission is also monitoring the developments of the Community Strategy 2007-2012 on health and safety and work, closely related to the issue of cancer because, according to a recent study by the trade unions, at least 8% of annual cancer deaths are directly caused by exposure to carcinogens at the workplace.

On its side, the European Parliament has adopted a lot of important Declarations and Resolutions on the fight against cancer, like the Resolution of 25<sup>th</sup> October 2006 on breast cancer in the enlarged European Union, the Declaration of 11<sup>th</sup> October 2007 on the need for a comprehensive strategy to control cancer and the Resolution of 10<sup>th</sup> April 2008 on combating cancer in the European Union.

All these documents recognise that cancer is caused by many factors in multiple stages and therefore requires a new "cancer prevention program" that addresses lifestyle causes and occupational and environmental causes. They also insist on the fact that dealing with cancer means to consider not only healthcare and treatment, but also prevention and screening and to help people to have the best conditions to live with the disease. For example, psychosocial care of cancer patients can improve their quality of life and improved communication between the many and various actors involved is essential to spread information about research and cares.

Interestingly, these documents also shed light on the issue of the (difficult) reintegration in the labour market and of the protection of cancer patients in the workplace.

Actually, the most recent studies show that one fifth of former breast cancer patients do not return to work, although they are deemed fit to do so and that women who return to work are often faced with reductions in their income.

This situation is common to many workers affected by cancer, who often suffer many forms of discrimination (which in some cases can be considered as mobbing) after their return to work.

Therefore, in its Resolution of 10<sup>th</sup> April 2008, the Parliament invites the Member States and the Commission to work towards the development of guidelines for a common definition of disability that may include people with chronic illnesses or cancer and calls on the Commission to draw up a Charter for the protection of cancer patients and chronically sick people in the workplace with a view to requiring companies to enable patients to continue in employment during their treatment and to return to their normal professional activities. This request had already been launched, with specific reference to patients affected by breast cancer, with the Resolution of 25<sup>th</sup> October 2006 on breast cancer in the enlarged European Union.

There is here a remarkable convergence between the Resolution of the Parliament and the research project carried out by Adapt, thanks to the co-financing from the European Commission. Adapt's project, by anticipating the Parliament, is aimed indeed at drafting a protocol agreement between the social partners for the protection of workers with

cancer and at improving the implementation in the Italian case of the right to part-time work for employees with an oncological condition, as provided by The Biagi Law.

Significantly, in its Resolution of 10<sup>th</sup> April 2008, the Parliament also exhorts the Commission to take legislative action, where appropriate, and to ensure that Community legislation contains incentives for industry and researchers to engage in ongoing research and to keep on with deploying funds from the Structural Funds and the Seventh Framework Programme for Research with a view to pushing research ahead.

There are a lot of possibilities to get funds from the EU to carry out projects on cancer.

First of all, there is the Seventh Framework Programme for Research (FP7), which allocates funds to health research in the framework of the *Cooperation* programme and of the *Capacities* programme.

The Health theme is a major theme of the Cooperation programme and the EU has earmarked a total of  $\in$  6.1 billion for funding this theme over the duration of FP7. Priority is given to biotechnology, generic tools and technologies for human health; translating research for human health (making sure that basic discoveries have practical benefits and improve the quality of life); optimising the delivery of health care to European citizens.

Special attention is given to communicating research outcomes and engaging in dialogue with civil society, in particular with patient groups, at the earliest possible stage, of new developments arising from biomedical and genetics research.

Third Health call expected to be published in two parallel calls on 3 September 2008.

Concerning the *Capacities* programme, it is provided with a budget of almost  $\in$  4.1 billion to operate in seven areas, like research infrastructures, regions of knowledge, science in society, support to the coherent development of research policies. For example, The overall objective of the 'Research infrastructures' part is to optimise the use and development of the best research infrastructures existing in Europe. Furthermore, it aims to help to create new research infrastructures of pan-European interest in all fields of science and technology.

