Memorial Sloan Kettering Cancer Center

PATIENT & CAREGIVER EDUCATION

A Guide for Adolescents and Young Adults (AYAs): How To Be a Self-Advocate

This information explains what self-advocacy (AD-vuh-kuh-see) is and how you can be a self-advocate (AD-vuh-kit) during your cancer treatment. It also lists support resources offered at MSK and other organizations.

What is self-advocacy?

Self-advocacy is being able to speak up about your needs, values, and priorities. Being a self-advocate can help you:

- Learn more about the kind of cancer you have and better understand your diagnosis.
- Talk with your care team about what you need and what's most important to you in your care.
- Learn about treatment options and think about the risks and benefits of each one.
- Choose the treatment that's right for you.

Self-advocacy can be hard

It's normal for self-advocacy to feel hard at first. Getting a cancer diagnosis and learning about the different treatment options is overwhelming.

You also probably have more healthcare providers and appointments now than ever before. It can be uncomfortable to ask questions or talk about serious things when you're not used to it.

It may seem easier to have your care team make all your treatment decisions because they're the cancer experts. You may also be used to your parents or caregivers making the decisions about your care.

But over time, you may want to take a more active role in managing your care. Your care team and parents or caregivers may not always know what's best for you as a person. You're the expert in your own needs, values, and priorities.

Self-advocacy is important

You're part of your care team, and your voice matters the most. Talking with your care team about your needs, values, and priorities is important. It helps them provide the best care for you, which makes your quality of life better.

Your parents or caregivers may be good advocates, but the person who can speak best for you is you. Self-advocacy can be hard at first, but it's a valuable skill to learn. Practicing will help build your confidence so you're able to speak up and advocate for your own needs.

How can I be a self-advocate?

There are lots of ways you can advocate for yourself. Here are some things you can do.

Learn about cancer and treatment options

Learn more about the kind of cancer you have and treatment options for it. This can help you better understand your diagnosis. It can also help you make treatment decisions that are right for you. Here are some ways you can learn.

Ask your care team

Besides being your healthcare providers, you can think of your care team as your teachers, too. You can learn a lot about your care by asking them questions.

Your care team is your best source of information because:

- They know your medical history and cancer diagnosis.
- They have special training in caring for people your age.
- They use the newest, best treatment methods.

If you want more information after talking with your care team, ask them for educational materials. They may give you written information, such as a handout, or share a video.

Look online

You can also search for information online about the kind of cancer you have and treatment options for it. But it's important to remember that not all websites are reliable (trustworthy). Many websites can have wrong or old information.

Before you look online, ask your care team for suggestions about which websites to visit.

Which websites are reliable?

Reliable websites have information that's updated often by experts. The American Cancer Society (www.cancer.org) and the National Cancer Institute (www.cancer.gov) are examples of reliable websites. You can find other reliable websites in the "External resources" section of this resource. You can also visit MSK's Patient and Caregiver Education website at www.msk.org/pe to search for materials.

For more information on how to find information online,

read *How To Find Health Information You Can Trust* (www.mskcc.org/pe/find-information).

Health information on social media

Many people look on social media for cancer information. Just like websites, social media accounts can have wrong or old information. Some accounts may only have opinions on a topic, with no scientific facts or evidence (proof) to back them up.

That's why it's important to only follow accounts from reliable sources, like the ones listed above. They will always have the most current and correct information.

Think carefully about the information you find on social media. Some of the tips and advice offered in posts, chat rooms, and discussion forums may not apply to you. What worked for one person may not work for you. Always talk with your care team before trying anything new.

Communicate with your care team

You will get lots of information and instructions during your care. This can be overwhelming and stressful. Your care team knows this and wants you to communicate with them. It's OK and expected to:

- Ask them questions.
- Share your thoughts and feelings with them.

- Use MSK MyChart to communicate with them between visits.

Ask questions

An important part of being a self-advocate is asking questions. Asking questions can help clear up any confusion or ease any worries you may have about your care.

A great way to keep track of your questions is to make a list. You can use a note-taking app on your phone or a notepad.

Bring the list to your appointments. At the start of your appointment, tell your care team that you have questions for them. This helps them set aside time to answer what's most important to you. Make sure to write down their answers so you can go over them later.

For examples of questions you can ask your care team, read *A Guide for Adolescents and Young Adults (AYAs): Questions To Ask Your Care Team* (www.mskcc.org/pe/aya-questions-to-ask).

When your care team is answering your questions, make sure you understand what they're saying. If you're confused or unsure about anything, speak up.

- If you don't know what a word means, tell your care

team. They can explain what it means using words you understand.

- If you don't understand something, ask your care team to explain it in a different way. You can even ask them to draw a picture if you think it will help.
- If your care team gives you instructions that are not clear, ask them to explain it again. You can also ask them to write it down for you.

Repeat your questions until you fully understand the answers. You will not be bothering your care team or taking up their time. Their job is to make sure you feel comfortable and understand the information they're giving you.

Remember, your care team is here to support you and answer all the questions you have.

Share your thoughts and feelings

You may have many feelings about your diagnosis and treatment. Many people feel angry, afraid, sad, and worried. Everything can feel overwhelming, but there are ways you can cope with your fears and worries.

