



# Cancer Survivorship Challenges and Opportunities for Employers

November 2020

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# Introduction

**N**ortheast Business Group on Health (NEBGH) has previously released guidance to help employers deliver high-value cancer care to employees and family members.<sup>1</sup> But a cancer diagnosis and treatment together comprise just one part of the patient journey. **What happens when people move beyond active treatment to survivorship?**

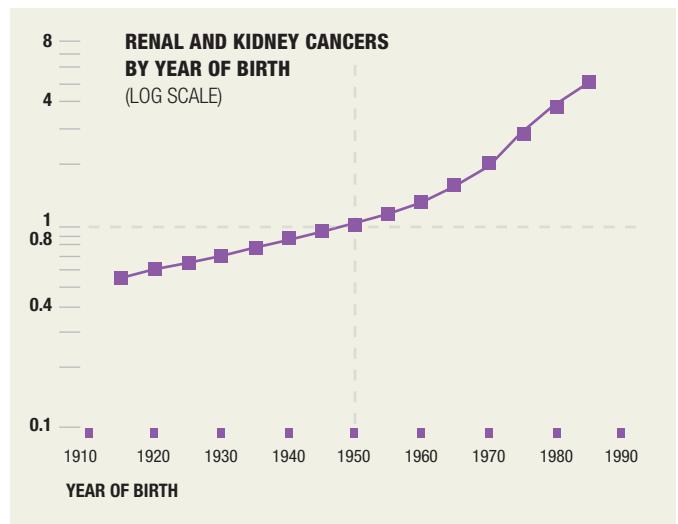
This guide is a product of literature reviews, interviews with experts and cancer survivors, and conversations with employers. We also collaborated with our partner in our work on survivorship, CancerCare. **It is designed to provide you with information on the challenges and opportunities associated with cancer survivorship and practical guidance on creating a workplace that supports people living with cancer and is productive for all.** Furthermore, we hope our efforts lead to additional exploration of this important topic, including ways of addressing critical gaps in survivorship understanding and care, by physicians and other healthcare stakeholders.

<sup>1</sup> <https://online.flippingbook.com/view/654153/>

# Background

Cancer is a relatively common disease in the U.S. Approximately 39.5% of men and women will be diagnosed with cancer at some point during their lifetime (based on 2015-2017 data).<sup>2</sup>

Cancer also impacts millennials, who make up the largest generation in the U.S. workforce. Year after year, the rate of increase for developing six obesity-linked cancers (kidney, pancreas, gallbladder, endometrium, colon/rectum and multiple myeloma) has been faster in younger adults than in those older than age 50. The youngest groups (ages 25 to 34) had the fastest increase for those six cancers.<sup>3</sup>

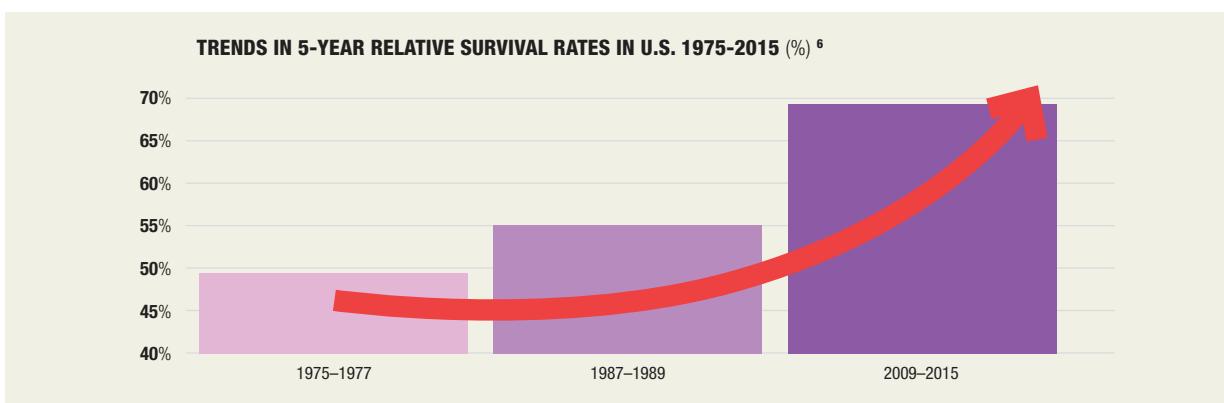
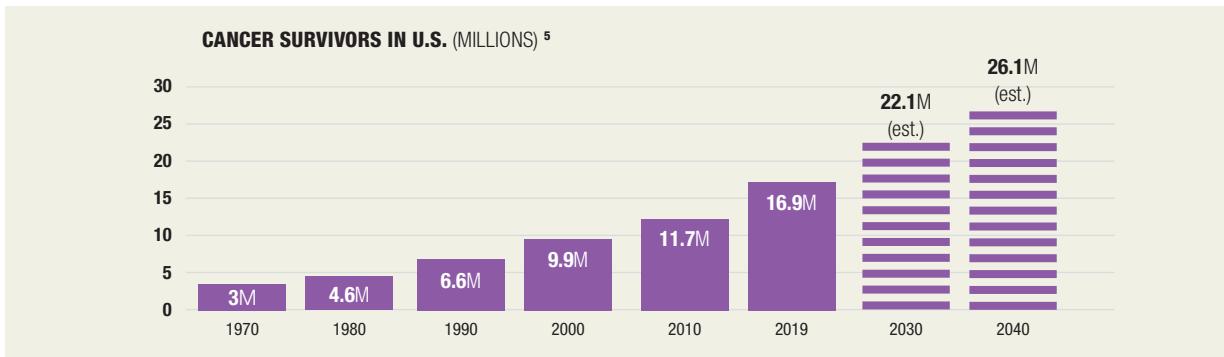


2 <https://seer.cancer.gov/statfacts/html/all.html>

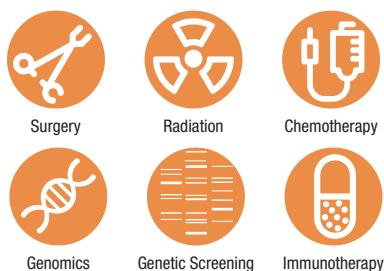
3 <https://www.cancer.org/latest-news/study-millennials-increased-risk-for-some-obesity-linked-cancers.html>

## At the same time, the number of cancer survivors is increasing.

It has been estimated that by 2040, the number of cancer survivors in the U.S. will increase to 26.1 million.<sup>4</sup>



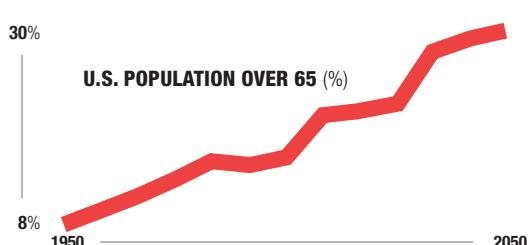
## The number of cancer survivors in the U.S. continues to increase due to a combination of factors.



Better treatments that help people live longer



Improvements in early detection



A growing aging population<sup>7</sup>—age is still a factor despite the growing incidence of cancer among younger people.<sup>8</sup>

## As cancer survivorship increases, it is vital for employers to understand the needs of this growing portion of their workforce.

4 <https://cancercontrol.cancer.gov/ocs/statistics/index.html>

5 <http://valueofinnovation.org/a-world-free-from-cancer/>

6 <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2020/cancer-facts-and-figures-2020.pdf>

7 <https://acsjournals.onlinelibrary.wiley.com/doi/10.3322/caac.21565>

8 [https://commons.wikimedia.org/wiki/File:Percentage\\_of\\_US\\_Population\\_Over\\_Age\\_65\\_1950-2050.png](https://commons.wikimedia.org/wiki/File:Percentage_of_US_Population_Over_Age_65_1950-2050.png)

# What is Cancer Survivorship?

**T**his question is fairly complex as there are many different definitions. For some, the term refers to anyone who has been diagnosed with cancer, regardless of whether they are currently or have ever been in treatment. Others consider a cancer survivor to be someone who has completed active treatment and is free of any signs of disease. Still others include family members and caregivers.

Varied definitions arise in part because cancer is not simply a linear journey from diagnosis to cure. Cancer can be a chronic condition controlled through ongoing treatment instead of a one-time event, and people can also oscillate between remission (i.e., no evidence of disease) and recurrence (i.e., the same or a different cancer comes back after a period of time).