Secondly, there is the Second Programme in the field of health 2008-2013. Its financial envelop is more than € 321 million and its objectives are to improve citizens' health security; to promote health, including the reduction of health inequalities; to generate and disseminate health information and knowledge.

Thirdly, there are the Structural Funds, and especially the European Regional Development Fund (ERDF) and the European Social Fund (ESF).

The ERDF can be used in the new Member States for the development of health care structures.

The ESF could provide further training for medical personnel and finance actions aimed at improving information and education activities during the return to work phase.

Lastly, the Competitiveness and Innovation Framework Programme (CIP) aims at promoting all forms of innovation in the enterprises. In this context, it would be interesting to support innovative projects of corporate social responsibility (CSR), aimed at improving working conditions for people affected by cancer.

# Appendix 5

## Questionnaire

Taking account of the Italian legal provisions concerning the protection of workers with an oncological condition



Associazione per gli Studi Internazionali e Comparati sul Diritto del Lavoro e sulle Relazioni Industriali

Part I. Personal data





## Questionnaire

Promoting new measures for the protection of women workers with oncological conditions by means of social dialogue and company-level collective bargaining

Age					
Place of reside	nce		-		
How many year	ırs y	ou have been	resident i	n this m	nunicipality?
Municipality			-		
Country of birt	h		-		
Sex:			-		
	0	M			
	0	F			
Marital status:					
	0	Single			
	0	Separated or	divorced		

0	Married or cohabiting	
Please indicate you	ur level of educational achievement:	
0	None	
0	Elementary school	
0	Middle school	
0	High school	
0	High school diploma (at least 5 years)	
0	Degree	
0	Postgraduate education	
0	Master or other advanced degrees	
Do you have child	ren?	
0	Yes	
0	No	
Number of childre	en	
Age of the youngest child		
With who do you	live? (more than one answer is acceptable)	
0	Alone	
0	With my parents	
0	With my partner	
0	With my partner and children	
0	With my friends	
0	With my children	
0	Other (please specify)	

o Widowed

Are there older people or people who need assistance in your family (even if they do not live in your apartment)?

0	No
Part II. Occupati Occupational posi	
0	professional status
0	level
0	professional field
Please specify you	ar employment status:
0	Open-ended full-time contract
0	Open-ended part-time contract
0	Fixed-term full-time contract
0	Fixed-term part-time contract
0	Contract of collaboration
0	Temporary agency work contract
0	Occasional autonomous work contract
0	Association in participation
0	Other
How old were you	when you started working?
How many years h	nave you been working in this place?
Но	w many months (if less than one year)?
How many years of	of social insurance contributions do you have?
How many month	s (if less than one year)?
Do you have vario	ous periods of social insurance contributions that have been combined?
0	Yes
0	No

o Yes

During the treatment did you receive a health inspection from the institutions authorised to carry out such inspections? (National Institute of Social Insurance (INPS) and competent local health authority ASL) to verify your absence from the work (between the hours 10/12 - 17/19)?

0	Yes
0	No

### Part III. Oncological pathologies of the interviewed person

Are you:

- o a smoker
- o an ex smoker
- o a non smoker

Are the legal provisions on smoking respected in your work place?

- o Yes
- o No

Are you aware of the legal italian provisions concerning the protection of workers with an oncological condition?

- O Sick leave for medical treatment and the right to choose a work place nearest to your home (Act No. 104/1992);
- Right to change the employment contract from full-time to part-time (Decree No. 276/2003);
- Examination to verify civil disability within 15 days of the application (Act No. 80/2006);
- O Right to benefits for the whole period of chemo or radiotherapy (Act No. 18/1980);
- Exclusion from the calculation of the leave of absence of the days of hospitalisation, day-hospital and medical treatment (CCNL Enti Locali 14/09/2000).
- O Act No. 80/2006 that in case of the oncological condition makes provision for the rapid ascertainment of disability with the obligation for the medical commission of the competent local health authority to carry out an examination within 15 days of the date of the application.
- o Right to benefits for the entire period of chemo o radiotherapy.

