

# Cancer Survivors at Work: A Generation of Progress

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**ABSTRACT** Before the 1970s, a substantial percentage of cancer survivors faced blatant employment discrimination with little legal recourse, a paucity of support services, and limited medical options for curative treatment. Since then, survivors have benefited from improvements in cancer treatment, the passage of state and federal antidiscrimination laws, and a sea change in perceptions about living with and beyond cancer. Consequently, cancer survivors now face fewer barriers to employment opportunities. Because millions of cancer survivors, more than ever before, are now working age adults, advocacy efforts should shift from expanding legal protection from cancer-based discrimination to providing resources to help survivors meet their individual employment-related concerns. (*CA Cancer J Clin* 2005;55:271-280.) © American Cancer Society, Inc., 2005.

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This article is available online at <http://CAonline.AmCancerSoc.org>

## INTRODUCTION

A generation ago, cancer survivors' quality of life, including employment experiences, differed significantly from today. Fewer than one half of those diagnosed with cancer survived more than five years. Treatments were less precise and more disabling. Myths about cancer prevailed. Consequently, many survivors experienced substantial problems obtaining and retaining employment.<sup>1-3</sup>

Significant medical, social, and legal progress has extended and enhanced the lives of millions of cancer survivors. Advances in cancer treatment fostered changes in attitudes about cancer. Attitudinal changes about cancer, as well as about other serious and chronic medical conditions, provided support for legislation to expand employment opportunities for persons with actual or perceived disabilities. As a result, cancer survivors now seldom face blatant employment discrimination. Instead, survivors now work in more tolerant and compassionate environments where, armed with knowledge about their medical needs and legal rights, they often can minimize the effect of cancer on their careers.

This article will review how the lives of cancer survivors at work have changed over the past generation. It will also discuss how survivors can preserve their legal and social gains and protect their rights to equal employment opportunities.

## CANCER SURVIVORSHIP: MYTHS AND FACTS

In the 1970s, a cancer diagnosis was often construed as a death sentence.<sup>4,5</sup> Most individuals, the media, governments, and survivors commonly referred to themselves as cancer victims.<sup>1,3</sup> To employers and insurers, a cancer diagnosis meant potential lost profits and productivity.<sup>3</sup> A cancer survivor was the spouse who was left behind to cope alone with unpaid bills and unfulfilled dreams. A cancer diagnosis was seldom discussed publicly.<sup>1,3</sup> Many feared cancer to be contagious.<sup>1,4</sup> Physicians expected survivors to be satisfied with achieving medical remission; few considered or responded constructively to psychosocial sequelae, such as the impact of cancer on work.<sup>5</sup> The five-year survival rate for the top 15 cancers as identified in SEER data from 1975 to 1979 was only 42.7% for men and 56.6% for women.<sup>6</sup>

A generation of medical progress has brought a sea change in opinions about cancer. The five-year survival rate for the top 15 cancers from 1995 to 2000 improved to 64% for men and to 64.3% for women.<sup>6</sup> Cancer is no longer considered a death sentence. More than 87% of 957 respondents to a national survey taken in 2002 recognized as false the statement:

“Cancer is something that cannot be effectively treated.”<sup>7</sup> Only 1% of 1,002 individuals believed that “cancer is contagious; you can catch it from other people” (personal communication with Ted Gansler, May 5, 2005). All aspects of American society, including the media, research literature, state and federal governments, treatment centers, and millions of Americans who have been diagnosed with cancer, have replaced the passive word “victim” with the active term “survivor.”<sup>8</sup> As cancer survivors have become greater advocates for themselves, their health care providers have responded to their demands for greater flexibility in scheduling medical care to accommodate survivors’ work schedules.<sup>9</sup> These medical and societal changes have contributed to dramatic improvements in cancer survivors’ quality of life at work.

