

### PATIENT & CAREGIVER EDUCATION

# A Guide for Adolescents and Young Adults (AYAs): Coming Out to Your Care Team

This information has tips to help lesbian, gay, bisexual, transgender, queer, and intersex (LGBTQI+) patients come out to their care team. It also lists support resources offered at MSK.

### What does "coming out" mean?

Coming out describes the process of sharing your LGBTQI+ identity with others. Coming out to your care team means talking with them about your sexual orientation and gender identity.

### Sexual orientation

Sexual orientation is the emotional, romantic, physical, or sexual attraction you could feel toward another person. Sexual orientation identities include homosexual, heterosexual, bisexual, pansexual, and asexual.

### **Gender identity**

Gender identity is how you see yourself and what you call yourself. Gender identity can be man/male, woman/female, a mix of both, or neither. It can be the same or different from your sex assigned at birth. Gender identity is something you feel inside of you. It cannot be seen by other people.

Gender identity is not the same as gender expression. Gender expression is how you choose to show your gender identity on the outside. It's how you present yourself to the world. Forms of gender expression include how you look, dress, and act.

### **Nonbinary**

Nonbinary is a gender identity for people who do not identify as only male or female. Someone who is nonbinary may feel like a mix of male and female. Or, they may feel like they have no gender at all.

### **Transgender (Trans)**

Trans is a gender identity for people who do not identify with their sex assigned at birth. A trans person may have the body of one gender but feel like another gender on the inside. Many trans people feel like they were born into the wrong type of body.

A trans woman is someone who was assigned male at

birth but now identifies as a woman. A trans man is someone who was assigned female at birth but now identifies as a man.

Some trans people may not identify as either male or female. Others may identify as a mix of male and female.

### Do I have to come out to my care team?

It's normal to feel stressed, worried, afraid, very sad, or hopeless after learning you have cancer. For LGBTQI+ patients, it's also normal to question if you should come out to your care team.

It can be hard to talk with them about your sexual orientation and gender identity. You may be overwhelmed because you're already dealing with cancer. It also can feel uncomfortable to talk about the topic. You may be unsure of how to start, or worried about how they may react.

We understand you may be afraid or worried about coming out to your care team. You do not have to come out to them if you do not want to. But if it's an important part of who you are, it may help for them to know. Coming out could make things easier or less stressful for you. It also helps your care team give you the best care.

Making the choice to come out to your care team can be

hard. But it's a personal choice that only you can make. Whatever you choose, your care team is here to support you.

### Is it safe to come out to my care team?

Coming out to your care team can feel scary and unsafe. You may have had bad experiences in the past that made you not trust healthcare providers. You may have faced discrimination (being treated less well or unfairly) because of your sexual orientation or gender identity.

MSK is committed to diversity, equity, and inclusion. We want people of all sexual orientations and gender identities to be treated fairly. We want you to feel welcome and included.

Your care team is here to support you, not judge you. Whether you identify as LGBTQI+ or are exploring your sexuality or gender identity, you're in a safe space here.

At MSK, your care team will:

- Treat you with fairness, dignity, and respect.
- Listen to your concerns and give you support.
- Offer affirming and inclusive healthcare.
  - Affirmative healthcare values and respects your identity and experiences and offers care that meets

your specific needs. It creates a safe space where you can be your authentic self without fear of judgment or discrimination.

 Inclusive healthcare is care that's open and welcoming to all. It ensures everyone has access to healthcare services, no matter their sexual orientation, gender identity, age, race, disability, etc.

We know the process of coming out in a healthcare setting is not the same for everyone. Some people may choose to come out when they first meet their care team. Others want to wait until they find someone on their care team they're comfortable with.

It may take some time before you feel safe to come out to your care team. That's OK. Your care team will be here for you whenever you're ready.

### What if I'm not out to everyone in my life?

You can come out to your care team even if you haven't come out to your loved ones. Your care team will keep this information private. Remember, you're in a safe space at MSK. Our social workers, counselors, and medical staff are here to support you in any way we can.

## Why is it important to come out to my care team?

Cancer does not affect everyone the same way. You will get different tests and treatments than someone else. Treatment is based on many things, such as your sex assigned at birth, gender identity, or sexual orientation.

That's why it's important to be open and honest with your care team. It helps them make a treatment plan that's right for you.

If you choose to come out to your care team, it's important to share this information with them:

### Your chosen name and pronouns

Some people may have a chosen name they would like to be called while getting care at MSK. A chosen name is a name you use that's different from your legal name. Your legal name is the name that's listed on legal documents, such as your birth certificate.

### A chosen name can be:

- Any name that's different from your legal name.
- A nickname.
- An affirming name (a chosen name that represents your gender identity). For example, a transgender woman named "James" at birth may choose "Jessica" as an affirming name.

If you want to share your chosen name, tell your care team. They will use it whenever they can. Sometimes, they may ask you to confirm your legal name for your medical records and other reasons, such as:

- To check your health insurance and make sure your plan covers your care.
- To follow MSK's rules for identifying patients. This is important for your safety.