How did you find out about your rights as a worker with an oncological condition?

- o Information or enterprise communication
- o Association of oncological or health volunteers
- o Trade union
- o Friends

0	Relatives
0	Other (please specify)
	at in your workplace there is clear and efficient information and communication protection of the rights of workers with an oncological condition?
0	Yes
0	No
Do you believe the	nat in your workplace the norms for protection of workers with an oncological ied?
0	Yes
0	No
Have you had an o	oncological condition?
0	Yes
0	No
When?	
Can you indicate a	a type?
0	Breast
0	Skin
0	Blood
0	Lymphatic system
0	Lung
0	Gastro-intestinal apparatus
0	Other (specify)
Have you received	l psychological support during this period?
0	Yes
0	No

Have you made contact with associations during this period?			
0	Yes		
0	No		
	d have you had problems linked to the working activity in your family in order eople (older relatives or children)?		
0	Yes		
0	No		
	ou solved these problems? (more than one answer is acceptable, please indicate rom 1 as the most important type of help)		
0	Major sharing of responsibilities by my partner		
0	Help from other family members		
0	Help from friends		
0	Help from associations		
0	Help from public services		
0	Other (specify)		
Were you working	g at the time of the initial diagnosis?		
0	Yes		
0	No		
If so, are you still	working for the same employer?		
0	Yes		
0	No		
Have you informe	ed your employer about your condition?		
0	Yes		
0	No		
If so, have you received due attention from your employer?			
0	Yes		
0	No		

Have you received	I psychological support and comprehension from your colleagues at work?
0	Yes
0	No
Have you continue	ed with the same work?
0	Yes
0	No
Have you continue	ed with the same contractual arrangements?
0	Yes
0	No
Have you used the	e possibility to change your contract into the part-time one?
0	Yes
	No
Have you since ch	anged it back to full-time?
0	Yes
0	No
If you have not ch	anged the contract, can you specify the reason?
0	Part-time work is more compatible with my contractual arrangements
0	Part-time work is more compatible with my actual family needs
0	The employer did not agree to change my contract to a full-time one
0	Another flexible contract arrangement was adopted
	to the workplace how do you see your working condition in comparison with the the first oncological diagnosis?
Hours	
0	Much better
0	Quite a bit better
0	The same as before
0	Just a little bit better

#### o Worse

## Current occupational position

- o Much better
- o Quite a bit better
- o The same as before
- o Just a little bit better
- o Worse

### Career prospects

- o Much better
- o Quite a bit better
- o The same as before
- o Just a little bit better
- o Worse

## Relations with colleagues

- o Much better
- o Quite a bit better
- o The same as before
- O Just a little bit better
- o Worse

### Relations with management

- o Much better
- o Quite a bit better
- o The same as before
- o Just a little bit better
- o Worse

### Remuneration

- o Much better
- o Quite a bit better
- o The same as before
- O Just a little bit better

#### o Worse

Job satisfaction (excluding remuneration)

- o Much better
- o Quite a bit better
- o The same as before
- o Just a little bit better
- o Worse

Job satisfaction (including remuneration)

- Much better
- o Quite a bit better
- o The same as before
- o Just a little bit better
- o Worse

How do you see the initiative to promote protection and opportunities for workers with oncological conditions and/or his/her family members?

- o Indispensable
- o Necessary
- o Useful
- o Useless
- Not important

From your point of view, what are the priorities?

- o Prevention
- o Hours
- O Waiting period (extension of the waiting period)
- O Subtraction from the waiting period of the days of absence for hospital treatment
- o Paid waiting period
- o Contractual flexibility
- o Support from family members
- Social security and contributions situation

0	Agreements enabling the worker to plan ahead
0	Other (specify)
	ould be given in writing.  any information that can identify you

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