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Cancer and the Workplace

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STATEMENT OF NEED

Despite a number of laws protecting the rights of employees with cancer and their caregivers in the workplace, numerous obstacles confront anyone continuing to work during treatments or reentering the workplace after active cancer treatments. Sadness, anxiety, fear, uncertainty, shame, and other emotional concerns may arise. Psychosocial support and guidance in coping is critically important at this time. To assist these patients, healthcare professionals should not only acquaint themselves with the laws but also work to identify those in need of support and to develop and implement outreach programs and services to meet their needs—before, during, and after treatment.

TARGET AUDIENCE

Advanced practice nurses, registered nurses, and other interested healthcare professionals, especially those caring for cancer patients

LEARNING OBJECTIVES

After completing this activity, the reader should be able to:

- Identify provisions of legal protections relating to cancer and the workplace
- Describe challenges specific to young adults with cancer

Significant progress in the treatment of cancer, coupled with early detection, has led to meaningful improvement in survival and quality of life. Novel symptom and pain-control interventions have made it possible for more patients with cancer to continue to work while receiving chemotherapy and radiation therapy, as well as biologic, hormonal, and targeted agents. In addition, the trend of delivering cancer treatments in the outpatient setting, as opposed to inpatient hospital stays, has reduced time away from work during treatments. For many, personalized medicine and oral agents for the treatment of cancer have normalized further the cancer treatment experience.

Today's cancer care paradigm has led to new challenges regarding cancer and the workplace. Despite a number of laws protecting the rights of employees with cancer and their caregivers in the workplace, numerous obstacles confront anyone continuing to work during treatments or reentering the workplace after active cancer treatments.

Many myths about cancer abound in our society, and also in the workplace. Employers, supervisors, and coworkers may assume that patients with cancer will not be able to perform job responsibilities

after cancer as they did before the cancer diagnosis. They also may perceive these individuals or their caregivers as a poor risk for promotion. Any or all of these attitudes may lead to subtle or blatant workplace discrimination.

In spite of the progress in the treatment of cancer, it is important to note that, for some, return to work may not be a feasible option. They might not be able to sustain a workday combined with their commute.¹

The Meaning of Work

"[Work] is about a search, too, for daily meaning as well as daily bread, for recognition as well as cash...."

—Studs Terkel

Working: People Talk About What They Do All Day and How They Feel About How They Do It

There are a number of reasons to continue or return to work: independence, identity, economic necessity, health insurance, social support, sense of purpose, satisfaction from work, and productivity. Many cancer patients and survivors appreciate the distraction work offers from thinking about cancer. Most adults spend more than half of their waking hours in the workplace. Returning to work during or after cancer treatments restores an important sense of self apart from the disease—something that may have been lost while not working. Continuing to work may be emotionally, socially, and cognitively helpful to patients during and after treatment.

When a person living with cancer returns to work, deciding to tell an employer about his or her condition is a personal decision. Some workplace legal protections, however, require disclosure to human resources or one's supervisor to benefit from these laws. Thanks to new laws put into place in the past few decades, this information remains confidential.

Key Legal Protections

The Americans with Disabilities Act (ADA). Enacted in 1990 by Congress, the ADA took effect in 1992. This national mandate eliminates discrimination against individuals with disabilities.

Organizations with 15 or more employees must comply with ADA guidelines. Patients with cancer are protected under the ADA if the following criteria are met²:

- Classified as a "disabled person" under ADA
- Qualified for the job
- Able to perform the essential functions of the job
- The employer has provided a reasonable accommodation; and this accommodation will not cause "undue hardship" to the employer
- The patient does not pose a direct threat to his or her own or others' health or safety.

The most frequent workplace accommodation required by patients with cancer is flexibility in their work hours. They may need to leave early or come in late because of scheduled radiation or chemotherapy appointments. If flextime is required, it is critical the patient request a workplace accommodation by disclosing to his or her supervisor or human resources personnel the cancer diagnosis, so the flextime comes under the protection of the ADA.² If no reason is given for a request of flex-

time, the employer could document time and leave problems, which could jeopardize job security.