Some people may have pronouns they would like others to use when referring to them. Examples of pronouns are he/him/his, she/her/hers, and they/them/theirs.

If you want to share your pronouns, tell your care team.

Make sure to tell them if you use a mix of pronouns or use different pronouns in certain cases. Your care team can use your chosen pronouns even if they're different from what's listed in your medical records.

We understand that sexual orientation and gender identity are fluid and may change over time. You may change your chosen name or pronouns more than once during your care. If you do, that's OK. Just let your care team know.

### If you identify as trans, nonbinary, or both

As cancer patients, trans and nonbinary people often face special challenges. One example is misgendering. This is when healthcare providers use your wrong gender or pronouns. This often happens if the sex listed in your medical records is different from your gender identity.

Being misgendered can be stressful. It can make you feel like you're not being understood or respected. It also can affect your care if you need tests or treatments that conflict with your gender identity.

That's why it's important to tell your care team if you identify as trans, nonbinary, or both. It prevents them from making assumptions about you and misgendering you. It also helps them understand you better. They can

build a trusting relationship with you.

### Person-centered and gender-affirming care

Knowing that you identify as trans, nonbinary, or both helps your care team understand your specific healthcare needs. It lets them offer person-centered and gender-affirming care with compassion and respect.

If you're transitioning, they'll take your gender identity into account when planning your treatment. That includes your transition stage.

Knowing how you identify also helps your care team make sure you get the right treatment for your body. Examples of this are:

- Giving you the correct doses (amounts) of cancer treatment, such as chemotherapy. This is based on your sex assigned at birth.
- Screening you for certain kinds of cancer. This is based on your sex assigned at birth. It also can be based on any gender-affirming hormones you've taken or gender-affirming surgeries you've had.

### **Organ inventory**

If you identify as trans, nonbinary, or both, your care team may take an organ inventory. This is a document they create that lists your internal anatomy (all the organs in your body). It also lists any gender-affirming surgeries you've had.

An organ inventory helps your care team:

- Know what body parts you have and how you refer to them.
- Identify any extra cancer screenings you may need.
- Talk with you about your body and any health concerns you may have.
- Explore family planning options with you, if you think you may want biological children in the future.

### What medicines you take

Make sure your care team knows all the medicines you take, including prescription and over-the-counter medicines, patches, and creams. A prescription medicine is one you can only get with a prescription from a healthcare provider. An over-the-counter medicine is one you can buy without a prescription.

It's very important to tell your care team about all the medicines you're taking. You may need to change your dose or stop taking a certain medicine before you start treatment. This is because certain medicines can harm your body if you take them during treatment.

For example, you may take PrEP (pre-exposure prophylaxis) to prevent HIV and Doxy PEP (doxycycline post-exposure prophylaxis) to prevent sexually transmitted infections (STIs). If you take these medicines while on certain chemotherapy drugs, they can harm your kidneys. That's why knowing what medicines you take can help your care team plan for your care safely.

### If you're getting gender-affirming hormone therapy (GAHT)

It's important to tell your care team if you're getting GAHT or plan to. If you're getting GAHT, you may need to stop it before you start treatment. This is because GAHT can make some treatments less effective (not work as well as they should).

Not everyone needs to stop GAHT during treatment. You may be able to keep getting it, based on the cancer you have and your treatment plan. Talk with your care team before you choose to stop GAHT.

### Who your caregivers are

It's important to have a support system of loved ones around you during your cancer treatment. Loved ones who help care for you are called caregivers.

Caregivers can be spouses, partners, close friends, or

family members. This includes members of your legal or biological family (blood relatives), and members of your chosen family. Your chosen family accepts and trusts you, whether or not they're blood relatives.

If you have caregivers, tell your care team who they are and their relationship to you. Have your caregivers and members of your care team schedule time to meet each other if they can.

It's also important to tell your care team who they can share your health information with. Someone may come with you to appointments or call your healthcare providers for you. Tell your care team it's OK for that person to hear about and be involved in your care.

# What are some tips to help me come out to my care team?

Here are some tips to help make coming out to your care team easier.

### Look for a way to start to talk

It can be hard to talk about your sexual orientation and gender identity with your care team. If you're not sure how to start, try looking for the right opening.

If someone uses the wrong pronoun, that's your chance to gently correct them. You can say, "Can you please call me they?" Then from there, you can talk about coming out.

If someone asks if you have any questions or concerns, you can say:

- "There's something I need to tell you."
- "I want to share information about my sexual orientation and gender identity."
- "I want to tell you about my partner/spouse."
- "I'm taking hormones as part of my transgender treatment. How will this affect my cancer treatment?"
- "How do you handle private patient information?"

### Bring a loved one with you for support

You do not have to come out to your care team alone. You may feel more comfortable if a loved one is with you. Coming out may be easier if you have someone there to give you comfort and emotional support. This can be a partner or spouse, family member, or friend.

If your partner or spouse is with you, just introduce them as your partner or spouse. It's an easy way to come out or start talking with your care team.

