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Authors
Tevaarwerk, Amye
Denlinger, Crystal S
Sanft, Tara
et al.

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Survivorship, Version 1.2021:

Featured Updates to the NCCN Guidelines

Amye Tevaarwerk, MD[1,*], **Crystal S. Denlinger, MD**[2,*], **Tara Sanft, MD**[3,*], **Shannon M. Ansbaugh**[4,*], **Saro Armenian, DO, MPH**[5], **K. Scott Baker, MD, MS**[6], **Gregory Broderick, MD**[7,*], **Andrew Day, MD, MPH**[8,*], **Wendy Demark-Wahnefried, PhD, RD**[9,*], **Kristin Dickinson, PhD, RN**[10], **Debra L. Friedman, MD, MS**[11], **Patricia Ganz, MD**[12], **Mindy Goldman, MD**[13], **Norah Lynn Henry, MD, PhD**[14,*], **Christine Hill-Kayser, MD**[15], **Melissa Hudson, MD**[16,*], **Nazanin Khakpour, MD**[17], **Divya Koura, MD**[18], **Allison L. McDonough, MD**[19], **Michelle Melisko, MD**[13], **Kathi Mooney, RN, PhD**[20], **Halle C.F. Moore, MD**[21], **Natalie Moryl, MD**[22], **Javid J. Moslehi, MD**[11], **Tracey O'Connor, MD**[23], **Linda Overholser, MD, MPH**[24], **Electra D. Paskett, PhD**[25], **Chirayu Patel, MD, MPH**[19], **Lindsay Peterson, MD**[26,*], **William Pirl, MD**[27], **M. Alma Rodriguez, MD**[28], **Kathryn J. Ruddy, MD, MPH**[7], **Lidia Schapira, MD**[29,*], **Lillie Shockney, RN, MAS**[30], **Sophia Smith, PhD, MSW**[31], **Karen L. Syrjala, PhD**[6,*], **Phyllis Zee, MD, PhD**[32], **Nicole R. McMillian, MS, CHES**[33,*], **Deborah A. Freedman-Cass, PhD**[33,*]

[1]University of Wisconsin Carbone Cancer Center

[2]Fox Chase Cancer Center

[3]Yale Cancer Center/Smilow Cancer Hospital

[4]Patient Advocate

[5]City of Hope National Medical Center

[6]Fred Hutchinson Cancer Research Center/Seattle Cancer Care Alliance

[7]Mayo Clinic Cancer Center

[8]UT Southwestern Simmons Comprehensive Cancer Center

[9]O'Neal Comprehensive Cancer Center at UAB

[10]Fred & Pamela Buffett Cancer Center

[11]Vanderbilt-Ingram Cancer Center

[12]UCLA Jonsson Comprehensive Cancer Center

[13]UCSF Helen Diller Family Comprehensive Cancer Center

[14]University of Michigan Rogel Cancer Center

[15]Abramson Cancer Center at the University of Pennsylvania

[16]St. Jude Children's Research Hospital/The University of Tennessee Health Science Center

[17]Moffitt Cancer Center

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[*]Provided content development and/or authorship assistance.

[18]UC San Diego Moores Cancer Center

[19]Massachusetts General Hospital Cancer Center

[20]Huntsman Cancer Institute at the University of Utah

[21]Case Comprehensive Cancer Center/University Hospitals Seidman Cancer Center and Cleveland Clinic Taussig Cancer Institute

[22]Memorial Sloan Kettering Cancer Center

[23]Roswell Park Comprehensive Cancer Center

[24]University of Colorado Cancer Center

[25]The Ohio State University Comprehensive Cancer Center - James Cancer Hospital and Solove Research Institute

[26]Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine

[27]Dana-Farber/Brigham and Women's Cancer Center

[28]The University of Texas MD Anderson Cancer Center

[29]Stanford Cancer Institute

[30]The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins

[31]Duke Cancer Institute

[32]Robert H. Lurie Comprehensive Cancer Center of Northwestern University

[33]National Comprehensive Cancer Network

Abstract

The NCCN Guidelines for Survivorship are intended to help healthcare professionals working with cancer survivors to ensure that each survivor's complex and varied needs are addressed. The Guidelines provide screening, evaluation, and treatment recommendations for consequences of adult-onset cancer and its treatment; recommendations to help promote healthful lifestyle behaviors, weight management, and immunizations in survivors; and a framework for care coordination. This article summarizes the recommendations regarding employment and return to work for cancer survivors that were added in the 2021 version of the NCCN Guidelines.