The ADA protects people living with cancer and cancer survivors when they apply for a job. The ADA prohibits an employer from asking any questions regarding health history or current medical status during job interviews or any time before an offer is made. Patients living with cancer, as well as survivors, are not required to share their health history with prospective employers. After a position is offered, however, if the company requires all employees to undergo a physical examination or drug testing, then it is prudent for the patient with cancer to provide full disclosure to the medical personnel conducting the examination.²

The Family and Medical Leave Act (FMLA). Enacted in 1993, the FMLA enables both patients with cancer and their family members to take an unpaid leave for health challenges that make them unable to perform their job functions. A person may take up to 12 weeks of unpaid leave within 1 year. The employer is required to

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- Rosemary Hansen has nothing to disclose.
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continue health benefits during FMLA leave. The FMLA applies to organizations with 50 or more employees, and the employee must have worked with his or her employer for at least 1 year, in which he or she has worked for 1250 hours (about 25 hours per week).³

The 12-week leave does not have to be taken all at once. Intermittent FMLA allows the employee to take time in blocks, such as several hours a day or 1 hour at a time. The FMLA also allows the employee to use accrued paid annual leave or accrued sick leave during family or medical leave. It is important to realize that the employer is not required to reinstate an employee who takes more than 12 weeks' leave in a year. In addition, to be defined as "family members," the employee must be either a parent (including parents of young and/or adult children), a child (including adult children), or a spouse. The employer may request a medical certification by a doctor or other healthcare provider.³

The Equal Employment Opportunity Commission (EEOC). This federal agency was created to address the needs of citizens who have been discriminated against in the workplace. An employee who feels that there is subtle or blatant discrimination in the workplace should contact the EEOC directly before retaining a lawyer. This underused public resource is the federal enforcer of the ADA and FMLA. The EEOC will investigate any allegations against an employer or perceived discrimination or inappropriate behavior and policies. EEOC staff is helpful for people currently working, as well as for those seeking employment, who have questions about the job interview process and preoffer phase of work reentry. A charge must be filed with the EEOC within 180 days of the discrimination. The EEOC is invaluable in assisting with workplace complaints. Knowing that they have the backing of the EEOC can provide strength to patients with cancer who are either reentering the workforce or who are in the workforce.⁴

The Health Insurance Portability and Accountability Act (HIPAA) of 1996. HIPAA ensures privacy of patient medical information. It protects medical diagnoses and/or treatment by limiting those who have access to the patient's health records and by requiring the patient's consent to share such information. It also protects the rights of people when they are part of group health plans and gives the option of bringing the patient's health insurance to another job in the future.⁵

The Genetic Information Nondiscrimination Act (GINA) of 2008. This act prohibits discrimination based on genetic information, with respect to employment opportunities and health insurance companies. Therefore, if a patient is looking for new employment, his or her cancer or disease risk and/or family history of disease cannot be a reason for an employer to not hire.⁶

Knowing that they have the backing of the EEOC can provide strength to patients with cancer who are either reentering the workforce or who are in the workforce.

Psychosocial Aspects of Returning to the Workplace

Cancer not only takes a toll on patients' and survivors' physical well-being, but also impacts their psychosocial outlook. Sadness, anxiety, fear, uncertainty, shame, and other emotional concerns may arise. Psychosocial support and guidance in coping is critically important at this time.⁷

In surveying 421 cancer experts, Greenfield and colleagues found that many correlated the receipt of information on cancer's late effects as a potential barrier for follow-up doctor visits. Many also believed that such information potentially could increase patient anxiety.⁸

