



COMPREHENSIVE CANCER SURVIVORSHIP ACT

Representatives Debbie Wasserman Schultz (D-FL-25), Brian Fitzpatrick (R-PA-1), and Mark DeSaulnier (D-CA-10) and Senators Amy Klobuchar (D-MN) and Ben Cardin (D-MD) introduced H.R. XXXX/S. XXXX, the Comprehensive Cancer Survivorship Act (CCSA), to improve survivorship, treatment, and transition for all cancer survivors.

NEED FOR SURVIVORSHIP CARE

Cancer survivors are some of the most vulnerable patients in the health care system. Care and the cancer journey do not end once active treatment ends, and survivors need lifelong support for their disease.

- Survivors are at risk of developing future health issues due to their treatments, sometimes years after completing treatment.¹
- By age 45, 95% of childhood cancer survivors experience a significant side effect due to toxicities from their treatment.²
- Cancer survivors also have a greater risk of being diagnosed with secondary cancers.³

To improve their quality of life and health outcomes, cancer survivors need resources to help monitor for these secondary cancers and late and long-term effects caused by their cancer treatment. Additionally, health care providers need resources to provide appropriate care for survivors throughout the entire continuum of care. The Comprehensive Cancer Survivorship Act addresses the existing gaps in survivorship care and improve quality of care and navigation of health care systems for survivors, their loved ones, and their health care providers.

HOW DOES THE COMPREHENSIVE CANCER SURVIVORSHIP ACT HELP CANCER SURVIVORS?

This bipartisan legislation includes the following provisions:

- Coverage of cancer care planning and communication
- Survivorship transition tools
- Alternative payment model
- Survivorship navigation
- Survivorship care demonstration program
- Employment assistance program
- Comprehensive cancer survivorship program
- Adult cancer survivorship study
- Survivorship progress report
- Easing transition to primary care for children with cancer
- Childhood cancer demonstration model and standard of care
- Medicaid coverage of fertility preservation

CANCER CARE PLANNING AND COMMUNICATION

The CCSA creates a Medicare service and payment for care planning and coordination services to help improve coordination of care and transition to primary care.

- A key recommendation from the Institute of Medicine's 2005 report From Cancer Patient to Cancer Survivor: Lost in Transition was that cancer survivors receive an individualized survivorship care plan when completing cancer treatment.⁴
- Coordinated cancer care outlined in a written care plan – care integrating active treatment and symptom management – improves patient outcomes⁵ and increases patient satisfaction.⁶
- Most cancer survivors never receive a care plan, which leaves them to navigate a cancer diagnosis without clear direction. According to the National Coalition for Cancer Survivorship's (NCCS) 2020 State of Cancer Survivorship Survey, only 17% of cancer survivors nationwide reported receiving a survivorship care plan.⁷

EMPLOYMENT ASSISTANCE PROGRAM

This legislation provides education and assistance to survivors and their families and caregivers experiencing barriers to employment as a result of a cancer diagnosis.

- Financial toxicity is a major concern for cancer survivors. Survivors have higher out-of-pocket costs and are 2.65 times more likely to face bankruptcy than individuals without a cancer history.⁸
- Many survivors experience reduced productivity, inability to work, or reduced hours because of their cancer treatment.⁹

- NCCS's 2022 State of Survivorship Survey found that 55% of survivors must make employment and/or educational sacrifices because of their cancer care. Numbers are higher among certain groups, including Hispanic cancer survivors (79%), young adults (78%), and survivors living with metastatic cancer (77%).⁷

Targeted assistance like career and training services, as well as transportation, financial, and psychosocial support, can help cancer survivors facing employment challenges remain employed and financially stable.⁸

ADULT CANCER SURVIVORSHIP STUDY

This bill requires an analysis assessing the benefits of creating an adult version of the Childhood Cancer Survivor Study, which would collect information about late and long-term effects of cancer to help better understand these effects and improve treatments and interventions to increase survival, minimize harmful health effects, and improve survivors' quality of life.

- Most survivors still experience symptoms years after their treatment ends. Specifically, 74% of those diagnosed 3-5 years ago, 69% diagnosed 6-10 years ago, and 58% diagnosed over 10 years ago still experience symptoms after treatment.⁷
- The Adult Cancer Survivorship Study would provide important data and insights to help survivors and their health care providers make informed decisions about their care and help ensure future survivors have access to the best possible care.