#### CANCER SURVIVORS AT WORK

Although the attitudes of cancer survivors and their coworkers have changed, one factor has remained constant over the past generation: cancer survivors want to and in fact, are able to perform their jobs and return to work after diagnosis in large numbers. Cancer treatment does, however, limit the ability of a minority of survivors to work as they did before diagnosis. An analysis of the 2000 National Health Interview Survey (NHIS) found that cancer survivors have poorer outcomes across all employment-related burden measures relative to matched control subjects.<sup>8</sup> One estimate is that 16.8% of working-age survivors (compared with 5% of matched controls) are unable to work because of a physical, mental, or emotional problem; of those who could work, 7.4% (compared with 3.2% of matched controls) were limited in the kind or amount of work they could do.<sup>10</sup>

Whether a survivor continues to work during treatment or returns to work after treatment, and if so, whether that survivor’s diagnosis or treatment will result in working limitations, depends on many factors. They include the survivor’s age, stage at diagnosis, financial status, education, and access to health insurance and transportation, as well as the

physical demands of the job and the presence of any other chronic health conditions.<sup>11–13</sup> For example, survivors in physically demanding jobs have higher disability rates than those in more sedentary jobs; survivors with advanced education have had higher return to work rates than those with less education.<sup>12,13</sup> Medical treatment decisions that consider quality of life and the shift toward providing cancer treatment in outpatient settings have contributed to the increasing number of survivors who can work during their treatment.<sup>14</sup>

For more than 30 years, the vast majority of working-age adults who were diagnosed with cancer have returned to work. A 1972 Bell Telephone survey of 800,000 Bell employees found that of the 1,351 employees with a cancer history, 77% returned to work after their diagnosis and treatment.<sup>15</sup> Surveys in the 1980s reported that approximately 80% of survivors return to work after diagnosis.<sup>16</sup> Mor found that a higher percentage of white collar workers (78%) than blue collar workers (63%) remained in their jobs 12 months postdiagnosis.<sup>17</sup>

Studies of cancer survivors since 1995 have reported similar findings. A survey of 10 studies that assessed return to work rates of a total of 1,904 cancer survivors from 1986 to 1999 found that a mean of 62% returned to work.<sup>18</sup> A study of 1,763 survivors who were first diagnosed between January 1997 and December 1999 found that, of the 1,433 who were working at diagnosis, 73% returned to work within one year of diagnosis and 84% returned to work within four years.<sup>12</sup> Bradley interviewed 253 long-term survivors in 1999 and found that 67% were employed five to seven years later.<sup>11</sup> Bloom found that young breast cancer survivors had the same employment rates five years after diagnosis as they had at the time of diagnosis.<sup>19</sup>

Most cancer survivors are able to continue working or return to work without limitations resulting from their diagnosis or treatment. In one of the earliest studies of cancer survivors in the workplace, Wheatley surveyed Metropolitan Life Insurance employees between 1959 and 1972.<sup>20</sup> He concluded that the work performance of employees who were treated for

cancer differed little from that of others hired at the same age for similar assignments.<sup>20</sup> When compared with similar employees, the turnover, absence, and work performance rates of cancer patients were so satisfactory that Wheatley concluded that hiring individuals with a cancer history was sound industrial practice.<sup>20</sup>

In 1992, Cerenex Pharmaceuticals commissioned Yankelovich Clancy Shulman to conduct a study of cancer survivors, employees, and supervisors. Of 503 cancer survivors, 60% reported that cancer did not affect their performance, and an additional 21% reported that cancer had “very little” effect on their performance.<sup>21</sup> In Short’s study conducted during 2001, only 16% of men and 21% of women who were working at diagnosis reported limitations in their ability to work that they related to cancer.<sup>12</sup>

Cancer has a greater impact on survivors’ physical than mental capabilities. Of the 253 long-term survivors in Bradley’s study, 18% reported problems completing some physical tasks.<sup>11</sup> The effects of cancer treatment, especially fatigue, can also impact some survivors’ ability to perform mental tasks, such as concentrating for longer periods of time (12%), learning new things (14%), and analyzing data (11%).<sup>11,22</sup> For example, survivors of thyroid cancer reported that work “productivity, concentration, and quality of life changed dramatically” within a few weeks of going off thyroid hormone medication.<sup>23</sup>

During the past 30 years, cancer survivors have reported decreasing incidences of work problems attributable to their cancer. In the 1970s, the California Division of the American Cancer Society (ACS) sponsored a five-year study of the work experiences of 344 white-collar workers, blue-collar workers, and youths with cancer histories.<sup>24</sup> Feldman found that 54% of white-collar and 84% of blue-collar respondents reported discrimination at work.<sup>24</sup>