**“**If we use the term ‘cancer survivor,’ it’s important to define it as being inclusive of all people. Some people say ‘I’m not a survivor; I’m a thriver.’ Others say ‘enough with the labels, just don’t call me anything at all.’ You won’t be able to find a term that everyone is going to embrace. It’s just important to be inclusive. **”**

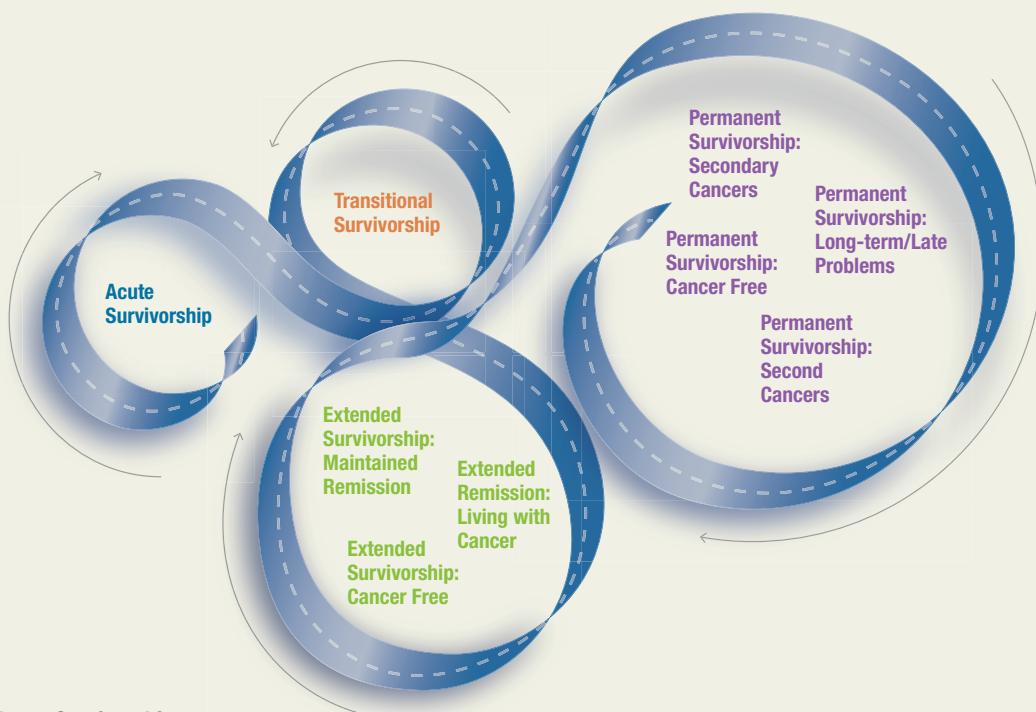
Catherine Alfano, Ph.D., Vice President, Cancer Care Management and Research,  
Northwell Health Cancer Institute

**National Cancer Survivors Day takes place each year on the first Sunday in June.<sup>9</sup>**

**“ The cancer experience doesn't end on the last day of active treatment. Patients report that people will say 'Yay, that's great! You finished; you beat it!' But often that's not how survivors feel or what their experience is. They're entering into a period of recovery that could take a long time for their bodies, their psyches and their experience. That's why some people balk at the survivor term because what does that even mean? Patients can think 'I will have to go in for screenings for the rest of my life. When can I say I'm a survivor?' The risk and fear of recurrence remains. ”**

Kristie Redfield, Clinical Social Worker, Memorial Sloan Kettering Cancer Center

To acknowledge the complex nature of cancer survivorship, Dr. Fitzhugh Mullan, a leader of the survivorship movement, developed a nuanced definition that consists of three "seasons" — acute, extended and permanent.<sup>10</sup> Since then, Dr. Mullan's work has been revised by Dr. Kenneth Miller, a medical oncologist and an oncology director, and now includes an additional season: transitional.<sup>11</sup>



### Seasons of Survivorship<sup>12,13</sup>

#### Acute Survivorship

The period of time during which a person is diagnosed and treated for cancer.

#### Transitional Survivorship

The period immediately after active treatment. Survivors may feel a mix of emotions including joy and celebration, but may also feel depressed or isolated. This period encompasses changes in medical and social support as well as challenges as someone transitions to a new normal.

#### Extended Survivorship

Several years after active treatment is complete but during which survivors continue follow-up care with observation and surveillance. This period includes people who are cancer free (i.e., treatment-free remission); those with

maintained remission (i.e., staying cancer free due to ongoing therapy); and those living with cancer as a chronic disease that requires continuing treatment.

#### Permanent (Long-Term) Survivorship

An extended period of time has passed since the last treatment. Long-term survivors are a varied group that includes those who are cancer free and asymptomatic; are cancer free but with long-term/late problems (such as fatigue or depression); develop new cancers (unrelated to earlier treatment); or have secondary cancers (related to earlier treatment).

#### End of Life

Part of cancer survivorship that can happen for acute survivors if the cancer progresses despite treatment, after a survivor is living with cancer as a chronic disease, after relapse from extended survivorship, or after some period as a permanent survivor.<sup>14</sup>

10 <https://www.canceradvocacy.org/wp-content/uploads/2013/01/Seasons-of-Survival.pdf>

11 [https://journals.lww.com/journalppo/Abstract/2008/11000/Seasons\\_of\\_Survivorship\\_Revised.5.aspx](https://journals.lww.com/journalppo/Abstract/2008/11000/Seasons_of_Survivorship_Revised.5.aspx)

12 <http://www.lifebridgehealth.org/CancerInst/CancerSurvivorship.aspx>

13 [https://journals.lww.com/journalppo/Abstract/2008/11000/Seasons\\_of\\_Survivorship\\_Revised.5.aspx](https://journals.lww.com/journalppo/Abstract/2008/11000/Seasons_of_Survivorship_Revised.5.aspx)

14 <http://oncpracticemanagement.com/issues/2012/february-2012-vol-2-no-1/269-seasons-of-survival>

# Why Cancer Survivorship Matters to Employers

“ When it comes to cancer, our goal is to give employees, family members and caregivers the most support we can, to help them navigate everything from prevention and early detection to treatment decisions and emotional health. We help find the best care as early as possible, and want to provide peace of mind so they can focus on their health needs and their family. We know the journey doesn't end when treatment ends; to be a cancer survivor includes dealing with complex physical, emotional and financial fallout as well as recurrence and the fear of recurrence. Finding ways of supporting those touched by cancer is a priority for us. ”

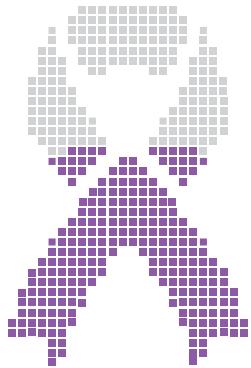
Michelle Martin, Vice President, Total Reward Experience, ViacomCBS

Employers need to recognize the strong linkage between cancer survivorship and work, the place where many people spend most of their waking hours. Nearly half of all cancer diagnoses (46.1%) are made in adults between the ages of 20 and 64 — prime employment years.<sup>15</sup> While some people are unable to work due to treatment or the effects of treatment, many are able to continue to work or to return to work after some period.

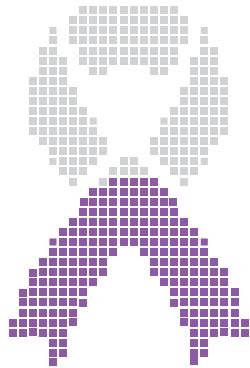
15 <https://www.cancer.gov/about-cancer/causes-prevention/risk/age>

**In fact, most cancer survivors are eager to continue to work or return to work as work provides a coping mechanism, enables a sense of purpose and motivation, boosts self-confidence, fosters social support and aids in financial stability.**

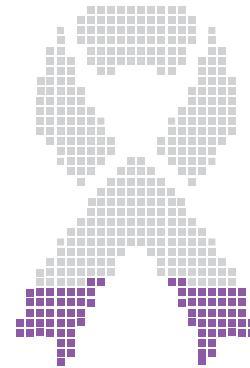
- A 2010 Livestrong survey found that 98% of cancer survivors experienced the physical, emotional and practical concerns of post-treatment survivorship. However, not everyone received help:<sup>16</sup>



Only 58% of those with **physical** concerns received help.



Only 50% of those who experienced **emotional** concerns received help.



Only 20% of those with **practical** concerns received help.

- A 2019 Cancer + Careers survey found that 59% of workers are not confident that management knows how to support employees with serious and/or chronic conditions.<sup>17</sup>

**Cancer survivors face challenges and need their employer's help, support, resources and accommodations.** Employers can answer cancer survivor questions such as:

- How do I balance work and treatment?
- What are my employer's policies?
- What are my legal rights?
- What do other people do in this situation?

**“**Don't make assumptions! Our research indicates that from a financial, emotional and practical perspective, being able to work during cancer treatment is extremely important to people. Don't assume they won't be working. Don't assume they'll be away for a long time. Don't assume they aren't capable of performing their work. **”**

Patricia Goldsmith, CEO, CancerCare

16 [https://www.livestrong.org/sites/default/files/what-we-do/reports/LSSurvivorSurveyReport\\_final.pdf](https://www.livestrong.org/sites/default/files/what-we-do/reports/LSSurvivorSurveyReport_final.pdf)

17 <https://www.cancerandcareers.org/en/at-work/employers-managers/workplace-survey-2019>

**“ Oncologists used to tell people ‘you need to rest and take time’ but now they recognize that work is generally the source of social support and health insurance. We don’t want to withdraw this support if we don’t need to. Work can also provide a sense of normalcy. If an employer can provide accommodations and help someone maintain their involvement in the workforce or enable the person to take a leave and come back, it’s better for the survivor. It’s also better for the employer because they’ve invested in that employee — better not to lose them and have to hire someone else. ”**

Catherine Alfano, Ph.D., Vice President, Cancer Care Management and Research, Northwell Health Cancer Institute

**The benefits of cancer survivors continuing to work or returning to work don’t accrue only to them. There are financial and productivity benefits for employers that include a decrease in turnover costs, which can be high.** In addition, it can be costly to lose the expertise, contacts and customer relationships employees have built.<sup>18</sup> Cancer survivors generally have higher annual medical costs than employees without cancer because of ongoing monitoring as well as the side effects of treatment or longer-term effects of the disease itself. Supporting survivors and their wellbeing at work enhances the value of these added healthcare expenditures.<sup>19</sup>

**“ If I were an employer, I would really spend time on this. There’s a big mental health aspect. The burden of cancer and everything that goes with it is important to understand, whether the employee has cancer or they’re supporting someone in the family with cancer. You want to support your employee, but you also have an investment in that employee so you need to be concerned about productivity issues. ”**

Ted Okun, Executive Director, Community Oncology Alliance

18 <https://www.benefitnews.com/opinion/how-employers-can-support-employees-during-cancer-treatment>

19 <https://www.benefitnews.com/news/how-to-build-an-effective-workplace-cancer-support-program>

# Survivorship Challenges and How Employers Can Help



**E**very cancer survivor has a unique journey, but we've identified six main categories of the challenges they may face.

