

Adolescents and Young Adults

Overview

Statistically, adolescents and young adults (AYAs) aged 15 to 39 years are more likely to be diagnosed with cancer than children under the age of 15. Although lymphoma is one of the most common cancers to develop in AYAs under the age of 25, other cancers such as leukemia, melanoma, testicular (germ cell tumors), breast, and thyroid are also commonly diagnosed in AYAs.

Lymphoma occurs when cells of the immune system called lymphocytes, a type of white blood cell, grow and multiply uncontrollably. Cancerous lymphocytes can travel to many parts of the body, including the lymph nodes, spleen, bone marrow, blood, or other organs, and form a mass called a tumor.

The relative youth and maturity level of AYAs will have a significant effect on their ability to manage their diagnosis and treatment. Factors such as a belief that “it cannot happen to me,” overall lack of healthcare-related knowledge, unique concerns regarding body image and fertility issues, and relationship matters must all be considered when building a treatment plan for AYAs. Additional issues such as health insurance questions, potential financial hardships, and peer concerns must all be managed carefully.

Potential challenges that AYAs may face include:

- Management of a diagnosis and treatment plan
- Identification of the most appropriate healthcare team who understands the unique treatment needs of AYAs
- The evolution of relationships with family members and peers
- Concerns about fertility and body image
- The transition to and from school and work environments
- Health insurance and financial challenges

Medical Challenges

AYAs may dismiss early warning signs and potential symptoms of cancer and delay seeking medical attention because many cancer symptoms are associated with normal body changes that are common at this age. However, delaying medical attention can impact their ability to obtain an accurate diagnosis and reinforces the need for AYAs to rely on sound medical care instead of depending on Web platforms or social media as a primary source of information.

Once cancer is diagnosed, AYAs often have unique biological development issues to consider. If you are among the younger-aged AYAs, your body is changing and growing rapidly, which is important

for a doctor to consider when developing a cancer treatment plan. For example, many body characteristics that are changing in an AYA, such as metabolism, muscle mass, and percentage of body fat, may affect the way drugs are absorbed in the body and what doses are most effective. Doctors will develop treatment plans that are individual to the AYA and his or her specific needs.

It is completely normal to be hesitant or embarrassed when describing what you are feeling or when asking questions, as you may have little experience speaking directly with a doctor. It is possible that, until recently, your parents may have managed medical issues for you. You should not feel uncomfortable when discussing questions and concerns about your diagnosis, treatment, side effects, or even topics like sexuality with your doctor or healthcare team. Communication between patients and their doctors is extremely important and is always kept confidential.

Some AYAs may feel more comfortable having their parents present during appointments, while others may prefer to speak with the doctor alone. It is important to do what makes you feel the most comfortable so you can actively participate in the discussion and play a role in making decisions about your care. It is also okay to talk with your doctor about whether you should consider getting a second opinion about your disease and/or treatment.

Physical Abilities

For many AYAs, appearance and physical strength are important parts of their self-image. Some cancer treatments can cause temporary or permanent physical changes to the body, including hair loss, surgical scars, fatigue (feeling tired all the time), and/or problems with balance and agility. This may make you feel self-conscious or insecure and may impact how you relate to others. Physical changes and reduced energy levels could require changes to your normal routine, and you may need to adjust your expectations at a time in your life when you crave normalcy and want to fit in with your peers.

Although it seems contradictory, some patients describe positive changes in their body image as a result of living with cancer. For example, they may gain an appreciation of their body's ability to recover or discover that appearance and body shape are less important than they used to be. Scars can be seen as signs of courage and survival.

It is a good idea to speak with your doctors and healthcare team before treatment about what kinds of physical changes to expect so you are fully prepared if they arise. There are many valuable resources available such as physical therapists, dieticians, fitness coaches, or counselors who specialize in oncology to assist you if you have concerns about these changes. AYAs are encouraged to utilize all the resources available to plan and work toward a post-cancer lifestyle that includes their passions and interests.

Emotional Impact

AYAs are at a time in their lives when they are becoming independent, establishing relationships and careers, exploring their sexuality, and forming their own view of the world. A cancer diagnosis can interrupt this process; instead of dealing with those life issues, you must face not only your own distress and emotions about your diagnosis but those of your family and friends as well. You may also find yourself reevaluating your priorities and goals.

Your personal and social priorities may often compete with your treatment, and you may feel resentful that time you would normally spend with friends and attending social events or other activities may now be spent at doctor appointments or having tests or treatments.

Even when treatment is over, it is normal to experience fear of recurrence, anxiety about returning to work or school, insecurity about physical changes caused by treatment, frustration over the pace of your recovery, concerns about medical bills and health insurance, and/or uncertainty about the future.

