



TRANSFORMING CHOICES

HEALTHCARE DECISIONS
STARTER GUIDE

TRANSFORMING CHOICES is a guide to help you make choices about your healthcare now and later in life. It is also a tool to help you talk about your choices with your healthcare team and people you trust.

Who may benefit from this guide?

Older transgender, gender-diverse, and gender-expansive people at any stage of transition or state of health who would like to make informed decisions about their healthcare now and in later life

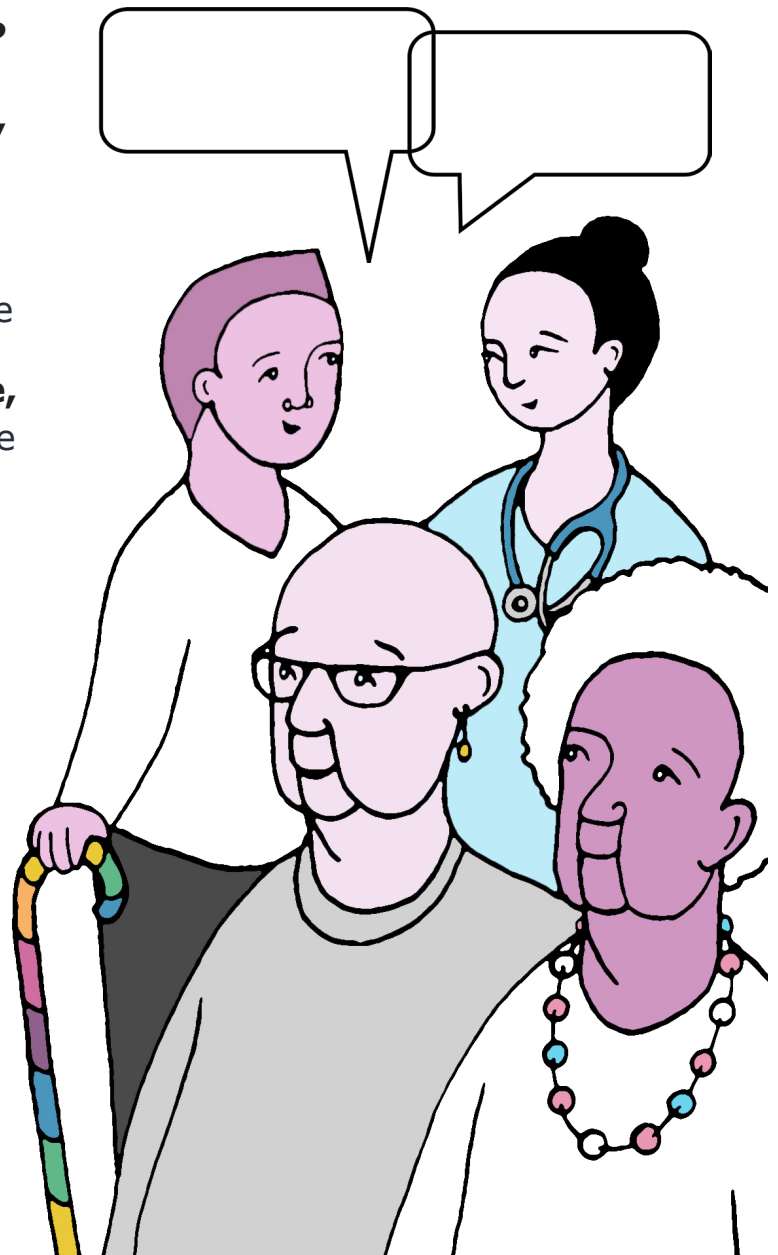
Younger transgender, gender-diverse, and gender-expansive people who have a serious illness or who want to know what to expect for their care in later life

Healthcare professionals and care partners who are helping transgender, gender-diverse, and gender-expansive people make decisions about their care

What's inside this guide?

Find tools to help you navigate health care decisions now and in later life.