Many survivors may not face all of these challenges; many say they also have experiences and life changes that turn out to be positive for themselves and those around them.

Exhibit A, page 32, contains a summary of the survivorship challenges described here.

*Throughout this section, all of the resources highlighted in green are detailed in Exhibit C on page 38.*



# Physical Health

## Challenges

- Determining **where to receive follow-up care** (oncologist, PCP or a combination). This decision depends on several factors such as type and stage of the cancer, treatment side effects, health insurance rules and personal preferences. Despite the importance of PCPs for overall health, some survivors are reluctant to leave the care of their oncologist.
- Ensuring a **smooth transition** from the oncology team to the PCP, when appropriate.
- Managing **side effects** that occur while receiving treatment, **long-term side effects** that linger beyond treatment, and **late effects** that develop months or even years post treatment.
  - Examples of side effects and long-term side effects include fatigue, fertility issues, hair loss, pain, memory problems and sleep issues. A more extensive list from the National Cancer Institute can be found here:  
<https://www.cancer.gov/about-cancer/treatment/side-effects>.
  - Examples of late effects include bone loss, brain changes, heart problems, hearing loss and joint changes. A more extensive list from the National Cancer Institute can be found here:  
<https://www.cancer.gov/about-cancer/coping/survivorship/late-effects#joint-changes>
- Managing being **immunocompromised** as a result of cancer or cancer treatment (i.e., having a weakened immune system to fight infections and other diseases).
- Needing care for **comorbidities** such as diabetes, hypertension or cardiovascular disease that are common in people with cancer.
- Monitoring for a **recurrence** of cancer after treatment. Risk of recurrence depends on factors such as type of cancer, stage of cancer at diagnosis, treatment received, passage of time since treatment, genetic factors and/or environmental exposure.<sup>20</sup>
- Monitoring for **second cancers**, which would be a completely new and different type of cancer than the first one. Some people who have had cancer are at a higher risk for developing a second cancer as a result of prior cancer treatment, environmental exposures and/or genetic factors.<sup>21</sup>

20 <https://www.mskcc.org/experience/living-beyond-cancer/resources-survivors>

21 <https://www.mskcc.org/experience/living-beyond-cancer/resources-survivors>

“

Coordinating a person's ongoing needs during and after cancer is something we don't do very well in the U.S. When a person is diagnosed with cancer, oncology takes over their care and the [primary care physician] is left not really knowing what's going on and not able to manage the patient's other issues. And so those issues aren't getting managed well during oncology treatment. Getting people the healthcare they need is a big problem. When patients switch into post-treatment and survivorship, it's 'oh well, we'll transition you into primary care,' but we know PCPs aren't very knowledgeable on what they need to look out for in terms of chronic and late effects of cancer treatment. It's a big gap. ”

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Catherine Alfano, Ph.D., Vice President, Cancer Care Management and Research, Northwell Health Cancer Institute

“

It's old thinking to transition someone out of primary care into oncology and then back to their PCP. It's not necessarily the best path. New models are being built that coordinate these two components of care, and they look different depending on where in the country they're springing up. Some integrate primary care with ongoing cancer care and others have PCPs managing comorbid conditions but coordinating that with post-treatment cancer follow-up. We can't leave coordination of care to the patient and their family. It's too much to put on them. ”

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Catherine Alfano, Ph.D., Vice President, Cancer Care Management and Research, Northwell Health Cancer Institute

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Unfortunately, I see more gaps than you can imagine. We live in a medical system that doesn't engender coordination. If PCPs are able to follow a patient, they will. You may see this happen within an ACO [accountable care organization] or a medical system, but how good the coordination is between oncology and a PCP in terms of hand-off is really on a local or regional basis. You would think coordination would be best in an integrated system where the hospital has bought up both PCPs and specialty networks, but unfortunately this is not always the situation. ”

”

Ted Okun, Executive Director, Community Oncology Alliance

## How Employers Can Help

- Provide cancer survivors with the resources and education to empower them to take ownership of their survivorship care.

**Exhibit B, page 34, contains a list of questions your employees should ask their oncologist/care team once they finish active treatment.**

- *By asking questions and obtaining information, survivors can become more informed about what treatment they received and what their **survivorship care plan** looks like. This information can also be shared with their PCP, who may not have been involved in parts of their cancer treatment. The **survivorship care plan** is a critically important part of survivorship care — a record of a patient's cancer and treatment history as well as any checkups or follow-up tests they need in the future. It may also list possible long-term effects of treatments and ideas for staying healthy.*
- *There are also mobile apps such as **Cancer.Net Mobile**, **CancerAid** and **Living with Cancer Support** that organize and track health information. (See Exhibit C, page 36, in the Appendix for more details.)*

“

Once someone completes treatment, it's regarded by many in the general public as an event to celebrate. Even in some radiation and chemo clinics, a bell is rung or an announcement might be made to signify or celebrate the completion of treatment for an individual. But the reality is that while some patients are pleased to hear they're finished, others are not pleased; they may be overwhelmed, terrified and sometimes confused. One client explained her confusion in this way: 'I was so glad not to have the side effects from chemo and get my energy, appetite and taste back, but then I felt like now the cancer is going to win because I am not in treatment.' Another said when he's in treatment, he feels like he's fighting the cancer, but when he's not, he feels like the cancer is winning.

Completing treatment means entering another phase of the cancer experience, which is the period of waiting. Has the treatment worked? Was I cured or just stabilized? Will or when will it come back? If I learn that treatment has not worked, will there be another treatment I can try? As one client told me, 'waiting is the worst part of cancer!'

My own cancer recurred every year for five years, and now I haven't had it for 3 1/2 years. But I can tell you that still every single cough, headache, hiccup and hangnail I experience — to me, it's cancer until proven otherwise. ”

Bill Goeren, Director of Clinical Programs, CancerCare; oncology social worker and cancer survivor

## How Physicians Can Help

“

**Avoiding or reducing gaps in care means making sure people who have finalized their treatment and are ready to transition back to their PCP understand when they should be seeking advice or a visit from their oncologist vs. their PCP. Guidance is key to this, and guidance needs to come from the oncologist on follow-up, surveillance and issues or ‘symptoms such as X, Y or Z.’ And it needs to come from the PCP: ‘Come see me every six months or every year or whatever, and if you experience X, Y or Z, please reach out to your oncologist.’ The PCP should have a discharge summary and survivorship care plan sent by the oncologist, which becomes part of the patient’s medical record.**”

”

Patricia Goldsmith, CEO, CancerCare

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**You have to give patients a chance to talk. One recent study showed that clinicians interrupted patients after a median of 11 seconds. If I don’t give you a chance to talk to me and tell me what your experiences and wants and needs are, I won’t know that you want to get back to work. Payment models need to encourage this type of discussion. One of the major roadblocks to success is failure to communicate. It’s all about time. I can’t have my hand on the door knob ready to leave. I can’t have my back to you when I’m talking, I can’t have a screen in front of my face as we are talking. We need to give clinicians the resources to focus on the patient instead of navigating through multiple computer screens.**

**Gaps in care may happen when patients are transitioning out of oncology-directed treatment without adequate discharge planning. Discharge planning should begin before admission. Plan it all ahead because you won’t be able to anticipate everything in the moment. A pharmacist should be on the team and a behavioral healthcare specialist too; it’s not just the oncologist and the PCP.**

**And the team is not just people with medical training. It’s the family and caregivers too. We aren’t talking about a one-and-done gall bladder operation. We are talking about how this might impact others in the family, including how it might impact them financially if I can’t work or how it might affect my significant other if they have to take care of me and help me get out of my chair for the next few weeks.**”

Sal Volpe, former President of the Richmond Medical Society  
and practicing primary care physician



# Mental and Social Health

## Challenges

- Living with **cognitive effects** such as fatigue, anxiety, depression, fear and PTSD.
- Handling **uncertainty** about the future including whether cancer will come back.
- Balancing the **guilt** of surviving with relief and feelings of accomplishment from survival.
- Having **low self-esteem or poor body image** due to treatments.
- Reflecting on one's experience, identifying changes that have taken place or that one would like to happen, and **re-prioritizing** elements in one's life.
- Embracing the idea of a **new normal** and finding a new stride.
- Feeling **isolated** and finding others to speak to who have gone through similar experiences.
- Having to **depend on other people**, even past acute treatment, when others expect the person to be the same as they were prior to being diagnosed with cancer.
- Having **Anxiety** about what their diagnosis may mean to family members if a cancer has a genetic risk.