Overview

The number of cancer survivors in the United States increased from approximately 3 million in 1971 to nearly 16.9 million in 2019.[1-3] These numbers are predicted to surpass 22 million by 2030.[3] This increase is generally attributed to rising cancer incidence rates (mainly resulting from an aging population), earlier detection, and better treatment.

The most common cancer sites in the survivor population are breast, prostate, colon/rectum, and melanoma, together accounting for approximately 58% of survivors.[4] Approximately

64% of survivors were diagnosed ≥5 years ago, whereas 15% of survivors were diagnosed ≥20 years ago, and approximately 5% have survived ≥30 years.[4] Approximately 64% of survivors are aged ≥65 years, whereas only <0.7% are aged ≤19 years.[3]

The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for Survivorship provide screening, evaluation, and treatment recommendations for consequences (eg, symptoms) of cancer and cancer treatment to aid healthcare professionals who work with survivors of adult-onset cancer. Guidance is also provided to help promote physical activity, a healthful diet and weight management, and proper immunizations in survivors, and to facilitate care coordination that ensures all needs are addressed. The NCCN Survivorship Panel comprises a multidisciplinary panel of experts that includes at least one of the following: oncologist (including surgical, medical, radiation, and transplant), cardiologist, primary care physician, psychologist or psychiatrist, nutrition scientist, nurse, epidemiologist, social worker, and cancer survivor. The panel meets annually to discuss the latest data emerging in the field of survivorship and to decide about requested changes to the guidelines from panel members or other health professionals at NCCN Member Institutions (internal requests) or submitted by outside individuals or groups (external requests).

Working and Returning To Work After a Cancer Diagnosis

Cancer and its treatment can interfere with the ability to work.[5-11] Several studies have shown that unemployment rates for cancer survivors are higher than for the general population.[5,12-14] In fact, cancer survivors are approximately 1.4 times more likely to be unemployed than those without a history of cancer, and roughly 25% of survivors will not have returned to work at 2 years postdiagnosis.[15-17] Furthermore, those survivors who do return to work often encounter difficulties, such as physical or cognitive limitations, fatigue, depression, anxiety, and discrimination.[5,18,19]

Survivors may work because they need to (eg, insurance, income), but they may also work because they want to (eg, for a sense of normalcy and personal identity, distraction, need for activity, social contacts).[20,21] Approximately 35% to 46% of people diagnosed with cancer in the United States are between the ages of 20 and 64 years, and thus are generally considered to be of working age.[1,3,22] Therefore, as many as 6 to 8 million cancer survivors in the United States are at risk for difficulties surrounding employment.

Considering these points and internal requests from panel members, the NCCN Survivorship Panel convened a subcommittee to draft recommendations aimed at managing issues surrounding employment and return to work for cancer survivors. The draft was then reviewed, discussed, and edited by the full panel. Draft recommendations were circulated at NCCN Member Institutions for further input, and the final version of a new section on employment and return to work was included in the 1.2021 version of the Guidelines. The data discussed by the subcommittee and the full panel as well as the new recommendations are described herein. Other recent updates can be seen in the full guidelines, available at NCCN.org.

Scope of Employment Issues Among Cancer Survivors

The subcommittee first discussed the scope of the issues they wanted to address. “Return to work,” although a commonly used phrase, is somewhat of a misnomer. The phrase may imply that cancer and employment represent a linear journey, but cancer journeys are rarely straightforward. The phrase implies that a cancer survivor stops working during cancer treatment and then restarts only once at the exact same job. In reality, however, survivors may never stop working after the cancer diagnosis, they may stop and start more than once, and/or they may resume employment at a different level or position and/or with a different employer.[23]

Many cancer survivors remain employed but may experience work limitations, which are changes in the ability to work or in productivity at work that can be physical, cognitive/emotional, or both.[24] Work limitations due to cancer can range from mild or transient to persistent, long-term dysfunction. Work limitations can lead to employment instability (eg, changes in job or employer), underemployment (eg, accepting less demanding or part-time positions), absenteeism, presenteeism (eg, working despite limited capacity), decreased productivity, an increased struggle at work without a decrease in productivity, and decreased well-being.[25-28] Data show that symptoms from cancer and/or its treatment can lead to poor work outcomes, such as prolonged sick leave, schedule and role changes, and job loss.[11,18,25,26,29-31] Loss of working days due to treatment may also be a main driver of decreased productivity, especially for those receiving curative therapy.[32]