In the 1980s, Fobair found that 43% of 403 Hodgkin disease survivors experienced difficulties at work that they attributed to their cancer history.<sup>25</sup> Eight of the 40 (20%) survivors of childhood/adolescent Hodgkin disease surveyed by Wasserman reported job discrimination.<sup>4</sup> Koocher and O’Malley studied 60 survivors of childhood cancer and found that 25% reported

employment discrimination (10 persons were refused a job at least once, three were denied benefits, three experienced illness related conflict with supervisor, four reported job task problems, and 11 were rejected by military).<sup>26</sup>

Of the 503 cancer survivors surveyed in the 1992 Yankelovich survey, one in five of the survivors who told their employer of their cancer reported discrimination, including changed job responsibilities, forced early retirement, denial of expected promotion, and termination.<sup>21</sup> A study of long-term breast cancer survivors reported only “minor difficulties with work.”<sup>27</sup> Thirteen percent reported difficulty getting time off from work for medical appointments, 8% reported “difficulty with their employer in regard to their breast cancer experience,” and 6% reported “difficulties with their coworkers in regard to their breast cancer experience.”<sup>27</sup> “Almost all” of the 253 long-term survivors interviewed in 1999 by Bradley reported that employers were completely cooperative in accommodating reduced schedules and absenteeism during treatment.<sup>11</sup>

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#### THE IMPACT OF CANCER SURVIVORS’ CURRENT EMPLOYMENT OPPORTUNITIES

Never before has cancer affected so many employed adults. In 2001, 38% of all cancer survivors—approximately 3.7 million Americans—were working age (age 20 to 64).<sup>28</sup> For most survivors, work is a financial and emotional necessity. Most survivors work not only for the obvious financial benefit but also for the accompanying health insurance, self-esteem, and social support.

In quality of life assessments, survivors have reported that being able to work full time and having an “enjoyable” job contribute to a better quality of life.<sup>29</sup> Work provides a “sense of normalcy” and “control” during a period when cancer strips survivors of control over life’s routines.<sup>30</sup>

The employment problems of cancer survivors take many forms. A cancer diagnosis may affect any type of job action, including dismissal, failure to hire, demotion, denial of promotion, undesirable transfer, denial of benefits, and hostility in the workplace.<sup>31</sup>

Although cancer survivors today experience fewer blatant barriers to job opportunities, many Americans still fear that cancer will have a negative impact on their ability to obtain and keep a job. A 1997 telephone survey of 662 employed adult Americans who did not have cancer found that 40% feared losing their job if they were diagnosed with cancer.<sup>32</sup> A survey of Hodgkin disease and leukemia survivors indicated that more than one third attributed at least one negative vocational (employment, income, or education) problem to their cancer.<sup>33</sup>

One reason survivors fear problems at work is because many supervisors and coworkers have misconceptions about survivors' abilities to work during and after treatment. A 1992 survey of 200 supervisors found that 66% were concerned that employees with cancer could no longer perform their jobs adequately.<sup>21</sup> Of 200 supervisors surveyed in 1996, 33% believed that a survivor could not handle the job and cancer, and 31% thought that the survivor needed to be replaced.<sup>34</sup> Yet after working with a survivor, 34% of the supervisors and 43% of coworkers said that they would be less concerned about working with a survivor in the future.<sup>34</sup> Nearly one half admitted that a current cancer diagnosis would affect their decision to hire a qualified applicant.<sup>21</sup> Of 662 employees surveyed by Ferrell, 14% believed that coworkers with cancer probably would not be able to do their jobs.<sup>30</sup> Twenty-seven percent of coworkers thought they would have to work harder to pick up the slack.<sup>30</sup>

#### WHEN CANCER-BASED DISCRIMINATION IS ILLEGAL

Under federal law and many state laws, an employer cannot treat a survivor differently from other workers in job-related activities because of his or her cancer history as long as the survivor is qualified for the job. Individuals are protected by these laws only if:

- 1) They can do the major duties of the job in question, and
- 2) Their employer treated them differently from other workers in job-related activities because of their cancer history.

