



Planning for Lifelong Care

**Guiding Questions for Transgender &
Non-Binary People to Plan for Dementia
and Other Serious Illness**

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It can be scary to imagine or remember times we could not advocate for ourselves in a medical setting.

Unfortunately, there may be times we cannot explain to health care workers how we want to be treated. It is common for transgender people to have our ability to make decisions questioned or disrespected. These questions and disrespect are even more common when we are Black, brown, and disabled.

Here are some examples of times we might not be able to advocate for ourselves:

We might be unconscious after an accident or an assault.

We might be having a mental health crisis.

We might have a brain injury, illness, or dementia that affects our thinking and memory.

Changes in our ability to self-advocate can be temporary or permanent.

We can do things now to prepare for times when we might not be able to say what we want or when people might not believe us. One thing we can do is make an **advance healthcare directive**. This is a legal document that tells people how we want to be treated if we cannot communicate what we want. **Advance healthcare directives** are also called "living wills," "medical directives," or just "advance directives."

As part of our advance healthcare directive, we can pick a person, or multiple people, we trust to help us make and support our decisions. This is called a **healthcare power of attorney**. This selection can also be called a "healthcare proxy" or "medical power of attorney." The official name of the advance healthcare directives and healthcare power of attorney and applicable laws vary from state to state.

Transgender People and Dementia

Dementia can make it hard to communicate with health care workers about our treatment. Dementia is a condition that can make it difficult to make decisions, remember, or think clearly. There are many types and possible causes of dementia.

Anti-Blackness and other forms of discrimination can make marginalized groups more likely to develop dementia. For example, Black and Latine/a/o elders are more likely to get dementia than white elders. Black elders are twice as likely, and Latine/a/o elders are 1.5 times as likely to develop dementia.¹

Research has started to show that transgender people are at higher risk of worsening confusion or memory loss. The risk is especially high for Black, Indigenous, and people of color (BIPOC) transgender people. We do not yet understand how dementia may affect transgender people's own sense of their gender identity.

Some people may continue to experience their gender identity as they did before

Black elders are

2x

as likely to get dementia than white elders¹

Latine/a/o elders are

1.5x

as likely to get dementia than white elders¹

dementia. Some people may experience changes in how they experience their gender. For example, someone who usually experienced their gender identity as being only a man or only a woman could begin to change their expression day-by-day or begin to experience more fluidity in their identity. Some people may begin to see themselves as the sex they were assigned at birth.

Gender-Affirming Advance Healthcare Directives

Transgender people may worry that dementia will make it hard for us to control how we express our gender. To help with this, we can think today about how we want to be treated in the future. We can write down how we want to be treated if we are not able to express our wishes ourselves. These instructions can be included in our **advance healthcare directive** and shared with our **healthcare power of attorney**, if we select one.

Questions to Ask Yourself

Here are some guiding questions to help us decide if we should include gender identity-specific instructions in our advance healthcare directive. These guiding questions were created to help with planning for dementia. They can help us think about how we would like to be treated when we are not able to express our wishes for other reasons.

1. I experience my gender identity as:

- A.** A permanent transition from my past from the sex I was assigned at birth to the gender I am now.
- B.** A fluid state--sometimes I feel masculine. Other times I feel feminine. Sometimes I may feel neither. Sometimes I may feel both. Sometimes I feel some other combination of genders.
- C.** A less binary experience--I am masculine but am comfortable with some femininity, or I am feminine but am comfortable with some masculinity.

2. If I have forgotten that I am a transgender person and begin feeling like the sex I was assigned at birth, how would I want people around me to relate to me?

- A.** I would want people to relate to my true self, the gender identity that I fought for a long time to be recognized.
- B.** I would want people to relate to me as whatever gender I present to them on any given day, regardless of my historical gender identity.
- C.** This question doesn't feel applicable to my situation.

3. The idea that I might one day have dementia and begin expressing a different gender identity:

- A.** Is deeply unsettling to me. Expression of my gender identity is one of the most important ways that I exercise control over my life.
- B.** Seems like a normal part of life for me. I would not view gender fluidity as a decline in my ability to understand myself.
- C.** This question doesn't feel applicable to my situation.

4. One of the things I worry about with dementia is that someone from my family who does not support my gender identity will try to convince my care team that I'm "not really transgender."

- A.** I worry about this and want to take actions to prevent this from happening.
- B.** This is not something I'm concerned about.
- C.** This question doesn't feel applicable to my situation.

5. I would feel less worried about dementia if I knew that people around me would have to follow my written directions about how to relate to me as a transgender person.