Your parents, family, and friends will want to offer you comfort and support; however, people your own age who are also dealing with a cancer diagnosis or treatment may be able to provide unique insights and support. You may find that the people you meet in these support groups are also experiencing the same feelings and concerns as you and may be able to offer insights and suggestions. The Web, smart phones, and social media have increased the number and variety of resources available, both in person and online, which can be helpful tools for developing a support network. Many people also benefit from speaking with a therapist or counselor trained in helping people with cancer.

Relationships and Family Dynamics

A cancer diagnosis may impact your attempts to establish independence from your parents, find a life partner, and raise a family. Each relationship will be affected differently. Some relationships will strengthen, while others may become strained. Although family support and unity are important, the various perspectives and expectations that family members can have may

contribute to different forms of stress. A professional counselor may be helpful for those who find it difficult to express their feelings with family or friends.

Parents. Following a cancer diagnosis, you may find it necessary or comforting to return home to live with your parents. Moving in with parents or another family member may feel like giving up newly found independence, and you may feel that your parents become overprotective or try to take charge. Remember that it is natural for parents to want to protect and take care of their children. It is also important to remember that your parents are dealing with their own emotions, as well as those of your other family members. In some cases, you may find yourself becoming overprotective of your parents or wanting to shield them from the stress of your disease. Although talking to your parents may be difficult, it is important to keep an open line of communication. Parents can often provide help with a range of challenges, both practical and emotional, at home and in the hospital.

Dating. Dating and developing new relationships can be challenging. Many struggle with decisions about when to reveal their health histories and the impact that their long-term survival or ability to have children may have. Deciding when to tell someone about your cancer diagnosis is a personal choice. The right time to share this information will differ for each person, but considering these situations and implications in advance and determining how you want to handle them can help ease any fears and tensions you may have.

Partners. Young adults typically do not expect a spouse or partner to face a life-threatening illness. Frequently, a cancer diagnosis means changes in a couple's roles and responsibilities, intimacy, parenting, and plans for the future. This can be overwhelming for both you and your partner, as you both may experience sadness, anxiety, depression, or anger. Professional counseling may be beneficial for couples whose relationship becomes strained after a cancer diagnosis. For others, facing the challenges of cancer together can strengthen a couple's relationship.

Fertility. Now that so many cancers diagnosed in AYAs are curable, there is more focus on the effects that cancer treatment may have on fertility and preserving patients' ability to have children. While fertility may return following treatment, it is important to address this critical issue and prepare for the possibility of permanent infertility. It is important to discuss fertility issues with your healthcare team at the time of diagnosis. Many AYAs take steps to preserve their fertility before their cancer treatment begins.

It is important to note that research shows that children born to cancer survivors are not at higher risks for birth defects or cancer because of cancer treatment compared with the general population.

School

It is not uncommon to take time off from school during your cancer treatment. When you return to school, it is natural to want to jump right in and return to a normal schedule, but going back to school can be physically and emotionally tiring. Before returning to your studies, you may want to meet with someone from the Office of Student Affairs to discuss and coordinate your transition back to school and explore available health, financial aid, and career planning resources. Frequently, attendance issues can be challenging when returning from cancer treatment, especially because of doctors' appointments. Meeting with your academic advisors can help you clarify the best course choices and how to complete your educational goals. You may also want to consider taking a reduced course load.

If you are in college, the medical staff in the student health center may want to discuss your cancer treatment, current health status, and expected needs for follow-up care. Most student health centers will want to do everything they can to help you with your transition back to school.

Some students may experience academic challenges when returning to school. Although rare, you may experience learning problems such as difficulties with concentration, memory, reading comprehension, or handwriting. These problems may be temporary, but some may be long-term. If any of these challenges arise, it is important that you ask for help from your healthcare team as well as teachers and academic administrators. Federal laws allow students with disabilities to receive special accommodations, which may include extended time to complete tests, audio textbooks, free tutoring, or modified housing, upon request.

Work and Career

AYAs are typically at an age when they are just entering the workforce. Cancer and cancer treatment can affect your ability to work. Although most patients are able to fully resume work, it can be challenging to incorporate doctor visits, appointments for exams and treatments, time needed to recover from treatment, and follow-up visits into your work schedule. Many cancer patients find their ability to perform certain tasks and/or their overall productivity at work is affected. It is common for AYA patients to make changes in their work schedule including taking time off, switching from full-time to part-time work, and changing to a less demanding job or to one with a more flexible schedule. It is important for you to

understand your rights as an employee, as well as how to work with your employer to arrange for accommodations that meet both of your needs. Consider arranging a meeting with the human resources representative in your workplace to discuss possible and appropriate accommodations prior to treatment and again before your anticipated return to work.