#### Federal Law

Four federal laws provide some job protection to cancer survivors: the Americans with Disabilities Act (ADA),<sup>35</sup> the Federal Rehabilitation Act,<sup>36</sup> the Family and Medical Leave Act (FMLA),<sup>37</sup> and the Employee Retirement and Income Security Act (ERISA).<sup>38</sup>

#### *The Americans with Disabilities Act*

The ADA prohibits some types of job discrimination by employers, employment agencies, and labor unions against people who have or have had cancer. The ADA covers private employers with 15 or more employees, state and local governments, the legislative branch of the federal government, employment agencies, and labor unions. Most cancers survivors—regardless of whether their cancer is cured, is in remission, or is not responding to treatment—are considered persons with a “disability” under the ADA. From July 26, 1992, through September 30, 2004, 2.5% of all charges brought under the ADA were cancer-based discrimination claims.<sup>39</sup>

The ADA prohibits employment discrimination against individuals who have a “disability,” have a “record of a disability,” or are “regarded as having a disability.” A disability is a major health problem that substantially limits the ability to do everyday activities, such as drive a car or walk. Because most cancer survivors, even those who do not consider themselves to be limited by their cancer, fit under at least one of these three groups, most cancer survivors are protected by the ADA from the time of diagnosis. For example, the ADA covers survivors:

- Whose cancer currently substantially limits their ability to do everyday activities, such as climbing stairs. A temporary, nonchronic impairment, such as a broken bone, usually is not considered a disability.
- Whose cancer, at one time, substantially limited the ability to do everyday activities, but no longer does. The ADA protects most cancer survivors who have completed treatment from discrimination based on their medical histories.
- Whose employer believes that the employee's cancer substantially limits the ability to

do everyday activities, even if the employee believes it does not.

Whether an individual is covered by the ADA is determined on a case-by-case basis. Most federal courts find that cancer survivors who are qualified for their jobs are covered by the ADA.<sup>30</sup> Some federal courts, however, have misapplied the ADA by placing cancer survivors in a catch-22 by concluding that a cancer survivor who is sufficiently healthy to work is not a person with a disability as defined by the ADA.<sup>31</sup> A cancer survivor who never has been substantially limited in a major life activity may not be a "person with a disability" as defined by the ADA. Additionally, cancer survivors who, through medicine or other measures, can alleviate the limitations caused by cancer treatment, may not have a disability as defined by the ADA.

The ADA prohibits discrimination in almost all job-related activities, including, but not limited to:

- 1) Not hiring an applicant for a job or training program.
- 2) Firing a worker.
- 3) Providing unequal pay, working conditions, and benefits such as pension, vacation time, and health insurance.
- 4) Punishing an employee for filing a discrimination complaint.
- 5) Screening out disabled employees.

In most cases, an employer may not ask prospective employees if they have ever had cancer. An employer has the right to know only if the applicant can perform the duties of the job in question. An employer may not ask a prospective employee about his or her health history, unless the employee has a visible disability and the employer could reasonably believe that it affects the ability to perform that job. A job offer may be contingent on passing a relevant medical exam, provided that all prospective employees are subject to the same exam. An employer may ask detailed health questions only after offering a job.

Employers must keep employee medical histories in a file separate from other personnel records. The only people entitled to see employee medical files are supervisors who need to know whether the employee needs an accom-

modation, emergency medical personnel, and government officials who enforce the ADA.

If a survivor needs extra time or help to do his or her job, the ADA requires an employer to provide a "reasonable accommodation." An "accommodation" is a change in working conditions, such as in work hours or duties. Common accommodations for cancer survivors during and after treatment are:

- Providing extended leave or flexible work hours to accommodate treatment schedules.
- Relocating an employee from a physical area that may compromise his or her health.
- Providing a fatigued cancer survivor sufficient time to rest.
- Allowing a survivor to work from home when practical.

An employer does not have to make changes that would be an "undue hardship" on the employer or other workers. "Undue hardship" refers to any accommodation that would be unduly costly, extensive, substantial or disruptive, or that would fundamentally alter the nature or operation of the business. For example, an employer may be permitted to replace a cancer survivor who has to miss a substantial amount of work time and whose work cannot be performed by a temporary employee. Studies of employers with disabilities report that most employees can be accommodated with relatively simple and inexpensive solutions.<sup>40</sup>

The ADA does not prohibit an employer from firing or refusing to hire a cancer survivor under any circumstance. Because the law requires employers to treat all employees similarly, regardless of disability, an employer may fire a cancer survivor who would have been terminated even if he or she were not a survivor.