In one study, 120 individuals receiving chemotherapy with curative-intent who were employed at diagnosis and intended to work or return to work were surveyed before chemotherapy, at the end of active treatment, and 3, 6, and 12 months after treatment; participants were largely diagnosed with breast and colon cancer, but cancers did include other curative-intent types, such as lymphoma and head and neck cancers.[20] Results showed that full-time employment decreased from 88% to 50% during therapy and returned to 78% by 12-month follow-up. Importantly, participant-perceived loss of work productivity was high during treatment and remained elevated 12 months after treatment. Patients in this study also reported a significant decrease in the number of hours worked (42 hours/week before diagnosis to 33 hours/week at end of treatment; $P<.001$). In addition, participants missed more full and partial work days during treatment than at 3 months after treatment (2 full and 2 partial work days missed vs 1 full and 1 partial day missed, respectively).

The panel noted that nonemployment (eg, loss of employment, early retirement) does not represent the full scope of the concerns seen following a cancer diagnosis. Survivors may struggle with underemployment, changes in work productivity, and/or other impacts on work ability that may be less visible than nonemployment. The panel agreed that it was vital to emphasize the importance of helping cancer survivors across the entire scope of work-related issues and acknowledged that early retirement, loss of employment, reduced work, and stopping/starting cycles also may be issues, but elected to include the phrase “return to work” given its common use in the literature. They therefore named the new section “Employment and Return to Work” to emphasize the scope of work-related considerations ranging from loss of employment to partial or full employment and early retirement.

The panel also discussed whether to address issues surrounding the effects of cancer on school attendance and education, because cancer survivors' education may be disrupted due to cancer and its treatment, especially in the adolescent and young adult (AYA) population. However, the subcommittee discussed the considerable differences that distinguish work from school attendance, and recommended they be addressed separately. They decided to hold the topic of education for a later iteration of these guidelines, perhaps in collaboration with the NCCN AYA Oncology Panel.

The panel further noted that caregivers often experience employment issues, as well. In one study, 25% to 29% of informal cancer caregivers made extended employment changes, with approximately 8% taking ≥2 months off of work.[33] Another study reported that 24% of cancer caregivers reduced work hours or transitioned to part-time employment and 11% retired early or stopped work completely; a total of 48% of employed cancer caregivers adjusted their work hours or took time off work for caregiving activities.[34] The panel did not address employment issues in cancer caregivers in this initial set of recommendations, but may include caregivers at a later time.

Consequences of Employment Difficulties

Employment helps protect survivors from the financial toxicity and financial distress associated with cancer treatment.[35] However, there can be consequences of employment difficulties beyond the loss of income. For instance, survivors may lose access to medical insurance and affordable medical care, given that insurance is often linked to employment in the United States.[36,37] Health insurance access may in fact be a main reason that survivors work even when they are not fully recovered.[38]

The psychosocial advantages derived from work may include a sense of purpose, emotional well-being, a link to identity, improved health-related quality of life (HRQoL), connection with others, and distraction. When employment is disrupted, these advantages can be lost. In fact, several studies have shown that cancer survivors who are unemployed or have greater work impairments experience greater long-term psychologic distress and worse HRQoL outcomes compared with other cancer survivors,[32,39,40] although caution should be applied to this interpretation given likely confounding. In addition, employment issues (and presumably subsequent income and insurance issues) may affect receipt of cancer treatment, leading to treatment delays, suboptimal treatment adherence, or treatment discontinuation.[41]

Populations at Increased Risk

Employment outcomes vary greatly depending on the population and geographic location.[15,32] Many factors, including but not limited to sex, age, race, ethnicity, cancer stage/type, rural residence, and educational attainment, have all been implicated in affecting the risk for difficulties related to work.[15,29,31,32,42-47] Other factors that affect the likelihood for employment problems include symptom burden, marital status, and emotional and functional well-being.[15,29,31,32,42-47] Increased employment difficulties are also seen in survivors with physically or cognitively demanding jobs.[42,48] Furthermore, factors related to the person (eg, coping strategies, motivation), social support (eg, family, workplace), and occupation (eg, job flexibility) can impact employment after cancer.[49]