## How Employers Can Help

- **Provide comprehensive mental health benefits** that include psychotherapy, medication, counseling and support groups. Benefits can encompass on-site, near-site and telehealth options. They can be offered through employee assistance programs (EAPs), external mental health vendors or health plans.
- **Offer a comprehensive EAP** that provides assessments, short-term counseling, referrals and follow-up services. EAPs can help in a number of ways including assisting people who are coping with stress, managing through loss/grief and supporting caregivers.
- **Offer an employee resource group (ERG) or cancer mentorship program for survivors to connect.**
  - ERGs can be organized across a range of interests and experiences including those for people diagnosed with cancer or who've lost someone to cancer and those for caregivers.
  - Pairing an employee recently diagnosed with cancer with an employee who has had a similar experience can be helpful, but programs like these must be voluntary because of personal health information confidentiality.
- **Educate survivors about external resources for receiving support, counseling and connections, many of which are free of charge.**

See Exhibit C, page 38, in Appendix for more details.

- Counseling, support groups and/or meetups include: **American Cancer Society, CancerCare, Cancer Hope Network, Cancer Support Community, SHARE, Stupid Cancer**
- Cancer social support mobile apps include: **Belong – Beating Cancer Together, CancerLife, CaringBridge, GRYT Health Cancer Community**
- Cancer social support websites include: **Cancer Survivors Network, Cancer Experience Registry, My Cancer Circle, MyLifeLine, SurvivorNet**

- **Educate survivors about external resources to boost self-confidence and help them feel their best.**

- **Free wigs:** Some insurance companies cover the cost of a wig when prescribed by a doctor as a “cranial prosthesis.” Those that can’t afford a wig can call the **American Cancer Society** (800-227-2345; some local offices offer wigs that have been donated) or **CancerCare** (800-813-HOPE; some branches have free wig clinics). **EBeauty Community**, a non-profit organization that supports women undergoing treatment for cancer, also offers a free wig exchange program.
- **Free beauty lessons:** Available through **Look Good Feel Better**, a non-profit organization focused on improving the quality of life and self-esteem of people undergoing cancer treatment.
- **Hair loss and mastectomy products:** Available through **TLC<sup>22</sup>**, a service of the **American Cancer Society**.

Some employers may have programs that cover the cost of products.

“ If you look at the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders, cancer diagnosis fits the criteria for trauma. Consider it a traumatic experience that is ongoing. Patients have to continue living in their bodies and have to keep returning to their treatment centers. It’s a normal response to an abnormal situation to have traumatic stress symptoms. It doesn’t mean they fit the criteria for post-traumatic stress disorder, but most patients have heightened anxiety, feelings of grief and sadness, and present with depression or symptoms that start to look like depression. They have ongoing fears of recurrence which are normal and tend to get better but don’t go away. ”

Kristie Redfield, Clinical Social Worker, Memorial Sloan Kettering Cancer Center

“ We had a longtime, well-known colleague receive a cancer diagnosis and pass away within a year. This person had a substantial presence, and for many at our organization, their death resulted in feeling a lot of loss. Employers can bring in counselors for lots of cancer support issues like this — EAP or other professionals who can provide resources and make sure colleagues have the support they need. I learned this first hand, and it was helpful in future situations as well. ”

Kathleen Harris, Consultant and former Global Benefits Head, Time Warner



# Wellness and Healthy Lifestyle

## Challenges

- Eating **healthier foods**.
- Finding safe and effective ways to engage in **physical activity**.
- **Stopping tobacco** use.
- **Limiting alcohol** consumption.
- **Managing stress**.
- Understanding how **lifestyle choices** impact side effects, comorbidities, recurrence, second cancers and overall physical and mental health.

## How Employers Can Help

- **Create an employee wellness program or enhance/continue your existing program.** Offerings may include:
  - *On-site and/or digital healthy eating programs*
  - *On-site and/or digital gyms and exercise classes*
  - *Weight management programs*
  - *Incentives to stop smoking*
  - *Stress management training*
  - *Meditation programs*
  - *Resilience programs*
  - *Sleep programs*
- **Include healthy living resources, ideas, and tips and tricks specifically for cancer survivors in your wellness portal.** These might include:
  - **Recipes for survivors:**  
<https://www.cancersupportcommunity.org/recipe-gallery>  
<https://www.mskcc.org/experience/patient-support/nutrition-cancer/recipes>
  - **Eating guides for survivors:**  
<https://www.cancer.org/healthy/eat-healthy-get-active/eat-healthy.html>  
<https://www.mskcc.org/cancer-care/patient-education/eating-well-during-and-after-your-treatment>
  - **Exercise programs for survivors:**  
<https://strengthforlifenyc.org/>  
<https://y4c.com/>
  - **Art programs for survivors:**  
<http://www.thecreativecenter.org/tcc/>
  - **University of California San Francisco's comprehensive wellness resources list** that addresses nutrition, exercise, managing stress, sleeping well, goal setting, sexual wellness, emotional wellness and spiritual wellness for cancer survivors:  
<http://cancer.ucsf.edu/support/survivorship-wellness/>.

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There's a real opportunity for employers to provide support and emphasize overall health — diet, exercise, lifestyle, etc. — for survivors and individuals in general. Survivors — both patients and caregivers — are not given as much information as they might need. Even in the most sophisticated cancer centers, time is limited and they're focused on their job: the cancer, the treatment and the treatment plan. ”

”

Patricia Goldsmith, CEO, CancerCare



## Family and Friends

### Challenges

- **Caregivers for cancer survivors, often family members and friends, are also greatly impacted by providing ongoing physical, emotional and practical support and care.** Effects may include fatigue, sleep problems, depression, anxiety, PTSD and fear of how caregiving may impact their other work. **According to one survey, cancer caregivers spend an average of 32.9 hours a week caring for a loved one, with 32% providing 41 or more hours of care a week. That's the equivalent of a full-time job.**<sup>23</sup>
- Preparing for the fact that cancer and/or treatments could potentially **impact fertility**.
- Having concerns that the **disease could be passed down** within one's family, if it is a genetic-related cancer.
- Dealing with **complex family dynamics** including talking with children about cancer.

### How Employers Can Help

- **Provide comprehensive benefits, programs and resources for caregivers.**<sup>24</sup>  
Examples:
  - Paid leave that can be used for caregiving
  - Flexible work schedules
  - ERGs
  - Counseling and support groups for caregivers
  - EAP with caregiver resources
  - Subsidized in-home back-up care
  - Digital caregiver tools
- **Provide comprehensive fertility benefits for cancer survivors and inform them of their covered options.** These might include: collecting and freezing sperm, eggs or embryos before treatment or protecting reproductive organs during treatment. **SaveMyFertility** offers information for cancer patients, survivors and their healthcare providers.

23 [https://www.caregiving.org/wp-content/uploads/2020/05/CancerCaregivingReport\\_FINAL\\_June-17-2016.pdf](https://www.caregiving.org/wp-content/uploads/2020/05/CancerCaregivingReport_FINAL_June-17-2016.pdf)

24 September 2017 NEBGH Supporting Caregivers in the Workplace Guide - <https://nebgh.org/initiative/caregiving/>

- **Provide coverage for genetic counseling services** if appropriate and recommended by physicians.
- **Encourage children of survivors to seek counseling, support groups and Exhibit.** For example, *CancerCare for Kids* provides help for children and adolescents with family members who have cancer or who have lost a loved one to cancer. Community organizations, religious groups and friends can provide valuable support as well.

**“** **Cancer care is changing to rely more on informal caregivers at home including spouses, family members and friends who provide care that used to be given in clinician offices. Employers should understand they have a role in supporting caregivers, some of whom are providing 10, 20 or more hours of care a week on top of a full-time job. Sometimes, as a patient gets better, the caregiver gets worse. They've been functioning at such a high level of stress that it's only when the person they're caring for starts to get better that they can begin to deal with the impact on themselves. **”****

Catherine Alfano, Ph.D., Vice President, Cancer Care Management and Research, Northwell Health Cancer Institute

**“** **Once active treatment for patients has stopped, caregivers may have traumatic stress symptoms that can be similar to those experienced by patients. There is pressure to go back to normal, but things seem anything but normal. Mental health coverage should be provided for caregivers as well as patients; this really needs to be recognized. **”****

Kristie Redfield, Clinical Social Worker, Memorial Sloan Kettering Cancer Center

**“** **Caregivers feel stressed and isolated, and too often they suffer in silence in the workplace. One of the things we plan to do is work with employers to develop caregiver support groups during lunch hours so people don't feel alone. In the early stages of cancer, caregivers may be more likely to talk with colleagues about a loved one's diagnosis before they know the full magnitude of what it takes to be a caregiver. But as responsibilities push on, there is that same fear that patients feel — fear of being passed over for a promotion or fear they won't be seen as productive. Employers can't say 'oh, go and take whatever time you need,' but they can show they want to be supportive. **”****

Patricia Goldsmith, CEO, CancerCare



# Finances

## Challenges

- **Getting and keeping health coverage.**
- **Understanding health coverage** and other relevant benefits.
- Finding **financial support**—cancer can be an expensive illness even with generous coverage and benefits.

## How Employers Can Help

- **Provide “cancer-friendly” benefits to employees and provide education on these benefits.<sup>25</sup>**
  - **Health coverage:** Affordable out-of-pocket maximum, tax deductible health and caregiving accounts, life insurance, long-term care insurance
  - **Disability:** Short-term disability pay, long-term disability coverage, paid time off, Family and Medical Leave Act leave, unpaid leave
  - **Work:** Support for returning to work including phased return to work, temporary and/or permanent job accommodations, job retraining
  - **Life:** Flexible work arrangements, caregiving support, EAP, well-being programs, external resources

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According to the National Business Group on Health and the National Comprehensive Care Network, employer-provided cancer benefits should include a medical benefit, a pharmacy plan, clinical support and condition management, short-term disability, family medical leave, an EAP and health improvement programs.<sup>26</sup> Benefits can also include care navigators and/or case managers to guide employees from diagnosis through treatment and back into the workplace.