The ADA allows employers to establish attendance and leave policies that are uniformly applied to all employees, regardless of disability. Employers must grant leave to cancer survivors if other employees would be granted similar leave. They may be required to change leave policies as a reasonable accommodation. Employers are not obligated to provide additional paid leave, but accommodations may include leave flexibility and unpaid leave.

The ADA does not require employers to provide health insurance, but when they

choose to provide health insurance, they must do so fairly. For example, an employer who provides health insurance to all employees with similar jobs may violate the ADA by refusing to provide health insurance to a cancer survivor. The employer must prove that the failure to provide health insurance is based on legitimate actuarial data or that the insurance plan would become insolvent or suffer a drastic increase in premiums, copayments, or deductibles.

Most employment discrimination laws protect only the employee. The ADA offers protection more responsive to survivors' needs because it prohibits discrimination against family members too. Employers may not discriminate against workers because of their relationship or association with a "disabled" person. Employers may not assume that an employee's job performance would be affected by the need to care for a family member who has cancer. For example, employers may not treat an employee differently because they assume that the employee would use excessive leave to care for a spouse who has cancer. Additionally, employers that provide health insurance benefits to dependents of employees may not decrease benefits to an employee solely because that employee has a dependent who has cancer. Unlike the ADA, state laws, however, do not prohibit discrimination against an employee because of his or her relationship with a "disabled" person.

#### *The Federal Rehabilitation Act*

Before the passage of the ADA in 1990, the Federal Rehabilitation Act was the only federal law that prohibited cancer-based employment discrimination. The Rehabilitation Act bans public employers and private employers that receive public funds from discriminating on the basis of disability. Some employees continue to be covered by the Rehabilitation Act, but *not* the ADA:

- Employees of the executive branch of the federal government (covered by Section 501 of the Rehabilitation Act).
- Employees of employers that receive federal contracts and have fewer than 15 workers (covered by Section 503 of the Rehabilitation Act).

- Employees of employers that receive federal financial assistance and have fewer than 15 workers (covered by Section 504 of the Rehabilitation Act).

For example, small companies that receive federal grants for research and development, physicians in small groups that receive Medicare Part B funds, and small health agencies that receive Medicaid payments, may be subject to the Rehabilitation Act but not to the ADA.

The military is not covered by either the ADA or the Federal Rehabilitation Act, although retired military personnel and civilian employees of the Department of Defense are protected. The Department of Defense Directive 6,130.3 permits the military to reject cancer survivors for appointment, enlistment, and induction if they have:

- A benign tumor that interferes with function, prevents wearing a uniform or protective equipment, requires frequent specialized attention, or has a high malignant potential.
- A malignant tumor.

Each military service has the option of waiving these standards on a case-by-case basis. The military does consider for service most survivors who have been treated successfully and are cancer free for a period of time; for example, childhood cancer survivors who are cancer free and have not received treatment for five years are eligible.

Like the ADA, the Rehabilitation Act protects cancer survivors, regardless of extent of disability. The Rehabilitation Act protects only qualified workers and requires employers to provide reasonable accommodations.

#### *The Family and Medical Leave Act*

In 1993, Congress enacted the FMLA to provide job security to workers who must attend to the serious medical needs of themselves or their dependents. The FMLA requires employers with 50 or more employees to provide up to 12 weeks of unpaid, job-protected leave for family members who need time off to address their own serious illness or to care for a seriously ill child, parent, spouse, or a healthy newborn or newly adopted child. An employee must have worked at least 25 hours per week for one year to be cov-

ered. The law allows employers to exempt their highest paid workers.

The FMLA affects cancer survivors in the following ways:

- Provides 12 weeks of unpaid leave during any 12 month period.
- Requires employers to continue to provide benefits—including health insurance—during the leave period.
- Requires employers to restore employees to the same or equivalent position at the end of the leave period.
- Allows leave to care for a spouse, child, or parent who has a “serious health condition.”
- Allows leave because a serious health condition renders the employee “unable to perform the functions of the position.”
- Allows intermittent or reduced work schedule when “medically necessary” (under some circumstances, an employer may transfer the employee to a position with equivalent pay and benefits to accommodate the new work schedule).
- Requires employees to make reasonable efforts to schedule foreseeable medical care so as to not to unduly disrupt the workplace.
- Requires employees to give employers 30 days notice of foreseeable medical leave or as much notice as is practicable
- Allows employers to require employees to provide certification of medical needs and allows employers to seek a second opinion (at employer’s expense) to corroborate medical need.
- Permits employers to provide leave provisions more generous than those required by the FMLA.