Click the icons below to jump ahead if you are viewing the guide electronically



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HOW TO USE THIS GUIDE

READ IT

Read [Information](#) about healthcare for transgender, gender-diverse, and gender-expansive people

WRITE ON IT

Write down what matters to you about your healthcare using the healthcare decisions [Worksheet](#)

TALK ABOUT IT

Discuss wishes for your care with people in your support network and healthcare professionals you trust

RECORD IT

Document your wishes using a form called an advance directive. Check out the [Resources](#) section for more

REPEAT IT

Your choices are not fixed or final!

Your wishes may change over time, so use this guide as often as needed!

TALK ABOUT IT, AGAIN

When your choices change, tell people in your support network and healthcare professionals you trust

NAVIGATE IT

The icons below represent different topics in this guide. Click or follow each icon to view related content.



TRANSITIONING



HEALTH CARE



SERIOUS ILLNESS



LONG-TERM CARE



PREPARE & SHARE



ABOUT THE GUIDE

This guide does **not** contain medical or legal advice. Consult a healthcare professional or an attorney before making medical or legal decisions.

INFORMATION



In this section you'll find a list of keywords and answers to frequently asked questions about healthcare in later life or during a serious illness for trans, gender-diverse, and gender-expansive people. This section provides an overview of available evidence and will be updated as new research comes out.

KEYWORDS

[Transgender \(Trans\)](#)

A word to describe gender identities that differ from sex assigned at birth

[Gender-diverse, Gender-expansive](#)

Words to describe a wide range of gender identities, like *nonbinary*, *genderfluid*, *gender nonconforming*, and others, that differ from societal gender norms

[Gender-affirming care](#)

Social, psychological, medical, surgical, and legal measures that support your gender identity and expression

[Long-term care](#)

Services, like nursing home care, that meet your health and personal care needs when you can no longer do everyday activities on your own

[Serious illness](#)

A health condition, like cancer, heart failure, or Alzheimer's disease, that has a negative impact on daily function and quality of life

[Palliative care](#)

Specialized medical care focused on relieving symptoms during a serious illness

[Hospice care](#) is a type of palliative care for people at the end of life

[Advance directive](#)

A legal document used to record your healthcare wishes if you are unable to make your own medical decisions because of a serious illness

[Healthcare proxy](#)

A trusted person, like a family member or friend, whom you authorize to make medical decisions for you if you are unable to do so

FREQUENTLY ASKED QUESTIONS



Is it possible to start transitioning later in life? What if I have an existing health condition?

It's possible! But it's important to talk to a healthcare professional who can help you weigh the pros and cons of your [gender-affirming care](#) options and what the risks would be based on your age and any health conditions you have.

EXAMPLE *A trans or gender-diverse older adult with a heart condition may need special precautions to prevent complications during gender affirmation surgery.*



Does my healthcare team need to know my sex assigned at birth and details about my transition?

It can be difficult to share information about your gender identity with your healthcare team. Healthcare professionals need to know this information to be able to recommend screenings, lab tests, treatments, and procedures that are right for your body. Many health systems collect information on sexual orientation and gender identity to ensure patients get care that is affirming and inclusive.

EXAMPLE *A transman may need to have routine screening for breast cancer, even after top surgery, depending on his family history and other factors.*

TIPS for talking to a healthcare provider about your gender identity:

- Ask around or search [online](#) for LGBTQ+ friendly medical practices
- Call ahead to ask whether a medical practice sees LGBTQ+ patients
- Bring a trusted person with you to your appointment
- When you feel comfortable, ask your provider for time during an appointment to talk about topics related to your gender identity



What should I know about getting support for my mental health and well-being?

With transphobia and anti-trans policies on the rise, coping with everyday life stressors may be all the more difficult for trans, gender-diverse, and gender-expansive people. It is important to ask for support from your community or trained professionals, especially if you are having thoughts of hurting yourself. Consider individual counseling, peer support groups, or calling a support line. For caregivers of people with serious illness, consider joining a care partner support group to prevent burnout.