In addition, Carlson and colleagues assessed 3095 representative cancer patients over 4 weeks with the Brief Symptom Inventory-18, a common psychosocial problem checklist, and their awareness and use of psychosocial support services. They found that almost half of all patients who were distraught did not seek professional psychosocial support, nor did they intend to do so in the future.⁹ Informed and evidence-based practice, however, recommends that patients should be encouraged to seek psychosocial support during and after cancer treatments.⁷

The interdisciplinary healthcare team, therefore, should work hard to identify those in need of support and to develop and implement outreach programs and services to meet their needs.¹⁰ To help in this effort, Manicom described psychosocial challenges facing patients and their families along each step of the cancer journey.¹¹ Whereas many clinicians are aware that, on diagnosis, many patients confront their mortality and experience overwhelming emotions, they may need to be remind-

ed that psychosocial challenges also are present at other stages of the continuum. For example, on ending treatment, patients may need to cope with a withdrawal of support from family and friends and adjust to a "new normal" that requires managing possible ongoing physical limitations. In addition, on terminal illness, patients will need to face the disappointment of stopping active treatment and moving to supportive care as well as plan for those who will be left behind.¹¹

Young Adults with Cancer and the Workplace

Young adults have unique priorities and psychosocial concerns related to their age and life-cycle developmental challenges. They experience particular life-cycle issues as they deal with the sequelae of cancer.¹² Young adults may be entering the workforce for the first time as well as trying to figure out and plan the future direction of their career and life choices. Their specific psychosocial challenges focus on establishing independence, dating and romantic relationships, discovering the impact of cancer treatments on fertility and body image, seeking to establish their personal identity, choosing a career, deciding whether to continue school, and obtaining health insurance.¹² More than one-third of cancer survivors are young adults.⁷ Yet, peer support may not be at its peak for young adults, who

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may be more focused on enhancing their education, starting a career, or handling the psychosocial challenges previously identified.

These developmental challenges may cause young adult cancer patients to experience significant isolation from peers as well as biological changes from their cancer and its treatments.¹² Clinical trial data often are based on older cancer patients; therefore, treatment side effects and the impact of treatments on loss of muscle mass or changes in metabolic rate may impact young adults differently and require further study (A. Eckhard, oral communication, 2011). Fortunately, in the United States and in developed countries globally, there is increased interest in the needs of young adult cancer patients and survivors. There is a proliferation of support groups for young adults as well as specialized cancer centers conducting research focused on young adults and cancer. In spite of this progress, the unique issues young adults confront may leave them with more dif-

Table Tips for Returning to Work

- 1. Ask about follow-up care.** If necessary, make sure you have a plan with your doctor, nurse, and/or social worker about any concerns regarding physical, emotional, or practical issues you may have. It is critically important that the medical team knows exactly what each patient's job entails. This information helps in scheduling doctor visits and their impact on time out of the office, work projects, or work flow.
- 2. Set up an interview with the human resource department and/or manager to discuss your needs.** It is always helpful to have a simple note from your treating oncologist to document any accommodations required. This can include flexible work schedule and necessary accommodations. Human resources and/or your manager can set up a plan to reasonably accommodate your requests.
- 3. Once back to work, move at your own pace.** It is essential for your physical and emotional well-being that you do not try to place too many tasks on your plate. Scheduling periodic 10- to 15-minute breaks can help ease stress and the process of returning to work. Along with this, you must remember to...
- 4. Diminish as many unnecessary stresses as possible.** With this, it is important be able to say "no" to tasks that are not imperative. This is so you do not become overburdened. Stress can be eased in a multitude of other ways too, from eating a well-balanced diet to going out for a walk.
- 5. Most importantly, stay true to yourself.** If you are naturally open, feel free to tell your coworkers how you are doing and, if you need their help, let them know what they can do to help. If you are more private, just tell everyone that you are glad to be back at work, appreciate their asking, and thank them for their interest. This approach will help protect your privacy during this time.