It can also help to practice what you're going to say with someone you trust. Think about questions your care team may ask you. Then, practice how you'll answer them. There's no right or wrong way to have this talk.

### **Ask questions**

It's important to learn about your care team's experience in LGBTQI+ care. The best way to do this is to just ask them. Their answers can help ease worries you may have about coming out.

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.

Here are some examples of questions to ask your care team:

- Do you have experience in caring for LGBTQI+ patients? Can you give examples of how you've supported LGBTQI+ patients in the past?
- Do you ask for pronouns and respect chosen names?
- How do you keep LGBTQI+ patients safe?
- Do you know about the health needs of different LGBTQI+ groups, such as trans people or queer people of color?
- How do you handle patient privacy and confidentiality? How do you handle this for LGBTQI+ patients who may not be out to everyone in their

lives?

 What LGBTQI+ support resources are available to me at MSK?

Once you make a list, bring it with you to your next visit. At the start of your visit, tell your care team 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.

### Share this information in writing

Some people may not feel comfortable coming out in person, over the phone, or during a telemedicine visit. You can write the information instead.

A good place to write it down is on a health questionnaire or intake form. Most people fill out these forms when they first become a patient at MSK.

You also can send a message to your care team through MSK MyChart, our patient portal. Your care team gets MSK MyChart messages from Monday to Friday. If you send your message on a weekend, they'll see it on Monday. To learn more, read *Communicating With Your Care Team: When to Call or Use MSK MyChart* (https://sandbox18.mskcc.org/pe/communicating-using-mychart).

### Only share what you're comfortable with

You may not be ready to share everything about your sexual orientation and gender identity right away. That's OK.

If you choose to come out to your care team, you do not have to share everything all at once. When you're ready, start off by sharing the information you're comfortable with.

You should never feel pressured to share your sexual orientation and gender identity with your care team. By law, they cannot ask you questions about this information if you choose not to share it with them.

It's very brave to choose to come out to your care team. They understand this and will support you any way they can. They will always respect your right to get care as your true, authentic self.

Remember, there's no right or wrong way to come out to your care team. Try to do what feels most comfortable for you, in your own time and in your own way.

# What does MSK do to support LGBTQI+ patients?

Here are some ways MSK supports and improves care for LGBTQI+ patients.

- Rainbow badges and lanyards: You may see some members of your care team wearing a rainbow badge or lanyard. This means they support the LGBTQI+ community and may even be LGBTQI+ themselves. You can talk with them about LGBTQI+ needs.
- Sexual Orientation and Gender Identity (SOGI)
  Program: This program lets new adult patients share
  SOGI information, such as their pronouns, if they want
  to. We add this information to their confidential and
  secure electronic medical records.
- LGBTQI+ Clinical Advisory Committee: This group, which includes patient representatives, advises MSK staff on the medical care of LGBTQI+ patients.
- The Human Rights Campaign Foundation's LGBTQ+ Healthcare Equality Leader: Since 2013, MSK has been named an LGBTQ+ Healthcare Equality Leader by the Human Rights Campaign Foundation. This honor is for MSK's commitment to putting inclusion policies and practices in place for LGBTQI+ patients and staff.

### **MSK** resources

### LGBTQI+ Support Resources

This patient education resource lists support groups and community organizations available to LGBTQI+ patients and their loved ones. You can find it at <a href="https://www.msk.org/pe/lgbtq\_resources">www.msk.org/pe/lgbtq\_resources</a> or ask your care team for a printed copy. You also can visit MSK's Patient and Community Education website at <a href="https://www.msk.org/pe">www.msk.org/pe</a> to search for more LGBTQI+ resources.

### **LGBTQI+ Cancer Care Program**

This program provides a safe, welcoming space for LGBTQI+ people getting screened or treated for cancer at MSK, or in our survivorship program. Our experts in caring for LGBTQI+ people are here to guide and support you during and after cancer treatment. You can talk with them about your care goals, treatment, and healthcare challenges. To learn more, visit www.msk.org/experience/patient-support/lgbtqi-cancer-care-program

# Outpatient Active Treatment Support Group for LGBTQ+ Patients and Caregivers

This is an online support group for LGBTQ+ MSK patients who are in active treatment, and their caregivers. Group members learn ways to cope with

cancer, share information and experiences, and support each other. To learn more or register, visit *Outpatient Active Treatment Support Group for LGBTQ+ Patients and Caregivers* (https://sandbox18.mskcc.org/cancer-care/patient-education/outpatient-active-treatment-support-group-lgbtq-patients-and-their-caregivers).

### **Adolescent and Young Adult (AYA) Program**

Learning you have cancer or a blood disorder in your teens or early adulthood is very challenging. MSK's AYA Program helps support young people ages 15 to 39. This program aims to meet your needs during your care at MSK. Visit www.msk.org/aya to learn more.

Working with your care team and specialty services, this program offers support with:

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

To learn more about the AYA program, email ayaprogram@mskcc.org or call 646-608-8336.

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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