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- **Provide survivors with resources and access to financial advice.**
  - Financial wellness vendors, financial counselors and/or financial advisors can disseminate expert advice.
  - **Cancer + Careers** offers advice on insurance issues for cancer survivors:  
<https://www.cancerandcareers.org/en/at-work/legal-and-financial/conquering-insurance-issues-and-problems>.
  - **Cancer + Careers** provides a list, and **CancerCare** provides a search tool, of organizations and programs that offer financial assistance for cancer survivors:  
<https://www.cancerandcareers.org/en/at-work/legal-and-financial/financial-assistance-for-those-in-need>  
<https://www.cancercare.org/helpinghand>

25 November 2019 NEBGH Delivering Value in Cancer Care: The Employer Perspective Guide - <https://nebgh.org/initiative/cancer/>

26 <https://www.shrm.org/hr-today/news/hr-magazine/0616/pages/how-to-support-employees-with-cancer.aspx>

**“Respecting privacy is the most important thing. Even though an employer wants to help, an employee may not want to talk about their surveillance post treatment. The employer pays for health insurance but the employee's journey is private. Employers need to respect this aspect of it at every level and not try to interject themselves. The employer needs to make sure employees are getting the best care by making sure they have rich benefits that apply to cancer care.”**

Donald Stangler, MD, Regional Vice President, Northeast and Chief Medical Officer, New York; UnitedHealthcare



## Work Challenges

- Balancing the **desire to work** for financial security and mental and social well-being against **possible difficulties** working due to side effects from cancer and treatment.
- Maintaining **attendance** with the need for follow-up appointments and care.
- Worrying about how one is **viewed and treated by colleagues and managers**.
- **Returning to work** if one was not working during active treatment, or transitioning back to full time after having been working part time.

**“I'm struck by the degree to which people want to continue to work while they're being treated for cancer — people who aren't cured and getting ongoing therapy. It's important for us to create an environment for them to continue to work, and we spend a lot of time talking about what is realistic for them. How to make accommodations so it's easier for them to work but also giving them a reality check of what they can and can't do and emphasizing the need to take it very slowly.”**

Medical director at a large investment bank

**“Someone made a good comment at one of the NEBGH cancer sessions: 'I would rather feel really ill for a few days than not myself for many, many days.' This can happen with ongoing treatment. Even though a survivor may seem to be feeling well, they may not be feeling 100%, and this can be hard for those around them to grasp because the survivor is present at work and the assumption is they must be feeling okay.”**

Kathleen Harris, Consultant and former Global Benefits Head, Time Warner

“

**We have a lot of clients who are concerned about how to be perceived as a productive employee when there might be limitations on their ability to work. They fear they'll be passed over for a promotion, that their co-workers will feel they're not carrying their weight. They struggle with how to communicate their needs for accommodations or time off to their managers.**”

”

Patricia Goldsmith, CEO, CancerCare

“

**We had someone who worked up until the Friday before the Saturday he died. Even though people had seen and struggled with the physical changes as his cancer progressed, the suddenness of him being gone was hard. People felt a lot of loss and it felt sudden even though they knew his cancer was terminal and had time to prepare themselves for the loss.**”

”

Kathleen Harris, Consultant and former Global Benefits Head, Time Warner

## How Employers Can Help

- **Stay updated and informed so you can be a useful resource and helpful support system for employees who are balancing survivorship with work.**
  - *In addition to this guide, sources of information include the American Cancer Society, American Society of Clinical Oncology, CancerCare, Cancer Support Community, Livestrong Foundation, National Coalition for Cancer Survivorship, SHARE, Stupid Cancer and Cancer + Careers.*
  - **Review and have a thorough understanding of employment laws and agencies.** (Exhibit D, page 40, contains a summary of employment laws and agencies.)
  - **Review and have a thorough understanding of your organization's policies, procedures and benefits related to cancer survivorship.** These may include medical and drug coverage, including cancer-specific programs such as a centers of excellence network, cancer/health navigator or advocacy programs, leave options, EAP, workplace accommodations, well-being programs and a list of community-based resources.<sup>27</sup> (Exhibit D, page 40, contains a summary of types of leave and workplace accommodations related to cancer survivorship.)
  - **Educate managers since they may have never supervised an employee who's been diagnosed with cancer.** Cancer + Careers has a Manager's Kit that contains information on what to expect when one of your employees has cancer as well as information on laws, work strategies, how to create a supportive work environment, and how to work with HR:  
[https://www.cancerandcareers.org/grid/publication/pdf/4e985ebef532f70001000054/publication\\_pdf.1578494615.Managers\\_Kit - 2019.10.23 - Final.pdf](https://www.cancerandcareers.org/grid/publication/pdf/4e985ebef532f70001000054/publication_pdf.1578494615.Managers_Kit - 2019.10.23 - Final.pdf)

27 <https://www.cancer.org/content/dam/cancer-org/online-documents/en/pdf/flyers/cancer-in-the-workplace-hr-tip-sheet.pdf>

- **Educate coworkers since they may have never worked with a colleague who's been diagnosed with cancer.** *Cancer + Careers* has an infographic on how one can help a coworker with cancer:  
<https://www.cancerandcareers.org/en/at-work/coworkers/helping-a-coworker-with-cancer>
- **Create formalized processes for what to do when employees report that they were diagnosed with a serious disease and/or report that they are returning to work after being out due to a serious disease such as cancer.**
  - **Educate employees on how to share news at work, if they so choose, about being diagnosed with a serious disease such as cancer.** It is up to the employee what information he or she wants to disclose about the diagnosis and treatment, and with whom the information can be shared within the organization.
  - **Formalize the steps that HR/benefits leaders and other managers should take if an employee decides to report that he or she has cancer or another serious disease,** including getting timely/relevant information to them such as benefits and policies, and determining if leave and/or workplace accommodations are needed and to what extent.
  - **Formalize the steps that HR/benefits leaders and other managers should take if an employee, who was out due to a serious disease such as cancer decides that he or she is able to return to work.** A formal return-to-work policy is necessary so everyone throughout the organization has a shared understanding.
    - Research shows that employers can support a successful return to work for survivors by showing emotional support, providing practical support, allowing sufficient sick leave, making a return-to-work plan with input from the employee, adjusting expectations regarding performance/work intensity, assessing workability (balance between work demands and capability), and showing appreciation (help employee feel they're wanted back).<sup>28</sup>
    - **Exhibit E, page 43, contains tips for cancer survivors returning to work after active treatment**

“

**Opening the door for discussion and showing flexibility is very important. Just to be able to have a flexible schedule that accommodates chemo or radiation is very meaningful to people. Cancer patients who feel supported by their employer — including in little ways — are repaid over and over in loyalty and gratitude. And colleagues see this and realize their employer cares about them. It has a big spillover effect.** ”

Patricia Goldsmith, CEO, CancerCare

28 <https://theconversation.com/how-employers-can-help-cancer-survivors-return-to-work-based-on-my-own-experience-128568>

**“**People are scared; they've been emotionally and physically traumatized by diagnosis and treatment. Many, especially those working, may attempt to minimize symptoms and side effects because they're concerned or even terrified they might lose their job, not get a promotion or have their position reduced. Many carry their families on their health insurance and will not consider not working because of the impact on their families of a loss of healthcare. I think it would be relieving and helpful for employers to designate a point person or peer that survivors can go to for whatever family, social and concrete issues or concerns they have when they're working or returning to work. **”**

Bill Goeren, Director of Clinical Programs, CancerCare;  
oncology social worker and cancer survivor

**“**I think employers should know about organizations like CancerCare and how we can provide support for education about cancer and needs like financial and emotional issues such as 'I don't know if the timing is right; I'm struggling with how to talk to my children about my cancer.' Referrals to credible sources are important and show caring on the part of employers. **”**

Patricia Goldsmith, CEO, CancerCare

**“**Many people don't know how to deal with a colleague who has cancer. Some feel uncomfortable and others think maybe it's best to act as if nothing has happened. This is difficult and complicated enough for the employee let alone an employer trying to provide assistance to managers. **”**

Donald Stangler, MD, Regional Vice President, Northeast; and Chief Medical Officer, New York; UnitedHealthcare

“ Employers need to be aware of the cognitive effects of cancer therapy — there's a lot of emerging science around this. 'Chemo brain' is a misnomer because it's not just chemo that causes this: radiation, immunotherapies, potentially, and the stress of going through treatment can all have an impact. Employers need to be thinking about the totality of what survivors might be dealing with including issues with attention, cognition and memory. Sometimes people just need help in the workplace to manage themselves. Admin support could be helpful, for example, because they aren't as on top of things as they usually are. This is common and needs some attention. ”

Catherine Alfano, Ph.D., Vice President, Cancer Care Management and Research, Northwell Health Cancer Institute

“ Our firm wraps its arms around its people who need help. When people return from challenging illnesses they're welcomed back, and managers and coworkers are extremely sensitive to their needs. The time that might be harder for them is six months later when people are still living with the ongoing consequences of their cancer and their treatment. The experience of coming back to work is still something that needs more innovation and solutions. ”

Medical director at a large investment bank

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I think it's a best practice to outsource leave administration. We have a structured program with a vendor who does a good job of coordinating the different types of leave available. People with a serious illness need to apply, and physicians have to submit information to get the ball rolling. Once processed, there are approved periods when people are out; they know they've done what they have to for a while, and they know when they need to provide new information.