Survivors with metastatic or chronic, incurable cancers have unique issues surrounding employment. They often have multiple courses or lines of treatment over time, even sometimes in a single year. Such survivors living with metastatic or incurable cancer must balance employment needs with HRQoL and end-of-life considerations. Survivors living with metastatic cancer report being unable to work more often than those without metastases.[32] In the Symptom Outcomes and Practice Patterns (SOAPP) study, which prospectively accrued patients with breast, prostate, colon, or lung cancer, 45% of patients with metastatic disease stopped working because of illness, and another 12% reported that they were still working but that there was instability in their work status.[50] Financial toxicity may be especially burdensome to survivors living with metastatic or incurable cancer.[51]

Intervention Studies

A limited number of interventions to enhance return to work in cancer survivors have been studied (eg, psychoeducation, physical training, vocational counseling).[52-56] Multidisciplinary interventions that combine vocational counseling with other elements (eg, patient education, patient counseling, behavioral training, physical exercises) may increase rates of return to work compared with usual care.[52] A systematic review published in 2015 identified randomized controlled trials that evaluated the effectiveness of psychoeducational, vocational, physical, medical, or multidisciplinary interventions for enhancing return to work in patients with cancer.[52] Trials that involved multidisciplinary interventions led to higher return-to-work rates than usual care (risk ratio, 1.11; 95% CI, 1.03–1.16). However, a systematic review published in 2019 found that identified randomized controlled trials showed no improvement in return to work among cancer survivors using interventions designed to help patients to return to work after cancer treatment.[54]

Clearly, additional research into interventions that improve employment outcomes among cancer survivors is greatly needed.[53]

Role of the Employer and Job Accommodations

Employers can support cancer survivors with job accommodations, such as job restructuring and/or modification, provision of mobility assistance, granting periodic breaks for rest or to make medical-related calls, improved building access and parking, moving a desk to a location with fewer distractions, and modified office temperatures. Survivors who receive workplace accommodations or whose jobs have more favorable employment protection policies have better employment outcomes.[57,58] A recent study indicated that employer flexibility of location and hours may be important.[59] The ability to perform some work at home or adjust hours around medical appointments or fatigue (eg, total hours remain the same but with breaks built into the day) allowed survivors to continue working successfully.

Several panel members expressed their belief that employment disability forms are not typically well suited to cancer, in that they are often intended to address single events, such as an accident or pregnancy, rather than to address the cyclical and often iterative nature of cancer and cancer therapies. Additionally, clinicians typically receive little support or training with respect to filling out such forms. Clinicians should consider the survivor’s

needs for flexibility in tasks and hours and other workplace accommodations as a starting point for completing the necessary forms.

Panel Recommendations

Based on the data and discussion presented earlier, the subcommittee developed recommendations aimed at helping clinicians address work-related concerns for survivors after active cancer treatment or for those living chronically with cancer (see SWORK-1, page 680), which were then reviewed and discussed with the panel. The panel recommends that communication about a patient's work and employment begin early in the course of decision-making about treatment and be revisited at regular intervals, to anticipate and identify concerns and provide appropriate supportive interventions and counseling. Alternative cancer therapy options (if possible) should be explored to mitigate the impact on work. A multidisciplinary team approach may be needed, and involvement of social work, primary care, physical therapy/occupational therapy, cancer rehabilitation, and/or career counseling services, if available, should be considered. Furthermore, clinicians should regularly reevaluate work-related concerns with survivors.

Screening, Evaluation, and Assessment—The panel noted that employment issues are often not discussed with patients and survivors until problems arise. Therefore, the panel recommends screening all survivors with the following question: Do you have concerns about how cancer and/or cancer therapy has affected your ability to work? (see SURV-A page 1 of 2, page 678).

For those that answer yes to this question, the panel recommends discussion of the survivor's concerns, needs, goals, and desires related to work (see SWORK-2, page 681). Some survivors may desire to work, but are unable for some reason. Others may want to stop working, but need to continue for money, access to health insurance, and/or other reasons.

For survivors who desire employment, clinicians should ascertain the abilities that are required for the job (eg, cognitive tasks, long periods of standing, use of hands), and any anticipated barriers to employment or return to work. Practical concerns may include transportation and caregiving responsibilities. The financial toxicity of cancer and its treatment should also be discussed, because it often relates to concerns surrounding work. Survivors need access to details about disability rules, regulations, and procedures.

Because treatable symptoms and comorbid conditions often contribute to an inability to work at the survivor's former level, common contributing factors should also be assessed. Contributing symptoms may include fatigue; pain and neuropathy; musculoskeletal and neurologic issues (eg, joint/extremity mobility, deconditioning/loss of muscle mass, sensory neuropathy, incontinence); cognitive dysfunction; anxiety, depression, and distress; and vision and hearing changes. Comorbid conditions that should be considered include alcohol/substance use; depression or other mental health problems; organ dysfunction, especially that resulting from cancer or its treatment (eg, cardiac, pulmonary, gastrointestinal, urologic); and hematologic dysfunction/infection risk in posttransplant survivors.