Health Insurance and Financial Concerns

Health insurance is a major issue for many AYAs, as the financial costs of diagnosis, treatment, and short- and long-term care can be extensive. Because AYA cancer survivors have a higher risk of developing long-term health problems including issues with infertility, their heart or lungs, and secondary cancers, it is important to keep health insurance coverage even after completing treatment as some of these issues may not arise for many years following treatment. Young adults in general are at risk of being uninsured, and it can be difficult to obtain or maintain health insurance if treatment and recovery have impeded their ability to obtain or hold down a job. A provision of the Patient Protection and Affordable Care Act allows young adults to remain on their parent's health plans until the age of 26 years as long as a parent has health insurance. There are people with expertise, such as social workers and case managers, who can help you to navigate this and other insurance and financial options. AYA-specific information about the Affordable Care Act can also be found at www.healthcare.gov/young-adults/.

Treatments Under Investigation

Many treatments at various stages of drug development are currently being tested in clinical trials, including some for the AYA population. For information on treatments under investigation, visit the Lymphoma Research Foundation's (LRF) website at www.lymphoma.org. It is critical to remember that today's scientific research is continuously evolving. Treatment options may change as new treatments are discovered and current treatments are improved. Therefore, it is important that patients check with their physician or with LRF for any treatment updates that may have recently emerged.

Clinical Trials

Clinical trials are an important treatment option for cancer patients of all ages since they provide the most up-to-date treatments. However, AYAs are far less likely to enroll in clinical trials than children and middle-aged adults. Currently, only about two percent of patients 20 to 39 years of age are treated in clinical trials, compared with more than 60 percent of children under the age of 15. The reasons include financial concerns, inadequate health insurance, patient and family reluctance to enter trials, lack of access and referrals to specialized cancer treatment centers, and lack of physician awareness of clinical

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Supported through unrestricted
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Getting the Facts is published by the Lymphoma Research Foundation (LRF) for the purpose of informing and educating readers. Facts and statistics were obtained using published information, including data from the Surveillance, Epidemiology, and End Results (SEER) Program. Because each person's body and response to treatment is different, no individual should self-diagnose or embark upon any course of medical treatment without first consulting with his or her physician. LRF is not responsible for the medical care or treatment of any individual.

Last Updated October 2014

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trials for this age group. Participation of more AYAs in clinical trials will help improve treatment, survival, and understanding of the types of cancers that occur in patients in this age group.

Patients interested in participating in a clinical trial should talk to their physician or contact the LRF Helpline for an individualized clinical trial search by calling (800) 500-9976 or emailing helpline@lymphoma.org.

Survivorship and the Importance of Long-Term Medical Follow-up

It is important for every cancer patient, regardless of age, to have a survivorship care plan that includes guidelines for monitoring and maintaining their health, including regular physical examinations to check for long-term side effects of treatment. This is particularly important for younger cancer survivors, as they have many years ahead and may be facing different concerns than older cancer survivors. Patients in remission should have regular visits with a physician who is familiar with their medical history and the treatments they have received because treatment effects may not appear until months or years after their treatment is completed.

Patients and their caregivers are encouraged to keep copies of all medical records and test results as well as information on the types, amounts, and duration of all treatments received. LRF has developed the free *Focus on Lymphoma* award-winning mobile app (www.lymphoma.org/mobileapp) that allows users to record doctor sessions, manage medications, keep track of blood work results, and document treatment side effects. This documentation will be important for keeping track of any effects resulting from treatment or potential disease recurrences. Review this plan with your healthcare team to ensure you understand what information is included. This plan can help improve your quality of life as you move beyond cancer treatment and help you communicate your cancer experience with new healthcare team members as you age.

Long-Term Emotional and Psychological Impact

The trauma of being diagnosed with cancer and having gone through physically and mentally challenging treatments can also have long-term psychological effects. AYA cancer survivors are at increased risk for anxiety, depression, substance abuse, and suicide; however, there are many forms of support available. Support groups or relaxation techniques are helpful for some people, but severe problems may require professional help.

Support

A lymphoma diagnosis often triggers a range of feelings and raises many concerns. In addition, cancer treatment can cause physical discomfort. Support groups and online message boards can help patients connect with other people who have lymphoma. One-to-one peer support programs, such as the LRF Lymphoma Support Network, match lymphoma survivors (or caregivers) with other AYAs who have gone through similar experiences. For more information about the Foundation's Adolescent and Young Adult Initiative, please visit www.lymphoma.org/eraselymphoma.

Resources

LRF offers a wide range of resources that address treatment options, the latest research advances, and ways to cope with all aspects of lymphoma. LRF also provides many educational activities, from in-person meetings to teleconferences and webcasts, as well as E-Updates that provide the latest disease-specific news and treatment options. For more information about any of these resources, visit our website at www.lymphoma.org, or contact the LRF Helpline at (800) 500-9976 or helpline@lymphoma.org.