EXAMPLE *A gender-expansive person who cares for their ailing spouse joins an LGBTQ-friendly care partner support group.*



What should I know if I go to the hospital for a surgery or an emergency?

In our fast-paced healthcare system, going to the hospital can be an overwhelming experience for any person, and trans, gender-diverse, and gender-expansive people may face unique challenges. Hospital providers may not have training in LGBTQ+ health or know about a person's individual gender history, so even the simple choice between a urinal or a bed pan could lead to uncomfortable or disaffirming conversations. If possible, have someone with you at the hospital who can speak up for you.

EXAMPLE *A nurse asks a trans person about their history of gender-affirming procedures to make sure a urinary catheter of the right size is used during their upcoming abdominal surgery.*

TIP To prepare ahead of time for unplanned or emergency hospital visits, think about scenarios you might face and make a plan for how you or a support person could respond to them.



What should I know about long-term care?

Older trans, gender-diverse, and gender-expansive people in [long-term care](#) settings, like nursing homes, may need assistance with personal care related to their gender identity from nurses and nurse's aides. They may also need to consider their gender preferences for rooming arrangements.

EXAMPLE *A transwoman living in a nursing home may need help with daily facial shaving as an essential part of her care.*



What should I know about care during a serious illness?

During a [serious illness](#), you may receive [palliative care](#) to ease your symptoms, and you may benefit from [hospice care](#) if you are near or at the end of your life. You can also weigh the pros and cons of continuing certain gender-affirming treatments and procedures with your healthcare team.

EXAMPLE *A trans person with dementia may be able to stop certain gender-affirming procedures to promote comfort if medically indicated.*



Why should I prepare for my care in later life?

Preparing for your care can help you identify and share your wishes with people in your support network and your healthcare team. Consider completing an [advance directive](#) and choosing a [healthcare proxy](#), especially if you would like someone outside your biological family to make healthcare decisions for you if you get sick.

EXAMPLE *A nonbinary person may choose a close friend as their healthcare proxy because they trust her to follow their wishes.*

WORKSHEET



Name/Pronouns _____ Date _____

Use this worksheet as a tool to help you make choices about your healthcare and to talk about your wishes with trusted people involved in your care.



Think about what matters to you about your healthcare. Check the statements below that align with your values.

- I value being **treated with respect** when I need healthcare as I age.
- I value being able to get **care that is affirming** to my gender identity.
- I value having **a voice to make decisions** about my healthcare.
- I value having people in **my support network involved in my care**.
- I have **other values**. (Please explain below or on [Page 10](#))



What would be important for healthcare professionals to know about you to provide the best care possible?



If you are just starting your transition journey, rank the goals below from 1 (most important) to 5 (least important). (Rank values of equal importance with the same number)

- ___ I would like to transition **socially** (name, pronouns, clothing).
- ___ I would like to transition **legally** (legal ID, gender markers).
- ___ I would like to start **hormone treatments/HRT**.
- ___ I would like to have **gender affirmation surgery**.
- ___ I have **other transition goals**. (Please explain on [Page 10](#))



How important would it be for you to get gender-affirming medical or surgical care if you had a health condition that could put you at risk for complications? (Select one)

- It would be **very important** to me. I accept the risks and I would like to find a way to receive gender-affirming treatment(s).
- It would be **important** to me, but it's not worth the risk. I'd like to know what other options I have.
- I am **not sure how important** it would be to me until it happens.
- I would say **something else**. (Explain below or on [Page 10](#))



If you were hospitalized or you were going to live in a long-term care residence, like a nursing home, what would be your rooming arrangement of choice? (Select one)

- I would like a roommate with the **same gender identity** as me.
- I would like a roommate with the **same sex assigned at birth** as me.
- I would like a roommate of **any gender identity**.
- I would like to have a single room with **no roommate**, if possible.
- I would like a **different arrangement**. (Explain below or on [Page 10](#))



If you were unable to keep up with grooming, dressing, and other personal care activities on your own, what would be important for the people caring for you to know?