Treatment of Contributing Factors—Symptoms and comorbid conditions that may contribute to the survivor's concerns surrounding work should be addressed (see SWORK-2, page 681). For many of the symptoms and comorbid conditions discussed earlier, management recommendations can be found in other sections of the NCCN Guidelines for Survivorship (available at NCCN.org). Pharmacologic interventions and/or referrals may be appropriate.

Survivor/Family Education and Counseling—Survivors need to understand their likely ability to work (as relates to cancer prognosis/outcomes and timing), consider their finances and personal/family needs, and be prepared to discuss potential work accommodations with their employers (see SWORK-3, page 682). Clinicians should help survivors identify goals with regard to working and barriers to achieving those goals. Guidance about expected duration/management of symptoms or comorbidities limiting employment should be provided. Survivors should be encouraged to review their employer's human resources (HR) policies, and be provided with community-based, national, and online career counseling resources that can help them understand options and communicate with their employers (see SURV-B page 2 of 5, page 679).

Referrals—Financial counselors, patient navigators, and social workers, when available, can offer a personalized approach to care and help navigate the complex resources available.[51,60] They can use patient-centered instruments to measure financial toxicity, provide appropriate counseling, address social determinants of health in underserved groups, mobilize resources available in the community, and help with concerns such as parking assistance, copayments, and costs of care.[11,60] Other referrals may include vocational/occupational rehabilitation specialists; physical or occupational therapists; and neuropsychology evaluation (see SWORK-3, page 682).

Conclusions

Employment difficulties for cancer survivors can include unemployment, underemployment, employment instability, absenteeism, presenteeism, decreased work productivity, and decreased worker well-being. Certain populations are at increased risk for adverse effects on employment after a cancer diagnosis, and these problems can result in financial toxicity/distress, loss of medical insurance and access to affordable medical care, psychologic distress, and interruptions in cancer treatment. Although evidence supporting specific interventions for improving employment outcomes in cancer survivors are limited, the NCCN Survivorship Panel has outlined a framework to aid clinicians in addressing work-related concerns of survivors after active cancer treatment or survivors living chronically with cancer, with the goal of improving work outcomes in cancer survivors.

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Disclosure of Relevant Financial Relationships

The NCCN staff listed below discloses no relevant financial relationships:

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Individuals Who Provided Content Development and/or Authorship Assistance:

To view all of the conflicts of interest for the NCCN Guidelines panel, go to NCCN.org/disclosures/guidelinepanellisting.aspx.

Crystal S. Denlinger, MD' Panel Chair, has disclosed serving as a scientific advisor for BeiGene, Bristol-Myers Squibb Company, Exelixis Inc., Merck & Co., Inc., and Zymeworks, and receiving honoraria from Eli Lilly and Company and Taiho Parmaceuticals Co., Ltd.

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Melissa Hudson, MD, Panel Member, has disclosed no relevant financial relationships.

Lindsay Peterson, MD, Panel Member, has disclosed no relevant financial relationships.

Lidia Schapira, MD, Panel Member, has disclosed no relevant financial relationships.

Karen L. Syrjala, PhD, Panel Member, has disclosed no relevant financial relationships.

Amye Tevaarwerk, MD, Panel Member, has disclosed no relevant financial relationships.

Nicole R. McMillian, MS, CHES, Guidelines Coordinator, NCCN, has disclosed no relevant financial relationships.

Deborah A. Freedman-Cass, PhD, Manager, Licensed Clinical Content, NCCN, has disclosed no relevant financial relationships.

NCCN CATEGORIES OF EVIDENCE AND CONSENSUS

Category 1:

Based upon high-level evidence, there is uniform NCCN consensus that the intervention is appropriate.

Category 2A:

Based upon lower-level evidence, there is uniform NCCN consensus that the intervention is appropriate.

Category 2B:

Based upon lower-level evidence, there is NCCN consensus that the intervention is appropriate.

Category 3:

Based upon any level of evidence, there is major NCCN disagreement that the intervention is appropriate.

All recommendations are category 2A unless otherwise noted.

Clinical trials:

NCCN believes that the best management of any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.