- A.** Yes, I would want people to relate to me with my correct name and pronouns. I would want them to continue any medical treatments needed to preserve my gender identity.
- B.** Yes, my gender identity is fluid. I would feel violated if anyone forced me to dress a certain way or be called by different pronouns than how I felt on that day.
- C.** Although I feel sure about my gender identity today, I am not sure I would want to be forced to dress a certain way or be called by different pronouns if dementia caused me to see myself as a different gender.

6. These are my values with respect to gender identity and fluidity:

- A.** My gender identity is something I fought hard to ensure that people around me recognize. I would not ever want to lose that.
- B.** Gender fluidity should be supported for people with dementia just as much as it is for people without dementia.
- C.** This question doesn't feel applicable to my situation.

7. When I think about dementia:

- A.** It is important to me to keep the gender identity I have now, even if I might feel just as sure about a different gender identity after I have dementia.
- B.** My ability to direct my own life and gender expression in the moment is most important.
- C.** It feels wrong to try to guess today what my gender identity will be in the future.

Mostly A's

If you answered mostly (a), you may want to write a gender-affirming advance healthcare directive. You may find more peace of mind when you think about dementia if you have written down the treatment you want to receive.

Mostly B's

If you answered mostly (b), you may want to write a gender fluid advance healthcare directive. You might feel less fearful about dementia if you have written about your gender fluidity. It might help your care team if you say you would like to express your gender however it feels right.

Mostly C's

If you answered mostly (c), you should still consider completing an advance healthcare directive, but specific gender identity clauses in an advance healthcare directive might not be the right answer. You might later regret having “boxed yourself in” to a particular gender identity that might not feel right anymore if you develop dementia.

Option A

Transgender-Specific Clauses for Advance Directives

You can add these clauses to the appropriate documents in your advance directive.

 [VIEW GOOGLE DOC FOR OPTION A](#)

Treatment Preferences or “Living Will”

A. RESPECTFUL RELATIONS

During any period of treatment, I direct my physician, all medical personnel, and anyone who is caring for me to refer to me by the name of _____ and to use _____ pronouns in reference to me, my chart, and my treatment, irrespective of whether I have obtained a court-ordered name change, changed my gender marker on any identification document, or undergone any gender-affirming treatment.

During any period of treatment, if I am unable to personally maintain my appearance, I direct my physician, all medical personnel, and anyone who is caring for me to do so to the extent reasonably possible, irrespective of whether I have obtained a court-ordered name change, changed my gender marker on any identification document, or undergone any transition-related treatment.

B. DEMENTIA TREATMENT PREFERENCES

I want my healthcare representatives, agents, proxies, medical providers, family members, caregivers, long-term care providers, and other loved ones to know and honor my wishes regarding the type of care I want to receive if I develop an advanced stage of Alzheimer's Disease or another incurable progressive dementia. Regardless of my physical and mental state, I would like the following treatment: maintenance of my gender-affirming healthcare and gender expression.

C. EFFECT OF STATED PREFERENCES

I realize I cannot foresee everything that might happen after I can no longer decide for myself. Still, I want whoever is making decisions on my behalf and anyone who is caring for me to follow my stated preferences exactly as written, even if they think that some alternative is better.

Healthcare Power of Attorney

Specific Powers Related to Gender Identity:

A. My Healthcare Agent's authority to act on my behalf concerning my medical care includes but is not limited to, requesting, asserting my rights to, giving consent for, and withdrawing consent for:

1. Any medical treatment related to maintaining my gender identity, including but not limited to:
 - a. Administration of exogenous hormones, including but not limited to estrogen, androgen blockers, and testosterone, as applicable;
 - b. Ongoing treatment related to surgical interventions, including but not limited to continued dilation of vagina, scar treatment such as silicone, collagen, massage, and any other medically necessary treatment, as applicable;

- c. Any other diagnostic and treatment procedures ordered by or under the authorization of a licensed healthcare provider under Medical Orders for Scope of Treatment.
 - 2. Use of my affirmed name, pronouns, and forms of address, in order to preserve my dignity as a transgender person, in any and all healthcare contexts.
 - 3. Placement, housing, clothing, grooming, medical records including death certificate, obituary, and disposition of my remains are all done in accordance with my gender identity, affirmed name, pronouns, and forms of address, including after my death. This authority takes precedence over any provision to the contrary in any prepaid funeral contract.
- B. These powers are enforceable regardless of whether I have obtained a court-ordered name change, changed the gender marker on any identification document, or undergone any transition-related medical treatment.**
- C. My Healthcare Agent may seek reimbursement for costs associated with the powers of this section from my Financial Agent.**

Financial Power of Attorney

Specific Powers Related to Gender Identity:

- A. My Financial Agent's authority to act on my behalf includes spending any funds necessary to carry out directives in my Healthcare Power of Attorney.**
- B. My Financial Agent will provide an accounting to my Healthcare Agent as frequently as reasonably requested by my Healthcare Agent demonstrating that funds are being used to carry out directives in my Healthcare Power of Attorney.**

Option B

Gender-Fluid Clauses for Advance Healthcare Directives

You can add these clauses to the appropriate documents in your advance healthcare directive.