#### *The Employee Retirement and Income Security Act*

ERISA may provide a remedy to an employee who has been denied full participation in an employee benefit plan because of a cancer history. ERISA prohibits an employer from discriminating against an employee for the purpose of preventing him or her from collecting benefits under an employee benefit plan. All employers who offer benefit packages to their employees are subject to ERISA.

ERISA also requires that employers may not condition eligibility for, contribution to, or scope of coverage under health benefits based on an employee’s or dependent’s health status. Health status means both past health claims and genetic information. Some employers fear that participation of a cancer survivor in a group medical plan will drain benefit funds or increase the employer’s insurance premiums. A violation of ERISA may occur when an employer, on learning of a worker’s cancer history, dismisses that worker for the purpose of excluding him or her from a group health plan.

If the employer fires the employee for the purpose of cutting off that employee’s benefits, regardless of whether the employee is considered disabled under the statute, then the employer may be liable for a violation of ERISA. Employee benefit plans are defined widely, and include any plan with the purpose of providing “medical, surgical, or hospital care benefits, or benefits in the event of sickness, accident, disability, death, or unemployment.”

An employer may also violate ERISA by encouraging a person with a cancer history to retire as a “disabled” employee. Most benefit plans define disability narrowly to include only the most debilitating conditions. Individuals with a cancer history often do not fit under such a definition and should not be compelled to label themselves so.

Under certain circumstances, ERISA may provide grounds for a lawsuit by workers with a cancer history. ERISA covers both participants (employees) and beneficiaries (spouses and children). Thus, if the employee is fired because his or her child has cancer, the employee may be entitled to file a claim. ERISA, however, is inapplicable to many victims of employment discrimination, including:

- Individuals who are denied a new job because of their medical status.
- Employees who are subjected to different treatment that does not affect their benefits.
- Employees whose compensation does not include benefits.

## State Laws

### *State Employment Discrimination Laws*

Most employers have to comply with federal and state employment discrimination laws. Cancer survivors who face discrimination by employers not covered by federal law may turn to state laws for relief. Every state has a law that regulates, to some extent, employment discrimination against people with disabilities. The application of these laws to cancer-based discrimination varies widely.

Many state laws have been amended to parallel the requirements of the ADA. Most state laws cover cancer survivors because they prohibit job discrimination against persons who

- Have a disability.
- Have a record of a disability.
- Are regarded by others as having a disability.

Different state and federal laws define “disability” in a variety of ways. For example, a cancer survivor may have a “disability” under the ADA, yet not have a “disability” as defined by a state law or by the Social Security Act.

All states, except Alabama and Mississippi, have laws that prohibit discrimination against people with disabilities in public and private employment. Alabama and Mississippi law cover only state employees. Several states, such as New Jersey, cover all employers regardless of the number of employees. The laws in most states, however, cover only employers with a minimum number of employees.

In states that do not protect individuals with a record of a disability or who are regarded by others as having a disability, a person actually must be disabled from his or her cancer to be protected by the law. A few states, such as California and Vermont, expressly prohibit discrimination against cancer survivors.

Although state discrimination laws differ substantially, they all share one requirement in common with the federal law: only “qualified” workers are entitled to relief. Most state laws prohibit discrimination in “terms and conditions of employment,” such as salary, benefits, duties, and promotional opportunities. Some state laws require employers to provide reasonable accommodations of an employee’s disabili-

ty and prohibit employers from asking about an applicant’s medical history before offering employment.

### *State Medical Leave Laws*

Some employers give their employees paid or unpaid medical leave. Employees who do not receive medical leave as a job benefit may have a right to medical leave under state law. Many states have leave laws similar to the federal FMLA in that they guarantee employees in the private sector unpaid leave for pregnancy, childbirth, and the adoption of a child. Some state laws provide employees with medical leave to address a serious illness, such as cancer. Several states provide coverage more extensive than the federal law.