PLEASE NOTE

The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) are a statement of evidence and consensus of the authors regarding their views of currently accepted approaches to treatment. **The NCCN Guidelines Insights highlight important changes in the NCCN Guidelines recommendations from previous versions. Colored markings in the algorithm show changes and the discussion aims to further the understanding of these changes by summarizing salient portions of the panel's discussion, including the literature reviewed.**

The NCCN Guidelines Insights do not represent the full NCCN Guidelines; further, the National Comprehensive Cancer Network® (NCCN®) makes no representations or warranties of any kind regarding their content, use, or application of the NCCN Guidelines and NCCN Guidelines Insights and disclaims any responsibility for their application or use in any way.

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SURVIVORSHIP ASSESSMENT (Patient Version)
Please answer the following questions:

Survivorship Concerns	Survivorship Care Survey
Cardiac Health	1. Do you have shortness of breath or chest pain after physical activities (eg, climbing stairs) or exercise? Yes/No 2. Do you have shortness of breath when lying flat, wake up at night needing to get air, or have persistent leg swelling? Yes/No
Anxiety, Depression, Trauma, and Distress	3. In the past two weeks, have you been bothered more than half the days by little interest or pleasure in doing things? Yes/No 4. In the past two weeks, have you been bothered more than half the days by feeling down, depressed, or hopeless? Yes/No 5. Has stress, worry, or being nervous, tense, or irritable interfered with your life? Yes/No
Cognitive Function	6. Do you have difficulties with multitasking or paying attention? Yes/No 7. Do you have difficulties with remembering things? Yes/No 8. Does your thinking seem slow? Yes/No
Fatigue	9. Do you feel persistent fatigue despite a good night's sleep? Yes/No 10. Does fatigue interfere with your usual activities? Yes/No 11. How would you rate your fatigue on a scale of 0 (none) to 10 (extreme) over the past week? 0–10
Lymphedema	12. Since your cancer treatment, have you had any swelling, fatigue, heaviness, or fullness on the same side as your treatment that has not gone away? Yes/No
Hormone-Related Symptoms	13. Have you been bothered by hot flashes/night sweats? Yes/No 14. Have you been bothered by other hormone-related symptoms (ex, vaginal dryness, incontinence)? Yes/No
Pain	15. Are you having any pain? Yes/No 16. How would you rate your pain on a scale of 0 (none) to 10 (extreme) over the past month? 0–10
Sexual Function	17. Do you have any concerns regarding your sexual function, sexual activity, sexual relationships, or sex life? Yes/No 18. Are these concerns causing you distress? Yes/No
Sleep Disorder	19. Are you having problems falling asleep, staying asleep, or waking up too early? Yes/No 20. Are you experiencing excessive sleepiness (ie, sleepiness or falling asleep in inappropriate situations or sleeping more during a 24-hour period than in the past)? Yes/No 21. Have you been told that you snore frequently or that you stop breathing during sleep? Yes/No
Healthy Lifestyle	22. Do you engage in regular physical activity or exercise, such as brisk walking, jogging, weight/resistance training, bicycling, swimming, etc.? Yes/No ▸ 22a. If you answered "Yes," how often? 23. Excluding white potatoes, do you eat at least 2½ cups of fruits and/or vegetables each day? Yes/No 24. Do you have concerns about your weight? Yes/No 25. Do you take vitamins or other supplements? Yes/No
Immunizations and Infections	26. Have you received your flu vaccine this flu season? Yes/No 27. Are you up to date on your vaccines? Yes/No/Don't know
Employment/ Return to Work	28. Do you have concerns about how cancer and/or cancer therapy has affected your ability to work? YES/NO