Some people say our structured program is too rigid. I say it's always better for people to be informed. When people are told 'don't worry about it, we'll take care of you,' you aren't doing them any favors. You have to be clear. People are using up their sick time and potentially their vacation time to keep their paycheck whole. Being clear at the start means it doesn't have to be discussed over and over again. You have to recognize in the long run what will be helpful even though it might not seem helpful initially. People find it reassuring. There isn't a big question mark lurking in the background. ”

Sue Gilkey, Senior Benefits Manager, Associated Press



## Summary

**E**ncouraging statistics that show an increase in the number of people surviving with cancer don't reveal how survivors are faring — physically, mentally, socially or economically. Employers can play a key role in this experience. With more survivors active in the workforce today and in the future, the challenges and opportunities posed by cancer survivorship are important to understand and support.

CancerCare and NEBGH have initiated pilot projects that provide targeted support services to survivors returning to work during or after cancer treatment, or employees caring for someone with cancer, as well as training and providing resources to their employers on how best to support them. The two organizations involved in these pilots are ViacomCBS and the New York City Office of Labor Relations, which administers health benefits and related programs for New York City employees. Outcomes from these projects, expected in early 2021, will be shared as a follow-up to this guide.

**“**The City of New York is excited to partner with CancerCare and NEBGH to bring services to our workforce. While our staff are busy caring for all New Yorkers through their work, we want to support our staff to care for themselves and their families. We believe this pilot will provide important options for us. **”**

Claire Levitt, Deputy Commissioner, NYC Office of Labor Relations

**This guide has described the actions employers can take to best support survivors when it comes to physical health, mental and social health, wellness and healthy lifestyle, family and friends, finances and work. When thinking about survivors, employers should strive for a comprehensive approach that supports people across all of these areas, not just one.**



Exhibit F, page 44, contains a checklist that employers can use in developing a holistic and supportive strategy and plan.

# Cancer Survivorship and the COVID-19 Pandemic

**As this guide nears completion, the COVID-19 pandemic continues to rage across various parts of the country. Whether we continue to battle this particular health crisis or a different one in the future, considerations to keep in mind include:**

- Patients with cancer may be at greater risk of being immunocompromised and therefore more vulnerable to complications from COVID-19 depending on the type of cancer they have, the type of treatment, other health conditions and their age. The risk of being immunocompromised is typically highest during active cancer treatment.<sup>29</sup>
- During this pandemic, some patients have needed treatment and received it, some had treatment postponed, and some switched treatment (e.g., intravenous chemotherapy to oral chemotherapy). In addition, some clinical trials were postponed.<sup>30</sup> There are many factors to consider when making an important decision such as postponing cancer treatment to avoid a potential infection with COVID-19. Patients should talk with their treating oncologist about the risks of postponing treatment vs. the potential benefit of decreasing their infection risk.<sup>31</sup>
- Safety measures such as keeping social distance, mask-wearing, frequent and proper hand washing, avoiding large crowds, keeping surfaces clean and disinfected, and not touching one's face without a thorough hand-washing are all good strategies for anyone, but critical for cancer patients and survivors who may be immunocompromised.
- Changes in care delivery, including using telehealth for follow-up and surveillance appointments and for support groups, prioritization of care, and the separation of coronavirus-positive patients to specialized units have taken place.<sup>32</sup>
- Perhaps one of the most important things this pandemic has demonstrated for employers is that remote work is effective in many instances.

29 <https://www.cancer.net/blog/2020-04/common-questions-about-covid-19-and-cancer-answers-patients-and-survivors>

30 eHealthInitiative webinar - Executive Insight Discussion with J. Leonard Lichtenfeld, MD, MACP Deputy CMO, ACS

31 <https://www.cancer.net/blog/2020-04/common-questions-about-covid-19-and-cancer-answers-patients-and-survivors>

32 <http://www.valuebasedcancer.com/avbcc/covid-19-webcast-series/webcast-coverage/2542-comprehensive-cancer-care-systems>

“ The fear that we all have about COVID-19 is magnified greatly for cancer patients: fear about getting to medical appointments, fear about mass transit, fear about going into the grocery store to get supplies. We have a tool called My Cancer Circle that enables a patient to build his or her own community of friends, family and coworkers and post about whatever help they might need. ”

Patricia Goldsmith, CEO, CancerCare

“ Chemo impacts the immune system significantly, and six-foot distancing may not be adequate for someone who is immunosuppressed. Employers would have to allocate additional distancing or place survivors in a separate room, and they'd need to think about the ventilation system and infection control with surfaces. The goal is to reduce the risk of contact with a contaminated surface as much as possible. ”

Sal Volpe, former President of the Richmond Medical Society and practicing primary care physician

“ Cancer patients generally endure some sense of isolation, and COVID-19 has increased it. As offices re-open, cancer patients may need to stay home longer, but this in turn leads to more isolation. ”

Kristie Redfield, Clinical Social Worker, Memorial Sloan Kettering Cancer Center

# Appendix

## Exhibit A: Summary of Survivor Challenges



### Physical Health

- Determining where to receive **follow-up care** (oncologist, PCP or a combination).
- Ensuring a **smooth transition** from the oncology team to the PCP, when appropriate.
- Managing **side effects, long-term side effects** and **late effects**.
- Managing potentially having a **weakened immune system** to fight infections and other diseases.
- Needing care for **comorbidities** such as diabetes, hypertension or cardiovascular disease that are common in people with cancer.
- Monitoring for **recurrence**.
- Monitoring for **second cancers**.



### Mental and Social Health

- Living with **cognitive effects** such as fatigue, anxiety, depression, fear and PTSD.
- Handling **uncertainty** about the future including whether cancer will come back.
- Balancing the **guilt** of surviving with relief and feelings of accomplishment from survival.
- Having **low self-esteem or poor body image** due to treatments.
- Reflecting on one's experience, identifying changes that have taken place or that one would like to happen, and **re-prioritizing** elements in one's life.
- Embracing the idea of a **new normal** and finding a new stride.
- Feeling **isolated** and finding others to speak to who have gone through similar experiences.
- Having to **depend on other people**, even past acute treatment, when others may expect the survivor to be the same as they were prior to being diagnosed with cancer.
- Anxiety** about the genetic implications of a cancer diagnosis on children and family members.



## Wellness and Healthy Lifestyle

Eating **healthier foods**.

Finding safe and effective ways to engage in **physical activity**.

**Stopping tobacco** use.

**Limiting alcohol** consumption.

**Managing stress**.

Understanding how **lifestyle choices** impact side effects, comorbidities, recurrence, second cancers and overall physical and mental health.



## Family and Friends

Supporting **caregivers** of cancer survivors, often family members and friends, who may be struggling with fatigue, sleep problems, depression, anxiety and PTSD, as well as physical health issues such as diabetes, obesity and cardiovascular illness.

Preparing for the fact that cancer and/or treatments could potentially **impact fertility**.

Having concerns that the **disease could be passed down** within one's family, if it is a genetic-related cancer.

Dealing with **complex family dynamics** including talking with children about cancer.



## Finances

**Getting and keeping health coverage**.

**Understanding health coverage** and other relevant benefits.

Finding **financial support** — cancer can be an expensive illness even with generous coverage and benefits.



Balancing the desire **to work** for financial security and mental and social well-being against **possible difficulties** working due to side effects from cancer and treatment.

Maintaining **attendance** with the need for follow-up appointments and care.

Worrying about how one is **viewed and treated by colleagues and managers**.

**Returning to work** if one was not working during active treatment, or transitioning back to full time after having been working part time.

## Exhibit B: Survivor Pullout

### Questions To Ask Your Oncology Care Team Once Active Treatment is Complete<sup>33, 34, 35, 36</sup>

What will recovery from treatment look like (including a timeline)?

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What prescriptions and over-the-counter medications will I need?

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What are possible physical and mental treatment side effects, long-term side effects and late effects? What actions should I take when symptoms arise?

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What should I do to balance managing post-treatment care and comorbidities?

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What is the risk of recurrence? Are there signs/symptoms I should watch for? What should I do and who should I contact if I notice one of these symptoms?

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33 <https://www.canceradvocacy.org/resources/cancer-survivorship-checklist/>

34 <https://www.cancer.net/survivorship/follow-care-after-cancer-treatment/importance-follow-care>

35 <https://www.livestrong.org/we-can-help/healthy-living-after-treatment/your-survivorship-care-plan>

36 <https://www.cancer.gov/publications/patient-education/life-after-treatment.pdf>



Is there anything I can or should be doing to keep cancer from coming back?

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What screenings do I need and how often do I need it to check for recurrence/new cancers?

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What tests and procedures will I need to monitor changes in my health?

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What recommendations do you have to maintain a healthy lifestyle?

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Are there complementary medicine and/or rehabilitation options?

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What support group, counseling or advocacy groups are available?

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What financial help is available for post-treatment care?

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What resources exist for cancer survivors and their caregivers?

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What can I do to manage side effects that might impact my work?

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What types of changes at work do you recommend for my situation?

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How can I adjust my post-treatment care to make it easier to balance with work?

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Do I need to be referred to any specialists for follow-up care?

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## **Topics to Discuss with your Oncology Team:**

You have your own definition of quality of life and your own goals. Discuss these with your care team.