- **Tell your care team about all the feelings you're having.** Sharing your feelings with them can help ease your mind and lessen your worries.

- **Ask your care team for support when you need it.** Asking for support is a sign of strength, not weakness. Your care team will listen to your concerns, comfort you, and give you guidance. They can also refer you to mental health experts, such as counselors and social workers, who can help you.

There may be times when you disagree with your care team about parts of your treatment plan. Or, you may feel that some of your healthcare needs are not being met. It's OK to have these thoughts.

When you have them, make sure to talk with your care team about it in a respectful way. Sharing your thoughts about your care and asking for what you want is part of being a self-advocate. It helps your care team make a treatment plan that's right for you.

It may take some time before you're comfortable sharing your thoughts and feelings with your care team. That's OK. Your care team will be here for you whenever you're ready.

Use MSK MyChart

Sometimes you can forget to ask your care team an important question. Or, you may feel uncomfortable asking them a question in person. If this happens, you can send them questions through MSK MyChart, MSK's patient portal.

Your care team will watch for MSK MyChart messages from Monday to Friday. If you send your message on a weekend, they will not see it until Monday. For more information, read *Communicating With Your Care Team: When to Call or Use MSK MyChart* (www.mskcc.org/pe/communicating-using-mychart).

Do not send urgent or emergency questions (for example, if you have a fever or are bleeding) through MSK MyChart. Call your doctor's office right away so you can be treated. If it's after 5 p.m., during the weekend, or on a holiday, call 212-639-2000. Ask to talk with the person on call (covering) for your doctor.

If you don't have an MSK MyChart account, visit mskmychart.mskcc.org or call 646-227-2593 to sign up.

Let your family and friends help you

Part of being a self-advocate is understanding that you can't do everything alone. Everyone needs help now and then. Sometimes, you may need help from a loved one, such as a friend or family member. Here are some ways they can help you.

Ask them for support

There are many ways a friend or family member can support you. They can offer emotional support and

comfort. Or, they can take a more active role in supporting you during treatment. Examples of this can be keeping track of your medications, tests, and procedures, or helping with meals and chores. Tell your loved one the kind of support you will need from them.

Ask them to advocate with you

While advocating for yourself is important, you don't always have to do it alone. It's helpful to have a friend or family member advocate with you, too.

There are many things they can do, such as help you research your diagnosis and treatment options. They can also help you make a list of questions for your care team. If you're uncomfortable or have trouble asking your care team questions, they can ask questions for you.

Ask them to go to appointments with you

Bringing a friend or family member to your appointments can help keep you calm and relaxed. They can sit with you in the waiting room, exam room, or while you're getting treatment.

If they can be in the exam room with you, they can also help by taking notes. This lets you listen to your care team while they write down what's being said. You can use these notes to help you remember important information from your visit.

To keep patients and staff safe and healthy, MSK's visitor policy may change from time to time. Visit www.msk.org/visit for the latest visitor policy information.

Talk with other AYA patients

Connecting with other AYA patients is another way you can be a self-advocate. You may find it comforting to talk with other people going through treatment. They may be feeling the same way you do. You can learn how they deal with their treatment and remember that you're not alone.

There are many ways to connect with other people, such as:

- **Joining a support group.** MSK's Young Adult Support Group is an online support group for young adults (ages 21 to 39) getting treatment at MSK. A social worker leads discussions about the special experiences of young adults who have cancer. Visit www.msk.org/event/young-adult-support-group for more information or to register.
- **Joining a virtual program.** 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.msk.org/events and searching for "young

adult."

- **Using The Lounge at MSK App.** The Lounge App is a private, social media platform for MSK patients ages 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 tyaprogram@mskcc.org to get an access code.

MSK Resources

Adolescent and Young Adult (AYA) Program

The AYA Program helps young adults meet the special challenges they face during cancer treatment. Working with your care team and specialty services, this program offers support with:

- Life outside of cancer treatment.
- Fertility and sexual health.
- LGBTQI+ resources.
- Working, going to school, or both during cancer treatment.
- Financial and insurance support.
- Mental health resources and counseling.
- Tips for managing treatment side effects.

For more information about the AYA Program, email ayaprogram@mskcc.org or call 646-608-8336.

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).

External Resources

Cancer.net's Taking Charge of Your Care

www.cancer.net/navigating-cancer-care/managing-your-care/taking-charge-your-care

This article offers helpful information on how to take an active role in your care.

Leukemia & Lymphoma Society's *Be Your Own Advocate* Patient Guidebook

www.lls.org/article/be-your-own-advocate

This resource has information to help guide you through your cancer diagnosis and treatment process. It's offered in English, Spanish, and Polish.

American Cancer Society's The Doctor-Patient Relationship

www.cancer.org/treatment/treatments-and-side-effects/choosing-your-treatment-team/the-doctor-patient-relationship.html

This article gives helpful tips on how to build relationships with the healthcare providers on your care team.

The National Coalition for Cancer Survivorship's Taking Charge of Your Care
canceradvocacy.org/resources/taking-charge-of-your-care
This resource helps you get ready for appointments with your care team. It also offers a guide to help you talk about your treatment goals with your family and care team.

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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