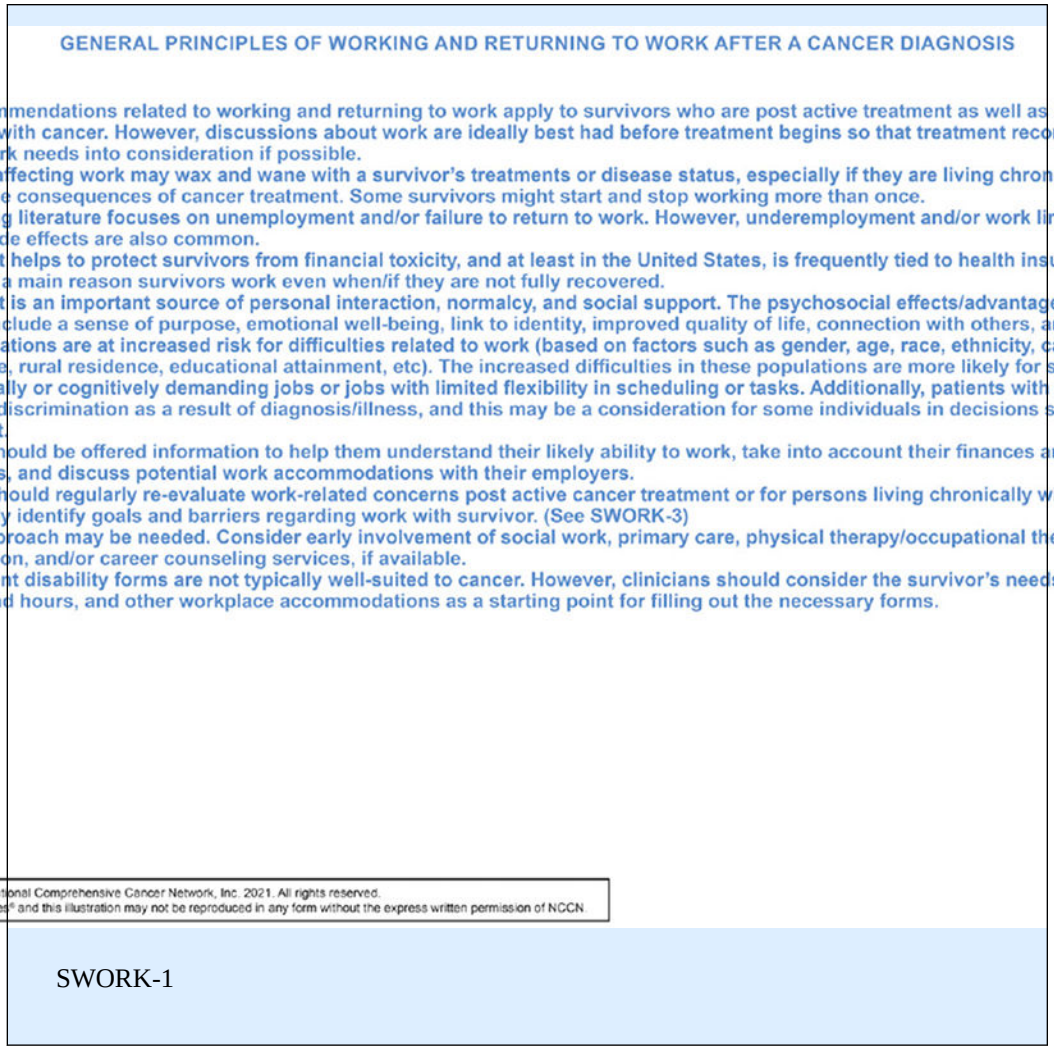
SURV-A

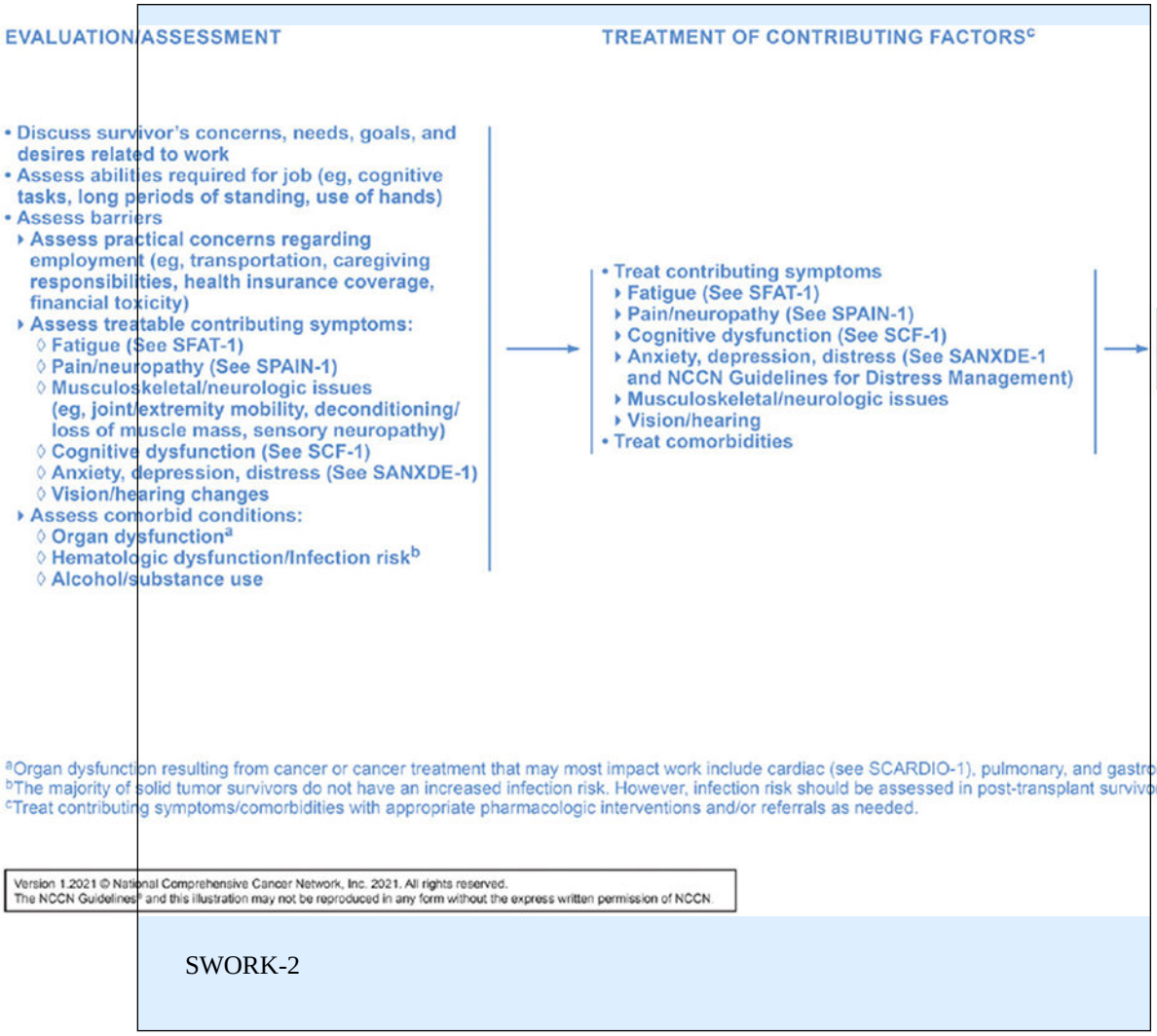
SURVIVORSHIP RESOURCES FOR HEALTH CARE PROFESSIONALS AND PATIENTS[a]

Other Survivorship Guidelines	
Children's Oncology Group: Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers	http://www.survivorshipguidelines.org/
Survivorship Care Planning	
ASCO Cancer Treatment Summaries	http://www.cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-and-survivorship-care-plans
Integrative Therapies	
Memorial Sloan Kettering Cancer Center's Herbs website	https://www.mskcc.org/cancer-care/treatments/symptom-management/integrative-medicine/herbs
National Center for Complementary and Integrative Resources for Health Care Providers	https://nccih.nih.gov/health/providers
Legal and Employment Issues	
Americans with Disabilities Act	www.ada.gov
The ADA National Network	https://adata.org
ASCO Cancer.net: Working When You Have Cancer: An Expert Q&A	https://www.cancer.net/blog/2018-12/working-when-you-have-cancer-expert-qa
Cancer and Careers: Patient information about working and dealing with cancer	http://www.cancerandcareers.org/en
Cancer Legal Resource Center	https://thedrlc.org/cancer/
Job Accommodation Network (JAN)	www.askjan.org
National Cancer Institute: Going Back to Work	https://www.cancer.gov/about-cancer/coping/day-to-day/back-to-work
National Coalition for Cancer Survivorship (NCCS) Employment Rights • "Employment Rights, "Working It Out" • "What Cancer Survivors Need To Know About Health Insurance"	http://www.canceradvocacy.org/resources/employment-rights/ https://canceradvocacy.org/wp-content/uploads/Working_It_Out.pdf https://canceradvocacy.org/wp-content/uploads/2013/01/Health-Insurance.pdf
National Cancer Legal Services Network (NCLSN)	www.nclsn.org
ACS: • Understanding Health Insurance • Returning to Work After Cancer Treatment	https://www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance.html https://www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-financial-and-legal-matters/working-during-and-after-treatment/returning-to-work-after-cancer-treatment.html
Social Security Administration	https://www.ssa.gov/disability

[a]There are many smart phone/tablet/mobile device apps, web-based programs, DVDs, and TV programs available to help survivors with various aspects of health care and wellness.

SURV-B





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