

#### PATIENT & CAREGIVER EDUCATION

# A Guide for Adolescents and Young Adults (AYAs): About Your Care as an AYA Patient at MSK

This information explains your care as an AYA patient at MSK.

#### What is an AYA?

AYA is short for adolescent and young adult. At MSK, people ages 15 to 39 are considered an AYA, no matter what your diagnosis is.

## How are my needs different?

As a young person, there are many things outside of your cancer diagnosis or treatment that need your attention. Whether it's finishing school, starting your career, or growing your family, a cancer diagnosis can affect your plans.

In the past, AYAs with cancer did not always get the care or support they needed. This was because many

healthcare providers focus on treating young children or older adults. We know what you're going through in life is different from what young children and older adults go through. The good news is now there is more support for people your age and at your stage of life.

To help support you, MSK offers the AYA Program. This program meets your unique needs throughout your cancer journey. For more information, visit www.mskcc.org/aya or read *The Adolescent and Young Adult (AYA) Program at MSK* (www.mskcc.org/pe/aya program).

## What can I do to get support?

It's normal to feel stressed, anxious (worried or afraid), or depressed (very sad or hopeless) after getting a cancer diagnosis. It's important to take care of yourself and remember you are not alone.

Here are some things you can do to get support.

#### Talk with other AYAs with cancer

It can be comforting to talk with someone who is going through or has been through a treatment like yours. You can share stories and resources, ask questions, and enjoy activities together. The AYA Program offers many opportunities to connect with peers. You can join a virtual group, activity, or use a private social media app for patients ages 18 and older.

- Virtual Programs lets you connect with your peers, chat, and enjoy activities together. Activities may include arts and crafts, yoga, trivia and game nights, educational workshops, and much more. You can find all our virtual offerings by visiting www.mskcc.org/events and searching for "young adult."
  - Our Young Adult Support Group is an online support group for young adults (ages 21 to 39) who are in active treatment at MSK. A social worker leads discussions about the unique patient experiences of young adults. Visit www.mskcc.org/event/young-adult-support-group to learn more or register.
- The Lounge App is a social media platform for patients aged 18 to 39. It can help you connect to other patients around your age. You can also find or suggest events at MSK or elsewhere, share experiences, ask questions, and get answers from experts. You can download The Lounge at MSK app in

the App Store or on Google Play. Email <a href="mailto:tyaprogram@mskcc.org">tyaprogram@mskcc.org</a> to get an access code.

You can also get connected with peers through the AYA Program by emailing ayaprogram@mskcc.org or calling 646-608-8336.

#### **Get emotional support**

There are many types of support at MSK. This includes social workers, psychologists, psychiatrists, chaplains (spiritual counselors), and art and music therapists. For more information about our other programs and support services, read *Support Resources for Adolescents and Young Adults (AYAs)* 

(www.mskcc.org/pe/aya support resources).

#### Accept help from family and friends

You may not have time or energy to do all the things you once did. Be willing to accept help and support from those around you. Ask your family and friends for help with household chores, preparing meals, or anything else you need. When people offer their help, accept it.

Feeling guilty about accepting help is normal. But needing support isn't a sign of weakness or failure. The less overwhelmed you feel, the better you'll be able to take of yourself.

#### Bring someone to your appointments with you

If you feel comfortable, bring someone you trust to your appointments with you. They can help you take notes or ask questions that you might forget in the moment. They may hear things that you miss or ask your healthcare provider questions to help you understand. If someone cannot join you in person, you can call or video chat with them during your appointment.

#### Take an active role in your care

You're a part of your care team, and your voice matters most. Be engaged in your care by speaking up for yourself in all discussions and decisions about your care.

Ask questions and talk with your care team about any concerns you have. Tell them how much or how little information you want to know. You can also tell them how you prefer to get this information. You know what is best for you. Make sure your care team understands your needs and what is important to you. For more information, read *A Guide for Adolescents and Young Adults (AYAs): How To Be a Self-Advocate* (www.mskcc.org/pe/aya\_self\_advocate) and *A Guide for Adolescents and Young Adults (AYAs): Questions To Ask Your Care Team* 

(www.mskcc.org/pe/aya\_questions\_to\_ask).

# Tell your care team who they can share your health information with

Be clear with your care team about who they can share your health information with. Someone may be coming to your appointments or calling your healthcare providers for you. Let your care team know it's OK for that person to hear about your care.

#### Be kind to yourself

Remember to be kind to yourself. You're experiencing a lot of different stresses and emotions. You may need extra help or someone to talk to, and that's OK.

Talk to your friends and family so you don't feel alone. Figure out which activities make you feel good and do them as often as you can. Some examples are:

- A hobby, such as cooking or playing a musical instrument.
- A physical activity, such as yoga or walking.
- A creative activity, such as writing or painting.

#### Reach out to the AYA Program

If you need help, have questions, or want more resources, email the AYA Program at <a href="mailto:ayaprogram@mskcc.org">ayaprogram@mskcc.org</a> or call 646-608-8336. There is a group of dedicated professionals available to help you as

an AYA patient. Visit www.mskcc.org/aya for more information.

If you have questions or concerns, contact your healthcare provider. A member of your care team will answer Monday through Friday from 9 a.m. to 5 p.m. Outside those hours, you can leave a message or talk with another MSK provider. There is always a doctor or nurse on call. If you're not sure how to reach your healthcare provider, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

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