

# Survivorship 101: “A” for Advocacy

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# Am I a “survivor”?

- ▶ A survivor is a person who remains alive and continues to function during and after overcoming a serious hardship or life-threatening disease.
- ▶ In cancer, person is a cancer survivor **from the time of diagnosis through the balance of their life.**

▶ National Cancer Institute

- ▶ Not everyone likes the term “survivor”
- ▶ Sometimes it is unclear when you ‘qualify’ to be a survivor... but you already are in the club!
- ▶ Some people, like parents or siblings, can be considered “co-survivors”

# What is “Survivorship”?

- ▶ Addressing the unique needs of cancer survivors after active treatment ends.
  - ▶ American Cancer Society
- ▶ This includes the physical, mental, emotional, social, and financial effects of cancer that begin at diagnosis and continue through treatment and beyond.
- ▶ The survivorship experience also includes issues related to follow-up care (including regular health and wellness checkups), late effects of treatment, cancer recurrence, second cancers, and quality of life.
- ▶ Family, friends and partners are part of survivorship.
  - ▶ National Cancer Institute

# Why is Survivorship important?

- ▶ Cancer Survivors may have long term effects from cancer and treatment:
  - ▶ Fatigue
  - ▶ Decreased endurance
  - ▶ Difficulty learning new things
  - ▶ Physical difficulties
  - ▶ Infertility
  - ▶ Anxiety, depression, PTSD, worry
- ▶ Cancer Survivors have potential late effects that might not show up for a long time:
  - ▶ Early “aging” symptoms
    - ▶ Bone thinning
    - ▶ Muscle weakness
    - ▶ Hormone changes
  - ▶ Heart problems
  - ▶ Lung problems
  - ▶ Other cancers

# “A” for Advocacy

## Be your own advocate:

- ▶ Speak Up!
  - ▶ Ask questions about your health
  - ▶ Know the treatments you had
  - ▶ Learn what risks to watch for
  - ▶ Ask for help
- ▶ Act Up!
  - ▶ Stay physically active
  - ▶ Don't take no for an answer
  - ▶ Be proactive

## Find advocates:

- ▶ Your oncology team
  - ▶ Treatment team
  - ▶ Survivorship program
- ▶ Primary care, specialists
- ▶ Support communities
  - ▶ In person or on-line
- ▶ Counselors
  - ▶ Personal
  - ▶ School or work
- ▶ Family, friend, partner

# Cancer Survivorship:

Three advocacy stories to consider

A young Black woman with her hand on her head, looking thoughtful. She is wearing a gold beaded necklace and a brown woven bracelet. The background is a light blue and white gradient.

# Moving away...

- ▶ Nan is 19 and heading off to college in the fall. She hasn't lived on her own before, and her mom has managed all the medical appointments.
- ▶ Medical care at school or just when she comes home for breaks?
- ▶ Support while away at school?
- ▶ Advocating proactively: Make a plan!
  - ▶ Home
  - ▶ Away

## Disability?

Marc is 24 and struggles to keep up with his college classes. He tried to live on his own with friends but ended up moving home because of expenses. He often calls in sick to work due to tiredness or worry.

- His insurance benefits will end when he turns 26.
- His parents worry he won't be able to make it on his own if something happens to them.





A photograph of two people kayaking on a body of water during sunset. The sun is low on the horizon, creating a warm, golden glow. The kayakers are seen from behind, wearing life jackets and paddling. The water is calm with gentle ripples.

# Planning for a family...

- ▶ Dianna is 27, engaged, and they've talked about having kids someday. She also wants to finish grad school, travel and work on her career a few years before becoming a mom.
- ▶ Is there something she should be doing now to be sure she can have kids later?
- ▶ Does she have plenty of time?
- ▶ What are her options?
- ▶ Who would she talk to about this?

# Ways to be your own advocate...

- ▶ Find the support you need
  - ▶ Stress reduction and mental health care
  - ▶ Supportive groups and activities
  - ▶ People you trust
- ▶ Address health needs
  - ▶ Primary care
  - ▶ Integrative care
  - ▶ Oncology care
  - ▶ Specialty care
  - ▶ Awareness & Prevention
- ▶ Be aware of personal lifestyle decisions
  - ▶ Movement and exercise
  - ▶ Nutrition
  - ▶ Alcohol, smoking, drugs
  - ▶ Risk taking
  - ▶ Stress: Situations & people
  - ▶ Advanced directives
- ▶ Stay up to date with
  - ▶ Routine wellness care
  - ▶ Routine cancer screenings
  - ▶ Oncology follow-up

## Resources:

- ▶ Books: This Should Not Be Happening: Young Adults with Cancer by Anne Katz; Everything Changes: The Insiders Guide to Cancer in Your 20's and 30's by Kairol Rosenthal
- ▶ Fertility: <https://oncofertility.msu.edu/for-patients>
- ▶ Camps & Retreats:
  - ▶ <https://www.cancer.net/navigating-cancer-care/children/camps-and-retreats-families-and-children-affected-cancer> ; <https://stupidcancer.org/>;
  - ▶ <https://www.youngsurvival.org/>
- ▶ Discussing End of Life Choices:
  - ▶ Free workbook <https://fivewishes.org/five-wishes/individuals-families/individuals-and-families>; Card game on care choices [www.gowish.org](http://www.gowish.org)
- ▶ Survivorship Guidelines and Further Information:
  - ▶ National Coalition for Cancer Survivorship (NCCS) [www.canceradvocacy.org](http://www.canceradvocacy.org)
  - ▶ Children's Oncology Group <https://childrensoncologygroup.org/index.php/survivorshipguidelines>
- ▶ Financial and Legal Assistance: Cancer Legal Resource Center <https://thedrlc.org/cancer/>; Triage Cancer Financial Program <https://triagecancer.org/>

The background is a vibrant green color. On the right side, there are several overlapping, semi-transparent geometric shapes in various shades of green, creating a dynamic, abstract design. A thin white line also runs diagonally across the lower right portion of the image.

# Thank you !

Do you have questions, ideas or stories to share?