 [VIEW GOOGLE DOC FOR OPTION B](#)

Treatment Preferences or “Living Will”

1. RESPECTFUL RELATIONS

During any period of treatment, I direct my physician, all medical personnel, and anyone who is caring for me to refer to me by the name and pronouns that I am using for myself that day in reference to me, irrespective of whether I have obtained a court-ordered name change, changed my gender marker on any identification document, or undergone any gender-affirming treatment.

During any period of treatment, if I am unable to personally maintain my appearance, I direct my physician, all medical personnel, and anyone who is caring for me to do so in accordance with my gender expression on that day, to the extent reasonably possible, irrespective of whether I have obtained a court-ordered name change, changed my gender marker on any identification document, or undergone any transition-related treatment.

2. DEMENTIA TREATMENT PREFERENCES

I want my healthcare representatives, agents, proxies, medical providers, family members, caregivers, long-term care providers, and other loved ones to know and honor my wishes regarding the type of care I want to receive if I develop an advanced stage of Alzheimer's Disease or another incurable progressive dementia. I value my gender fluidity, do not see it as a symptom of cognitive decline, and want to be supported in the gender expression that I am showing on that day or occasion, which may change in the future.

3. EFFECT OF STATED PREFERENCES

I realize I cannot foresee everything that might happen after I can no longer decide for myself. Still, I want whoever is making decisions on my behalf and anyone who is caring for me to follow my stated preferences exactly as written, even if they think that some alternative is better.

Healthcare Power of Attorney

Specific Powers Related to Gender Identity:

- A. My Healthcare Agent's authority to act on my behalf concerning my medical care includes but is not limited to, requesting, asserting my rights to, giving consent for, and withdrawing consent for:**
1. Use of the name, pronouns, and forms of address that I am using that day.
 2. Clothing and grooming in accordance with my gender expression on that day.
- B. These powers are enforceable regardless of whether I have obtained a court-ordered name change, changed the gender marker on any identification document, or undergone any transition-related medical treatment.**
- C. My Healthcare Agent may seek reimbursement for costs associated with the powers of this section from my Financial Agent.**

Financial Power of Attorney

Specific Powers Related to Gender Identity:

- A. My Financial Agent's authority to act on my behalf includes spending any funds necessary to carry out directives in my Healthcare Power of Attorney.**
- B. My Financial Agent will provide an accounting to my Healthcare Agent as frequently as reasonably requested by my Healthcare Agent demonstrating that funds are being used to carry out directives in my Healthcare Power of Attorney.**

SAGE

For 40-plus years, SAGE has worked tirelessly on behalf of LGBTQ+ older people. Building off the momentum of the Stonewall uprising and the emerging LGBTQ+ civil rights movement, a group of activists came together to ensure that LGBTQ+ older people could age with respect and dignity. SAGE formed a network of support for LGBTQ+ elders that's still going and growing today. SAGE is more than just an organization. It's a movement of loving, caring activists dedicated to providing advocacy, services, and support to older members of the LGBTQ+ community. LGBTQ+ elders fought—and still fight—for our rights. And we will never stop fighting for theirs. sageusa.org

The National Resource Center on LGBTQ+ Aging

The National Resource Center on LGBTQ+ Aging is the country's first and only technical assistance resource center aimed at improving the quality of services and supports offered to lesbian, gay, bisexual and/or transgender older adults. Established in 2010 through a federal grant from the U.S. Department of Health and Human Services, the National Resource Center on LGBTQ+ Aging provides training, technical assistance and educational resources to aging providers, LGBTQ+ organizations and LGBTQ+ older adults. The center is led by SAGE, in collaboration with leading aging and LGBTQ+ organizations from around the country. lgbtagingcenter.org

Transgender Law Center

Transgender Law Center (TLC) is the largest national trans-led organization advocating for a world in which all people are free to define themselves and their futures. Grounded in legal expertise and committed to racial justice, TLC employs a variety of community-driven strategies to keep transgender and gender nonconforming people alive, thriving, and fighting for liberation. transgenderlawcenter.org