

**Adolescent and Young Adults (AYA) with Cancer
Resource List for Primary Oncology Providers**

In the United States, approximately 70,000 young adults between the ages of 15 and 39 will be diagnosed with cancer yearly. While continued improvement has been seen in younger children and older adults, AYA patients have continued to lag behind in outcomes. The reasons for this are multifactorial and related to disease biology as well as a unique set of psychosocial needs. In order to address the disparity in outcomes seen in the AYA population, dedicated AYA programs are emerging throughout the country; however, not every institution or practice has the capability to form these multidisciplinary programs. ASCO therefore compiled the set of resources below that addresses some of the common concerns and issues faced by AYA patients. The information includes resources on fertility/sexuality, clinical trial enrollment, genetic testing, psychosocial needs including financial toxicity and peer support, as well as links to survivorship care recommendations. While these resources are generally applicable to the young adult age group, it is important to recognize that the needs of individuals at different ages (i.e., a 15-year-old versus a 39-year-old) may differ greatly.

Fertility and sexuality:

- 1) ASCO's [Guideline on Fertility Preservation in Patients with Cancer](#) provides current recommendations about fertility preservation for adults and children with cancer. ASCO recommends health care providers initiate discussion on the possibility of infertility with patients with cancer treated during their reproductive years or with parents/guardians of children as early as possible. Providers should be prepared to discuss fertility preservation options and/or refer all potential patients to appropriate reproductive specialists. Providers should also advise patients regarding potential threats to fertility as early as possible in the treatment process to allow for the widest array of options.

Below are some additional helpful resources:

- Estimating risk of infertility with proposed treatment: the following risk calculator from Livestrong may help with these predictions: <https://www.teamlivestrong.org/we-can-help/fertility-services/risks/>
- Discussions by primary oncology provider or reproductive endocrinology regarding general costs of fertility preservation by service, payment variations by state and financial assistance programs may be helpful to AYA patients when making decisions. Here is a helpful website that nicely summarizes this information as well as coverage information by state: www.allianceforfertilitypreservation.org/advocacy/state-legislation

Genetic testing:

- 2) Genetic testing may be important at the time of initial treatment decision making (e.g, BRCA testing in breast cancer related to surgical decision making) and/or later in their disease trajectory, when it may help with longer-term treatment decisions, family planning and screening of siblings or children (colon cancer, breast cancer, myelodysplastic syndrome, pancreas cancer, etc).

ASCO has developed the [Hereditary Cancer Genetics Toolkit](#) to provide oncology professionals with the tools and resources that will assist them in effectively integrating hereditary cancer risk assessment into practice. The toolkit includes information on and links to:

- Additional ASCO Educational Resources
- Guidelines on Hereditary Risk Assessment and Management
- Resources for Patients and Families

Genetic specialists can help identify those at risk for an inherited cancer syndrome and facilitate discussions about screening and prevention options. The specialist may also help patients and providers apply the results of genetic

testing to medical management decisions. The following organizations maintain directories which may be helpful if you do not have a specialist in your facility

- [American College of Medical Genetics Provider Directory](#)
- [National Cancer Institute: Cancer Genetics Service Directory](#)
- [National Society of Genetic Counselors: Find a Genetic Counselor Directory](#)

Clinical Trials:

3) Like all patients with cancer, AYA individuals may be eligible for a treatment or supportive care trial available at your institution or a neighboring institution. Exploring the possibility of clinical trials participation may be particularly important for patients with relapsed, rare or treatment intensive cancers.

- ClinicalTrials.gov is a database of privately and publicly funded clinical studies conducted around the world and is a helpful resource provided by the U.S. National Library of Medicine. <https://clinicaltrials.gov>

Psychosocial Issues:

Having a patient complete a brief survey may help to help identify which types of psychosocial services an AYA patient may wish to access or anticipate needing in the future. One example, based on the survey developed by Dr. Bradley Zebrack, is available for [download here](#).