### **Genetic-Based Discrimination**

A growing concern among cancer survivors and their relatives is whether employers will use genetic information as a basis for discrimination. Some people who have tested positively for a genetic change that increases their chances of getting cancer face discrimination because employers fear they will become ill, miss work, and raise insurance costs. Several federal laws provide limited protection to cancer survivors—the Genetic Privacy Act, Genetic Privacy and Nondiscrimination Act, the ADA, and the Health Insurance Portability and Accountability Act.<sup>41</sup> Although the ADA does not specifically mention whether it prohibits discrimination based on genetic information, the Equal Employment Opportunities Commission, which enforces the ADA, recognizes that a healthy individual who has a genetic predisposition to a disease is “regarded” as disabled, and therefore is covered by the law. Thus, an employer may violate the ADA by discriminating against a person because he or she has a genetic marker for cancer. Additionally, the ADA permits employers to test current employees for genetic information that is job-related and consistent with business necessity.

Federal employees have the greatest right to privacy of their genetic information. Executive Order 13,145 prohibits federal departments

and agencies from making employment decisions about civilian federal employees based on protected genetic information. The Order also prohibits federal employees from being required to take genetic tests as a condition of being hired or receiving benefits.

More than 30 states have genetic nondiscrimination laws. All prohibit discrimination based on the results of genetic tests, and many restrict employer access to genetic information.<sup>42</sup> The protection offered by these laws varies widely.

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#### HOW TO AVOID EMPLOYMENT DISCRIMINATION

Lawsuits are neither the only, nor usually the best, way to fight employment discrimination. State and federal antidiscrimination laws help cancer survivors by discouraging discrimination and offering remedies when discrimination does occur. These laws, however, should be used as a last resort because enforcing them can be costly and time consuming and does not necessarily result in a fair solution. Indeed, employers prevail in the vast majority of ADA cases.<sup>43</sup>

The first step is to try to avoid discrimination. If that fails, the next step is to attempt a reasonable settlement with the employer. If informal efforts fail, however, a lawsuit may be the most effective next step. The most constructive efforts against cancer-based discrimination do not react to discrimination but instead eliminate opportunities for discrimination in the first place. Cancer survivors can take several measures to lessen the chance of encountering employment discrimination:

- Do not volunteer information about a cancer history unless it directly affects qualifications for the job.
- Do not lie on a job or insurance application.
- Be aware of legal rights.
- Suggest specific reasonable accommodations where appropriate.
- Keep the focus on current ability to do the job in question.
- Apply only for jobs for which the survivor is qualified.
- Provide an employer with a physician's letter that explains the survivor's current health

status, prognosis, and ability to perform the essential duties of the job in question.

- Seek help from a job counselor with resume preparation and job interviewing skills.
- If interviewing for a job, do not ask about health insurance until after receipt of a job offer.
- If possible, look for jobs with state or local governments or large employers (50+ employees) because they are less likely than small employers to discriminate.
- Seek information and assistance from organizations that advocate for cancer survivors, such as:

The National Coalition for Cancer Survivorship

(877) 622-7937

[www.canceradvocacy.org](http://www.canceradvocacy.org)

Cancer Care, Inc.

(800) 813-HOPE

[www.cancer.org](http://www.cancer.org)

ACS

(800) ACS-2345

[www.cancer.org](http://www.cancer.org)

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#### CONCLUSION

A generation ago, most cancer resources were directed toward medical treatment. Few survivors had assistance finding and keeping employment. In the past 30 years, improvements in cancer treatment, the passage of antidiscrimination laws, and a sea change in perceptions about living with and beyond cancer have greatly enhanced the employment opportunities of the nearly 4,000,000 Americans who are working age adults.

Now that great strides have been made in improving the legal rights of cancer survivors, advocacy resources should focus on enhancing survivors' quality of life at work. Despite a significant increase in survivorship research, further studies are needed to more accurately assess the impact of cancer on work. Future studies should employ a uniform definition of terms such as "cancer-related problems" and "discrimination." They should survey large,

diverse populations with matched control groups. Many factors that impact a survivor's experience at work, including age, gender, type of cancer, stage at diagnosis, income, education, type of occupation, whether the survivor is in treatment or posttreatment, and medical conditions not related to cancer, should be assessed.

From the time of diagnosis, survivors need team-based, long-term support in managing their employment opportunities. National and personal advocacy should focus on all aspects of cancer survivorship that impact a survivor's ability to work, including symptom management, physical and mental health rehabilitation, legal rights, and reasonable accommodations.

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