IMPORTANCE OF SURVIVORSHIP CARE

The number and age of cancer survivors is growing. An American Cancer Society report highlighted the following statistics:

- 2022: 18.1 million Americans are cancer survivors, with substantial racial disparities in treatment and survival.
- 2022: Since their diagnosis, 69% of survivors have lived 5+ years; 47% of survivors have lived 10+ years; and 18% of survivors have lived 20+ years.
- 2032: The number of cancer survivors is projected to increase by 24.4%, to 22.5 million.
- 2040: There will be an estimated 26 million cancer survivors.¹⁰

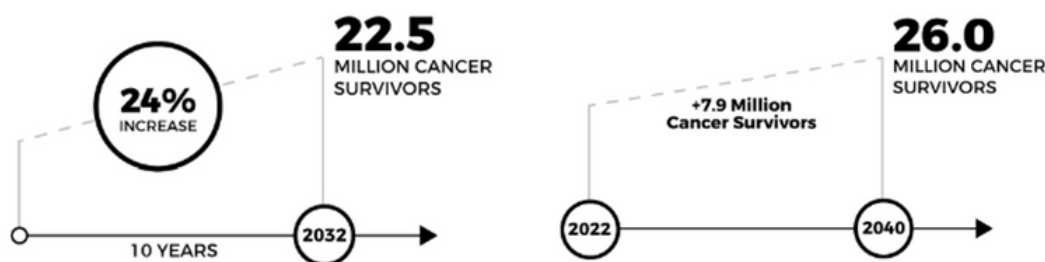


Image Credits: National Cancer Institute, Office of Cancer Survivorship

For more information or to support this survivorship legislation, please contact:

- Haley Smoot, NCCS Director of Public Policy, at hsmoot@canceradvocacy.org
- Patrick Koetzle in Representative Wasserman Schultz's office at patrick.koetzle@mail.house.gov
- Jacqueline Baggett in Representative Fitzpatrick's office at jacqueline.baggett@mail.house.gov
- Ruth McDonald in Senator Klobuchar's office at Ruth_McDonald@klobuchar.senate.gov

1. National Cancer Institute. Coping – Late Side Effects. National Cancer Institute. Published August 6, 2021. <https://www.cancer.gov/about-cancer/coping/survivorship/late-effects>
2. Hudson MM, Ness KK, Gurney JG, et al. Clinical Ascertainment of Health Outcomes Among Adults Treated for Childhood Cancer. JAMA. 2013;309(22):2371-2381. <https://doi.org/10.1001/jama.2013.6296>
3. Adjei Boakye E, Wang M, Sharma A, et al. Risk of second primary cancers in individuals diagnosed with index smoking- and non-smoking- related cancers. Journal of Cancer Research and Clinical Oncology. 2020;146(7):1765-1779. <https://doi.org/10.1007/s00432-020-03232-8>
4. Institute of Medicine. From Cancer Patient to Cancer Survivor: Lost in Transition. National Academies Press; 2005. <https://doi.org/10.17226/11468>
5. Chrischilles EA, McDowell BD, Rubenstein L, et al. Survivorship care planning and its influence on long-term patient-reported outcomes among colorectal and lung cancer survivors: the CanCORS disease-free survivor follow-up study. Journal of Cancer Survivorship. 2014;9(2):269-278. <https://doi.org/10.1007/s11764-014-0406-y>
6. Blinder VS, Norris VW, Peacock NW, et al. Patient perspectives on breast cancer treatment plan and summary documents in community oncology care. Cancer. 2012;119(1):164-172. <https://doi.org/10.1002/cncr.27856>
7. National Coalition for Cancer Survivorship. 2020 State of Cancer Survivorship Survey. canceradvocacy.org. Published 2020. <https://canceradvocacy.org/policy/2020-state-of-cancer-survivorship-survey/>
8. Yabroff KR, Zhao J, Zheng Z, Rai A, Han X. Medical Financial Hardship among Cancer Survivors in the United States: What Do We Know? What Do We Need to Know? Cancer Epidemiology Biomarkers & Prevention. 2018;27(12):1389-1397. <https://doi.org/10.1158/1055-9965.epi-18-0617>
9. Ramsey S, Blough D, Kirchhoff A, et al. Washington State Cancer Patients Found To Be At Greater Risk For Bankruptcy Than People Without A Cancer Diagnosis. Health Affairs. 2013;32(6):1143-1152. <https://doi.org/10.1377/hlthaff.2012.1263>
10. American Cancer Society. Cancer Treatment & Survivorship Facts & Figures 2022-2024. cancer.org. Published 2022. <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/cancer-treatment-and-survivorship-facts-and-figures/2022-cancer-treatment-and-survivorship-fandf-acf.pdf>

ABOUT NCCS

NCCS's mission is to advocate for quality cancer care for all people touched by cancer. Founded by and for cancer survivors in 1986, NCCS created the widely accepted definition of survivorship and defines someone as a cancer survivor from the time of diagnosis and for the balance of life. NCCS represents the millions of Americans who share a common experience – the survivorship experience – living with, through, and beyond a cancer diagnosis.