4) Financial counselors can play an integral role in helping AYA, and all, patients address the out-of-pocket costs of their cancer treatment. Counselors can help with the following:

- Current insurance coverage and if none, plan for application for coverage
- Current job situation, anticipated length of time needed away from work or work adjustments and assistance with short or long term disability if indicated
- Discussion of current financial situation, ability to pay for needed medications, medical co-pays and ability to continue to pay regular living expenses.
- If in school, discussion of loan deferment programs if needed: Department of Education Appropriations Act, 2019 allows for deferment on federal loans while in active treatment and 6 months after treatment
- Referral to local and national resources for financial assistance: <https://stupidcancer.org/get-help/resource-directories/financial-assistance/>; The Samfund - <http://www.thesamfund.org>

5) Offering comprehensive support can come in many forms. Below is some information on local or regional AYA support groups:

- [Cancer Support Community](#) - the largest professionally led nonprofit network of cancer support worldwide, dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.
- [I Had Cancer](#) – offers a peer-to-peer support community that empowers people to take control of life before, during and after cancer.
- [Imerman's Angels](#) – provides free, personalized one-on-one cancer support for cancer fighters, survivors, and caregivers using a unique matching process.
- [Stupid Cancer](#) - creates shared experiences by producing life-changing live events and digital content specifically for the AYA cancer community that end isolation, build community, provide education, and foster meaningful relationships that last a lifetime.
- [Teen Cancer America](#) – working to transform the experience, outcomes and survival of teenagers and young adults battling cancer by generating specialized programs, building state of the art facilities, and creating therapeutic experiences for young people in hospitals throughout America.

Also consider the possibility of facilitating a one-on-one mentorship connection with another young cancer patient in your practice, ideally one with the same diagnosis and close in age.

- 6) Written materials on cancer diagnosis and supportive care information in both print and digital formats have been developed for many AYA cancer types and issues and can serve as an important resource for your patients and their families.
- [ASCO patient guidelines](#)
 - [NCCN patient guidelines](#)
 - [UpToDate patient information](#) (subscription-based member-only content)
 - [Cancer.Net](#)
 - [Livestrong.org](#)
 - [Teencanceramerica.org](#)
 - [Savemyfertility.org](#)
 - [Cancerfinances.org](#)
- 7) For AYA patients with children, child life specialists can help facilitate discussion between patients and their children regarding their diagnosis, treatment plan and prognosis. Resources to locate a child life specialist are below. Also, there may be resources to help pay for or provide childcare while the patient undergoes treatment.
- A Tiny Boat at Sea by Izetta Smith
 - <https://www.wondersandworries.org>
 - https://www.youtube.com/watch?v=u1erqxA_0uk
 - [Mommies in Need](#)

Survivorship:

- 8) At the completion of treatment, ASCO recommends all cancer patients receive a completed survivorship care plan, with a printed and digital copy provided to the patient and reviewed by an oncology provider. Written treatment and summary care plans can help ensure appropriate coordination among the members of the extended care team, including primary care providers. Issues related to surveillance, health maintenance and diet/exercise recommendations are incorporated into the process of survivorship care planning. For AYA patients, additional items that may be relevant to include are transition planning back into the workforce and any accommodations that need to be made. Also, if the patient is in school, the survivorship care planning discussion could include a discussion of transitioning back to school as well as indications for special needs testing and accommodations.

Below are some helpful resources that may aid in the transition:

- [Cancer and Careers](#)
- [ASCO Survivorship Care Plan templates](#)
- [Guidelines on Survivorship Care](#)
- Addressing Lifestyle Behaviors
 - [Obesity & Cancer: A Guide for Oncology Providers](#)
 - [Managing your Weight after a Cancer Diagnosis: A Guide for Patients and Families](#)
 - [Tobacco Cessation Guide for Oncology Providers](#)
 - [Stopping Tobacco Use after a Cancer Diagnosis: Resources and Guidance for Patients and Families](#)
 - [Alcohol Use](#)

- 9) Additional Resources for Patients

- Australian Youth Cancer Framework - <https://www.canteen.org.au/youth-cancer/resources/aycf/>
- On Treatment AYA Oncology Psychosocial Care Manual (includes tools): <https://www.canteen.org.au/youth-cancer/resources/aya-psychosocial-care-manual/>
- Survivorship AYA Oncology Psychosocial Care Manual (includes tools): <https://www.canteen.org.au/youth-cancer/resources/aya-oncology-psychosocial-survivorship-care-manual/>

- YCS Website Life After Cancer Resources: <https://www.canteen.org.au/youth-cancer/life-treatment/>
- Getting Cancer Young YouTube resource Survivorship Playlist:
https://www.youtube.com/playlist?list=PLDEPHWSxsQy50AyZMTzIJYODhY9P_xwwH
- Thinking Ahead: Your Guide to Study, School, and Work
https://www.petermac.org/sites/default/files/Thinking%20Ahead_FINAL_web.pdf?