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Ask who will manage your follow-up cancer care and other medical care now that active treatment is over. Will this be your oncology team, PCP or both? You need guidance based on your personal circumstances.

If care will continue with your oncology team, ask how records will be shared so your PCP can stay updated.

If care will now be managed by your PCP, ask how the hand-off from oncology will occur, including ensuring that essential information and communication is shared in front of you and your family members.

If care will be managed by both your oncology team and PCP, ask how coordination will take place.

Some health systems offer survivorship centers or clinics that provide follow-up care once active cancer treatment is complete.

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Ask for a written survivorship care plan, which includes a treatment summary and a follow-up care plan, for your own records and to share with your PCP. A treatment summary includes items such as type of cancer with the date/stage at diagnosis, types of treatment received, complications experienced and other services used. A follow-up care plan includes items such as future schedule of visits, who will deliver follow-up care, tests that will be done, how to assess/treat side effects, and steps to adopt a healthy lifestyle.<sup>37</sup> *According to Trish Goldsmith, CancerCare CEO, it is vital not only to include the physical/mental care piece, but also the wellness/healthy lifestyle piece in the follow-up care plan.* Your oncology care team should provide you with a tailored plan and clearly explain it to you. In addition, standard templates exist for educational purposes on the websites of ASCO and Memorial Sloan Kettering:

<https://www.cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-and-survivorship-care-plans>

<https://www.mskcc.org/sites/default/files/node/3019/documents/summary-cancer-treatment-and-follow-plan.pdf>

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Schedule appointments that are needed, based on the care plan. Document these appointments and set up reminders.

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Bring a pre-prepared list of questions and concerns that you have to medical checkup appointments, whether at the oncologist, the PCP or another setting. At the appointment, take notes so you can remember answers to your questions and concerns.



37 [https://www.cancercare.org/publications/248-survivorship\\_care\\_plan\\_follow-up\\_care\\_and\\_returning\\_to\\_work](https://www.cancercare.org/publications/248-survivorship_care_plan_follow-up_care_and_returning_to_work)

## Exhibit C: Survivor and Employer Pullout

### Cancer and Cancer Survivorship Resources

Organization	Resource	Description
<b>Overall Cancer Support</b>		
American Cancer Society	<a href="https://www.cancer.org/">https://www.cancer.org/</a>	Helpline, live chat, publications, patient navigator program, rides to treatment (road to Recovery), lodging near treatment (Hope Lodge), and breast cancer support (Reach to Recovery).
	Tlc: <a href="https://www.tlcdirect.org/">https://www.tlcdirect.org/</a>	Website to purchase hair loss/masectomy products for cancer patients.
	Cancer Survivors Network: <a href="https://csn.cancer.org/">https://csn.cancer.org/</a>	Website to share experiences, practical tips and hope.
	Belong—Beating Cancer Together: <a href="https://belong.life/">https://belong.life/</a>	Social network mobile app for cancer patients.
American Society of Clinical Oncology	<a href="https://www.cancer.net/survivorship">https://www.cancer.net/survivorship</a>	Information, guides and resources on cancer survivorship.
	Cancer.Net Mobile: <a href="https://www.cancer.net/navigating-cancer-care/managing-your-care/cancernet-mobile">https://www.cancer.net/navigating-cancer-care/managing-your-care/cancernet-mobile</a>	Mobile app to record questions, log meds, track symptoms, keep track of appointments and other activities.
CancerCare	<a href="https://www.cancercare.org/">https://www.cancercare.org/</a>	Counseling and support groups, educational workshops, publications, financial assistance, and free wig and prostheses clinics for cancer patients, survivors, and caregivers.
	Helping Hand: <a href="https://www.cancercare.org/helpinghand">https://www.cancercare.org/helpinghand</a>	Online database to find organizations that provide financial or practical help to cancer survivors (Helping Hand).
	My Cancer Circle: <a href="https://mycancercircle.net/">https://mycancercircle.net/</a>	Website that offers a support community for caregivers.
	CancerCare for Kids: <a href="https://www.cancercare.org/forkids">https://www.cancercare.org/forkids</a>	Support services for children and adolescents affected by cancer.
Cancer Support Community	<a href="https://www.cancersupportcommunity.org/">https://www.cancersupportcommunity.org/</a>	Support helpline, live web chat, and local support groups for cancer patients and survivors.
	MyLifeLine: <a href="https://www.mylifeline.org/?ga=2.126337934.208022215.1587526195-532384725.1582732904">https://www.mylifeline.org/?ga=2.126337934.208022215.1587526195-532384725.1582732904</a>	Website that connects patients and caregivers with a personal support community and to others like them on discussion boards.
	Cancer Experience Registry: <a href="https://www.cancerexperienceregistry.org/">https://www.cancerexperienceregistry.org/</a>	Website that allows people with cancer to share their experiences.
Livestrong Foundation	<a href="https://www.livestrong.org/">https://www.livestrong.org/</a>	Support/navigation, fertility program, and guidebook/brochures for cancer survivors.
	Livestrong Guidebook: <a href="https://www.livestrong.org/what-we-do/program/livestrong-guidebook">https://www.livestrong.org/what-we-do/program/livestrong-guidebook</a>	
	Livestrong at the YMCA: <a href="https://www.livestrong.org/what-we-do/program/livestrong-at-the-ymca">https://www.livestrong.org/what-we-do/program/livestrong-at-the-ymca</a>	Free or low-cost physical activity programs for cancer survivors.
National Coalition for Cancer Survivorship	<a href="https://www.canceradvocacy.org/">https://www.canceradvocacy.org/</a>	Cancer survival toolbox, cancer survivorship checklist, employment rights guide, resource guide, and other information and resources for cancer survivors.
	Cancer Survival Toolbox: <a href="https://www.canceradvocacy.org/Appendix/cancer-survival-toolbox/">https://www.canceradvocacy.org/Appendix/cancer-survival-toolbox/</a>	
SHARE	<a href="https://www.sharecancersupport.org/">https://www.sharecancersupport.org/</a>	Support groups, educational programs, helplines, online communities, educational tools, and survivor-patient navigation services for women affected by breast, ovarian or metastatic breast cancer.
Stupid Cancer	<a href="https://stupidcancer.org/">https://stupidcancer.org/</a>	Peer support, education and resources for the young adult cancer community.



<b>Organize/Track Health Information</b>		
<b>CancerAid</b>	<a href="https://www.canceraid.com/">https://www.canceraid.com/</a>	Mobile app to track medical information and side effects.
<b>Living With Cancer Support</b>	<a href="https://www.thisislivingwithcancer.com/living-with-app">https://www.thisislivingwithcancer.com/living-with-app</a>	Mobile app to share how one is feeling, ask for support, remember important information and stay organized.
<b>Social Support</b>		
<b>Cancer Hope Network</b>	<a href="https://www.cancerhopenetwork.org/">https://www.cancerhopenetwork.org/</a>	Support volunteers for cancer patients, survivors, and caregivers.
<b>CancerLife</b>	<a href="https://www.cancerlife.com/">https://www.cancerlife.com/</a>	Social network mobile app that aims to improve quality of life for patients and survivors.
<b>CaringBridge</b>	<a href="https://www.caringbridge.org/">https://www.caringbridge.org/</a>	Website and mobile app for patients and caregivers to share health updates with one's community.
<b>GRYT Health Cancer Community</b>	<a href="https://grythealth.com/">https://grythealth.com/</a>	Cancer support group mobile app to empower patients and caregivers to live according to their own standards.
<b>SurvivorNet</b>	<a href="https://www.survivornet.com/">https://www.survivornet.com/</a>	Website to share knowledge and cancer survivors' stories.
<b>Beauty</b>		
<b>EBeauty Community</b>	<a href="http://www.ebeauty.com/">http://www.ebeauty.com/</a>	Free wig exchange program for cancer patients and survivors.
<b>Look Good Feel Better</b>	<a href="https://lookgoodfeelbetter.org/">https://lookgoodfeelbetter.org/</a>	Free group and virtual sessions that teach beauty techniques to help people with cancer face their diagnosis with more confidence.
<b>Physical Activity</b>		
<b>Strength For Life</b>	<a href="http://strengthforlifeny.org/">http://strengthforlifeny.org/</a>	Free exercise programs, wellness retreats and other free programs for cancer patients and survivors.
<b>Yoga4cancer</b>	<a href="https://y4c.com/">https://y4c.com/</a>	Free yoga classes for cancer patients and survivors.
<b>Art</b>		
<b>The Creative Center at University Settlement</b>	<a href="http://www.thecreativecenter.org/tcc/">http://www.thecreativecenter.org/tcc/</a>	Free art workshops for people with cancer and other chronic illnesses.
<b>Fertility</b>		
<b>SaveMyFertility</b>	<a href="https://www.savemyfertility.org/">https://www.savemyfertility.org/</a>	Online fertility preservation toolkit for patients and their providers.
<b>Career/Legal</b>		
<b>Cancer + Careers</b>	<a href="https://www.cancerandcareers.org/en">https://www.cancerandcareers.org/en</a>  Manager's kit: <a href="https://www.cancerandcareers.org/en/at-work/employers-managers/managers-toolkit">https://www.cancerandcareers.org/en/at-work/employers-managers/managers-toolkit</a>  Resume Review: <a href="https://www.cancerandcareers.org/resume_reviews/new">https://www.cancerandcareers.org/resume_reviews/new</a>	Publications (including a manager's kit) and educational series on career topics, along with career coaches and resume review services for cancer survivors.
<b>Job Accommodation Network</b>	<a href="https://askjan.org/">https://askjan.org/</a>  Accommodation Search: <a href="https://askjan.org/soar.cfm">https://askjan.org/soar.cfm</a>	Consultations along with resources/publications on workplace accommodations and disability employment issues.
<b>Cancer Advocacy Project</b>	<a href="https://www.citybarjusticecenter.org/projects/cancer-advocacy-project/">https://www.citybarjusticecenter.org/projects/cancer-advocacy-project/</a>	Assistance with drafting life-planning documents, challenging unjust health insurance decisions, and advising on cancer-related employment discrimination for low- and moderate- income cancer patients and survivors who reside in New York City.