Source: Cancer and Careers. Your mindset. www.cancerandcareers.org/en/at-work/Your-Mindset. Accessed August 29, 2011.

facilities when pursuing employment because of their lack of experience and knowledge of their legal protections and/or their many psychosocial concerns. These may put young adults at a competitive disadvantage in the labor market, especially if cancer has caused a noticeable physical disability or a perceived difference in the self-image of a young adult.⁷ Young adult survivors need opportunities to learn about the laws that protect them against discrimination as well as their rights for workplace accommodations due to cancer, its treatment, or long-term side effects. If a young adult is undergoing treatment and wants to continue working for financial or other reasons, legal protections exist to protect his or her job as long as he or she is able to perform the essential functions of the job.

There is no “right” way to cope with

Young adult survivors need opportunities to learn about the laws that protect them against discrimination as well as their rights for workplace accommodations due to cancer, its treatment, or long-term side effects.

cancer. Every individual is different and responds to psychosocial life crises in his or her own way. There are increasing numbers of young adults living with cancer, and survivors are using psychosocial and practical support services to cope with their cancer experience and journey. To help, Cancer and Careers, an organization that helps

empower and educate people with cancer to thrive in their workplace, has devised tips for cancer patients and survivors looking to return to work (**Table**).

Financial Resources

Unfortunately, many young adults do not have health insurance. In addition, their cancer may be diagnosed at a later stage because of their age. If not able to work, there are resources for financial assistance. They should start looking for this financial aid with the Social Security Administration. Supplemental Security Income (SSI) is what most young adults will receive if they have not worked enough quarters to qualify for Social Security.¹³ Older adults may apply for retirement benefits from their workplace, private insurance, or investments. Those who have worked adequate quarters can apply for Social Security Disability benefits.

With supportive guidance and a dedicated healthcare team, the cancer journey becomes more manageable.

The SSI application process includes an interview. If a patient is rejected, he or she must make sure to appeal. During treatment, money is a concern, so any aid can be beneficial. Once determined eligible for SSI, the patient will be enrolled automatically for Medicaid, which will pay for medical expenses. Patients also should apply for food stamps from the US Department of Agriculture.

The Patient Protection and Affordable Care Act (ACA) of 2010. This recent law helps patients with the struggles of health insurance companies denying coverage for any reason. These reasons may include health status and/or gender, which can cause rates to skyrocket. This act also requires most people to have health insurance by 2014.⁵

The Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1986.

This act provides the continuation of group health coverage that might otherwise be terminated. It offers the right to temporary continuation of health coverage for 18 months after an individual has left the company and lets the patient continue seeing his or her doctors, because the healthcare plan has remained unchanged.⁵

Help for Young Adults

Young adults with cancer should never feel as if they are alone. There are a variety of specific resources available for them and more aid is being created every day (**Sidebar**). When reentering the workforce or if entering it for the first time, young adults should be aware of their rights. They should familiarize themselves with the laws that protect them, the psychosocial effects they may feel before, during, and after treatment, and the many ways to cope that would be beneficial for them. With supportive guidance and a dedicated healthcare team, the cancer journey becomes more manageable. ●

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Selected Resources for Cancer Patients and Survivors in the Workplace

American Cancer Society

www.cancer.org

800.227.2345

Americans with Disabilities Act

www.ada.gov

800.514.0301

Cancer and Careers

www.cancerandcareers.org

CancerCare

www.cancercare.org

800.813.HOPE (4673)

Equal Employment Opportunity Commission

www.eeoc.gov

800.669.4000

I'm Too Young for This Cancer Foundation

www.i2y.org or www.stupidcancer.com

877.735.4673

Intercultural Cancer Council

www.iccnetwork.org

713.798.4614

LIVESTRONG

www.livestrong.org

866.673.7205

National Cancer Institute

www.cancer.gov

800.4.CANCER (22.6237)

National Coalition for Cancer Survivorship

www.canceradvocacy.org

888.650.9127

Planet Cancer

www.planetcancer.org