CONSIDER preferred clothing type, accessories, shaving, makeup, etc.





Thinking about end-of-life circumstances, what would you like people in your support network and your health care team to know about your care? (Select all that apply)

- I would like to have end-of-life care that is respectful and affirming to my gender identity and sexual orientation.
- I would like to receive gender-affirming hormones for as long as it is possible for me.
- I would like some gender-affirming treatments to be discontinued:
- I would like people in my support network to be with me. Name(s):
- I would like something else. (Use the space on [Page 10](#) to explain)



Which steps would you like to take to prepare for your future care? (Select all that apply)

- Talk to someone in my support network about what matters to me.
- Talk to a healthcare professional about what matters to me.
- Sign papers (advance directive) to document what matters to me.
- Sign papers to name a healthcare proxy who knows my wishes.

Who could you ask?



Have you already taken steps to prepare for your care?

You can attach a copy of your documents to this worksheet. Make sure to give copies to your healthcare proxy and to your healthcare provider for your medical record.

This worksheet is **not** an advance directive. Find the advance directive form for your state [online](#) or check out the [Five Wishes](#), a form that meets requirements in nearly all states. In most cases, you can prepare these documents *without* an attorney.



Use the space below to answer any question in more detail or to write down anything else that is important to you about your care.

TALKING TO YOUR TEAM

You can start a conversation with your healthcare team about what you wrote down on this worksheet. Here are some tips:

- **Save a copy** of this worksheet on your phone or print a paper copy
- **Bring a digital or paper copy** of the worksheet with you to an appointment with a medical provider you trust
- **Bring a trusted person** with you to the appointment for support
- **Choose a couple topics** to focus on when talking with your provider
- **Start the conversation** with something like, “I’ve been thinking a lot about my health. I’d like to talk more about what to expect in the years ahead and how I can prepare myself for future medical decisions”
- **Discuss a couple topics** you would like to cover with your provider
- **Follow up** on this conversation at future appointments

WRAPPING IT UP

The questions in this worksheet are meant to help you start thinking about what matters to you about your care. This guide gives a broad overview of health topics relevant to trans, gender-diverse, and gender-expansive people during a serious illness or in later life. Use this as a *starting point* for making decisions about your care. For more detailed information and support, check out the resources on the next page.



RESOURCES



RESOURCE LIST

Click the links to the right or scan the QR code below to access resources that can help you learn more about your healthcare and how to prepare for it in the future.

Among these resources you'll find:

[A tool to find affirming long-term care](#)

[Information about cancer care](#)

[A toolkit for advance care planning](#)

CHECK IN

Thinking about your future health and possible illnesses can be difficult. If you would like to talk to someone about how you're feeling, seek support from a trusted person, speak with a counselor, or check out [SAGEYou](#), a site with support options for LBGTQ+ older adults.

CONTACT US

info.transformingchoices@gmail.com
transforming-choices.org

Click or scan the QR code to view the guide online



TRANSITIONING

[Later Life Transitioning](#)
TRANScestors, Vol. [1](#) & [2](#)



HEALTH CARE

[Standards of Care](#)
[Know Your Rights](#)



SERIOUS ILLNESS

[Serious Illness Workbook](#)
[LGBTQIA+ Cancer Care](#)



LONG-TERM CARE

[Housing & LTC](#)
[LTC Equality Index](#)



PREPARE & SHARE

[Advance Care Planning](#)
[Planning for Lifelong Care](#)



CRISIS CARE

Dial 911 or [988](#)
[Trans Lifeline](#) 877.565.8860

ABOUT



TRANSFORMING CHOICES was developed as part of a research project called *Shaping Affirming Futures with Elders of all gender experiences* (SAFEage). Project contributors shared ideas for a new resource to help transgender and gender-diverse adults prepare for their healthcare in later life, and researchers put these ideas together to form this guide.

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Contributors

Twenty-one transgender and gender-diverse older adults and six professionals in healthcare, aging services, and design from across the United States whose ideas shaped this resource

Researchers

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