## **Exhibit D: Summary of Employment Laws and Agencies, Types of Leave and Workplace Accommodations Related to Cancer Survivorship**

*\*None of the below information is intended to provide legal advice or legal opinion on any matter. NEBGH recommends seeking professional legal counsel for questions about a specific situation.*

### **Employment Laws and Agencies**

#### **Americans with Disabilities Act (ADA)**

Prohibits discrimination against people with disabilities. In addition, it requires eligible employers to make “reasonable accommodations” to enable employees who currently have a disability, or who have a history of having a disability, to function properly on the job. Generally, the ADA only protects those who have made their employer aware that they have a serious medical condition. For more information, call 1-800-514-0301 or visit the ADA website, [www.ada.gov](http://www.ada.gov).

#### **Family and Medical Leave Act (FMLA)**

Enables people dealing with a serious illness — or one of their family members — to take unpaid, job-protected leave for up to 12 weeks within one calendar year. The employee must have worked with his or her employer for at least one year (for at least 1,250 hours); employers must continue providing health benefits during the leave; and the leave does not have to be taken all at once but can be taken in blocks of time. Generally, the FMLA only protects those who have made their employer aware that they have a serious medical condition. For more information, visit the U.S. Department of Labor’s website, <https://www.dol.gov/agencies/whd/fmla>.

#### **Equal Employment Opportunity Commission (EEOC)**

A federal agency that enforces the provisions of the ADA and the FMLA and helps people who feel they have been discriminated against in the workplace. For more information, call 1-800-669-4000 or visit the EEOC website, [www.eeoc.gov](http://www.eeoc.gov).

#### **Consolidated Omnibus Budget Reconciliation Act (COBRA)**

Gives workers and their families who lose their health benefits the right to choose to continue group health benefits provided by their group health plan under certain circumstances such as voluntary or involuntary job loss, reduction in the hours worked, transition between jobs, death, divorce and other life events. Coverage is only allowed for a certain length of time after which the employee must take over payment of premiums. For more information, visit the U.S. Department of Labor’s website, <https://www.dol.gov/general/topic/health-plans/cobra>.

## Types of Leave

### Paid Time Off (PTO)

Some companies combine all an employee's paid time off (sick leave, vacation and personal leave) into one block of time, or bank, to be used as the employee sees fit. Typically, before an employee can go on disability, he or she must use all vacation and sick time.<sup>38</sup>

### Sick Leave

Some companies have separate leave banks for sick, vacation and personal time. Sick time can be used for an employee's own illness or injury and, in some cases, to care for a family member with an illness or injury.

### Leave Banks or Pools

Two types of leave sharing that are available at some companies to help employees who need more time off to deal with their illness but have used up their paid leave and cannot afford to take unpaid time-off. More specifically, the workforce as a whole donates some of their paid leave to be used by employees who need it. A bank is a program where employees "deposit" days off for anyone to use; pools are set up for donations to a particular person.<sup>39</sup>

### Family and/or Caregiving Leave

Provides employees additional time off to care for a child, spouse/partner, parent, grandparent, parent-in-law or other family members who are dependent on their support and care. Depending on the state, this can be paid or unpaid time off.

### Family and Medical Leave Act (FMLA)

Provides job-protected, unpaid leave to employees for qualified medical and family reasons for up to 12 weeks within one calendar year.

### Short-Term Disability (STD)

Designed to supplement a portion of the income an employee will lose if he or she needs a brief medical leave from work, usually up to 26 weeks away from work and pay between 55 and 100% of wages. The employer may hold the position for the employee during this period since he or she expects to return to work. However, the employer is only legally required to keep the position open if the employee is taking their 12 weeks of FMLA Leave. Short-term disability insurance can be purchased individually, administered through an employer or provided by a state or territory.<sup>40</sup>

### Long-Term Disability (LTD)

Similar to short-term disability insurance, long-term disability plans can be purchased individually or offered by employers. There are also two federal disability insurance programs: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). To be eligible for either of these programs, an employee must meet the Social Security Administration's definition of a disability, which is having an illness or injury that either is expected to last 12 months or longer or is predicted to be terminal.<sup>41</sup>

38 <https://www.workplacetransitions.org/toolkit/workplace-accommodations>

39 <https://www.workplacetransitions.org/toolkit/workplace-accommodations>

40 <https://www.cancerandcareers.org/en/at-work/legal-and-financial/filing-for-disability>

41 <https://www.cancerandcareers.org/en/at-work/legal-and-financial/filing-for-disability>

## Workplace Accommodations

Accommodations are changes to an employee's schedule, work environment or duties to allow the employee to continue working. Examples include:

- Flexible schedule
- Remote work options
- Part-time schedule
- Lighter workload/duties
- Temporary assignment to a less physically taxing job
- Reallocation of job responsibilities
- Change of roles
- Periodic breaks
- Private area to rest or to take medication
- Move to a different workstation (e.g., closer to the bathroom)
- Rearrangement of work space so equipment is easy to reach
- Modification of office temperature
- Modification of dress code to allow wearing a scarf, hat or unrestrictive clothing
- Reduction or elimination of the use of fragrant products in the work environment
- Special furniture (e.g., adjustable chair, mini fridge to store meds)
- Special equipment (e.g., anti-glare screen, cooling vest)
- Adaptive technology recommended by occupational therapists
- Permission to use the work telephone to call doctors
- Assistance with relocation, if needed

## **Exhibit E: Survivor Pullout**

### **Tips for Returning to Work**

- **Ask your care team** if they have any recommendations regarding returning to work.
- **Understand** the legal protections for employees working with cancer or returning to work after active treatment.
- **Get up to speed.** Join a support group of other cancer patients who are returning to work, evaluate your readiness to work, attend workshops or seminars to refresh your skills, and attend industry events to keep your knowledge up to date.<sup>42</sup>
- **Make a plan.** Create a schedule, determine if you can work full time or part time and examine your workstation and work environment to determine if you need workplace accommodations.<sup>43</sup>
- **Think ahead** about what you want to share and how you will handle other people's reactions.
- **Identify and implement** methods to reduce workplace stress. Examples include breathing, exercising, listening to music, taking breaks, heading outside, laughing, setting up boundaries, delegating and communicating.
- **Stay informed** about resources that your employer and/or external organizations can provide to help manage survivorship challenges including returning to work.

42 <https://www.cancerandcareers.org/en/at-work/back-to-work-after-cancer/back-to-work>

43 <https://www.cancerandcareers.org/en/at-work/back-to-work-after-cancer/back-to-work>



## **Exhibit F: Employer Pullout**

### **Supporting Cancer Survivors Checklist**

- Encourage survivors** to be active partners with their care team. Provide them with a checklist of questions to ask and areas for discussion included in this guide. Research has shown that people who feel more in control feel and function better than those who do not.<sup>44</sup>
- Provide survivors** with programs and resources to foster mental and social health. These opportunities can be offered internally through an EAP, an ERG or a mentor program, or externally through cancer support organizations. In addition, these opportunities can be offered in person and/or virtually.
- Create or enhance** your employee wellness program to help encourage healthy lifestyle choices. One component can include a wellness portal that contains information and resources specific to cancer survivors, many of which are listed throughout this guide.
- Put in place** benefits, programs and resources to support the caregivers of cancer survivors.
- Provide comprehensive**, cancer-friendly benefits that take into account physical health, mental and social health, wellness, fertility, caregivers, finances, work and disability.
- Educate yourself and your employees** (both managers and coworkers) on cancer survivorship challenges and opportunities.
- Understand and communicate** employment laws/agencies and company policies, procedures and benefits such as types of leave and workplace accommodations.
- Leverage external resources**, listed throughout this guide, many of which are free for cancer survivors and caregivers.
- Create a safe and inclusive work culture** for cancer survivors that reduces stigma, fosters transparency and collaboration, and encourages supportive continue-to-work or return-to-work practices.





## About NEBGH

Northeast Business Group on Health (NEBGH) is an employer-led, multi-stakeholder coalition that empowers members to drive excellence in health and achieve the highest value in healthcare delivery and the consumer experience. Our employer/purchaser members cover six million lives in the U.S. and 10 million globally. We help members manage costs, obtain more value from the benefits and services they purchase and improve the health and wellbeing of employees. We promote the purchasing power employers represent in efforts aimed at improving healthcare quality, value and transparency.

## About CancerCare

CancerCare, a nonprofit 501(c) 3 organization founded in 1944, is the leading national organization that provides free, professional support services and information to help people manage the emotional, practical and financial challenges of cancer. Comprehensive services include case management, counseling and support groups provided by phone, online and in person, as well as educational workshops, publications and financial and co-payment assistance. All of CancerCare's services are provided by oncology social workers and world-leading cancer experts.

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