

PALLIATIVE CARE

FINANCIAL AND
ESTATE PLANNING

3

HONORING
LIFE

1

LGBTQ+ Advance Care Planning TOOLKIT

A step-by-step guide
for the LGBTQ+ community
in preparing for healthcare needs
and end-of-life decisions

2

IMPORTANT
EMERGENCY
DOCUMENTS

LIVING WILL

4



Care and Choice at the End of Life

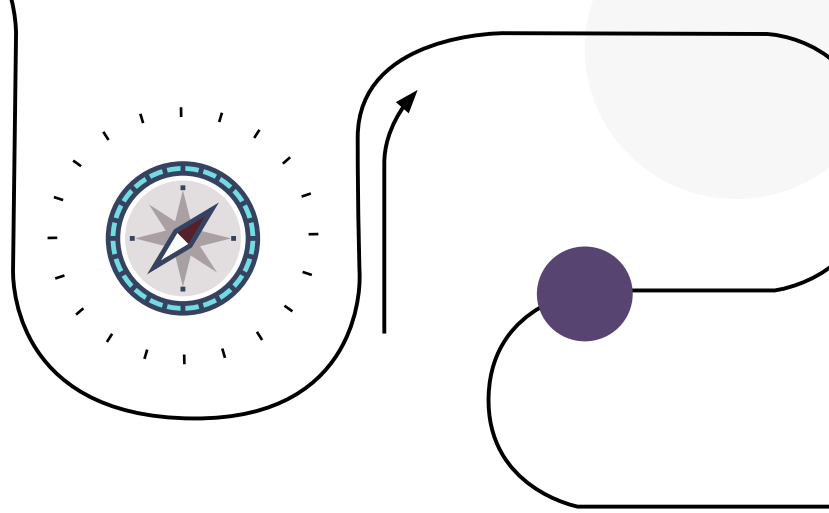
Compassion & Choices is the largest and oldest nonprofit working to improve care and expand options for the end of life in the United States, with 470,000 supporters nationwide. For more information, visit: CompassionAndChoices.org.



**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. lgbtagingcenter.org

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



Contents

INTRODUCTION 2

STEP 1 WHAT TO DO WHEN YOU'RE WELL

Healthcare Planning 3

- Health Care Proxy 3
- Living Will 6

Financial and Estate Planning 7

- Financial Power of Attorney 7
- Last Will and Testament 7
- Funeral Pre-Planning and
Disposition Rights 7

STEP 2 PREPARE FOR LIVING WITH SERIOUS ILLNESS

Caregiver Resources 9

- Letter to my Caregiver or Provider 10

Your Healthcare Team 11

- Social Worker and Social Services 11
- Find the Right Providers 12

Palliative Care for Serious Illness 13

In Case of Emergency Folder 13

- DNR and MOLST Orders 13
- Important Emergency Documents 14
- Assisted Living Facility Document 15
- Checklist for "In Case of Emergency"
Folder 16

STEP 3 END-OF-LIFE PLANNING

End-of-Life Planning and Hospice 17

- Paying for Hospice Care 17
- Hospice Care Settings 17
- Hospice and End-of-Life Resources 18
- Compassionate End-of-Life Options 18
- Saying Goodbye 18

After a Death 19

- Body and Organ Donation 19
- Notification of Death 19
- Registering the Death 20
- Settling an Estate 20

STEP 4 HONORING LIFE

- Choosing a Mortician and
Funeral Provider 21
- Planning your Memorial 21

CONCLUSION 23

APPENDICES

Resources 24

Goals of Care Worksheet 26

Letter to a Caregiver 27

About Me and Honoring Me 28

Introduction

Advance care planning is preparing for your future healthcare and life decisions. It is the ongoing process of making your wishes and values known to your providers and caregivers. **Think of it as a gift to loved ones to do this work before a crisis or health change.** If you do not make your preferences known, your providers and loved ones are left to make tough decisions without knowing what you'd really want. That hole in communication could result in extended intensive treatments or more limits on your care.

This is a toolkit to empower LGBTQ+ people who may face specific challenges in the legal and healthcare systems. You may need extra protections in advance care planning to ensure dignity and avoid conflict or discrimination. Inside this toolkit you'll find a step-by-step guide to help think and talk about your wishes and plan for healthcare decisions.

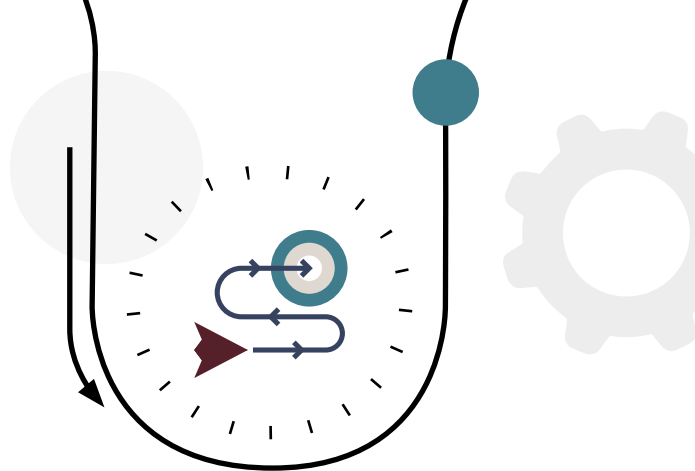
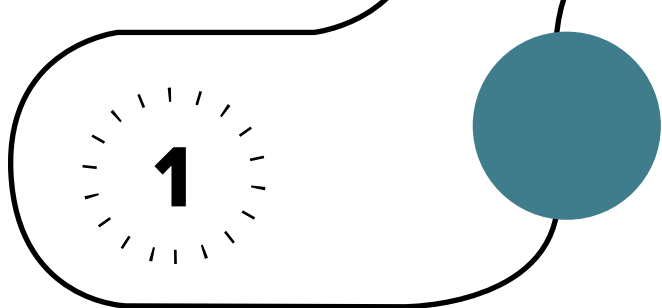
This toolkit will also review tips for LGBTQ+ people who have advanced illness, including information on palliative and supportive care, caregiver advice, and

healthcare resources. Lastly, this toolkit reviews hospice services, memorial and burial options, and bereavement support for the LGBTQ+ community.

Current resources for advance care planning do not serve the LGBTQ+ community sufficiently. [Research](#) suggests that loneliness, responsibilities, and sharing personal information — such as sexual orientation, gender identity, and sensitive health issues — make it difficult for LGBTQ+ people to do advance care planning. This toolkit aims to make the advance care planning process easy, approachable, and relevant to LGBTQ+ issues by creating a checklist of helpful documents to complete, conversations to have, and decisions to consider.

This document is not intended as individualized healthcare or legal advice. This is general guidance, and your state has specific instructions about how these advance care planning documents should be completed. You should consult a local healthcare provider, community leader, and lawyer for personalized advice that includes consideration of your religious, cultural, ethnic, economic, and racial identities. There is information in this guide on pages 7 and 9 about how to find trusted LGBTQ+-experienced professionals.





Step 1

What to do when you're well

Even when you are well, emergencies can occur. The COVID-19 pandemic has made us more aware of these unexpected changes and health injustices for minority communities.

Older adults who are LGBTQ+ may have strained relationships with family and health care providers due to a history of societal prejudice. They are also less likely to have caregivers through marriages and children.

It is important to be prepared with the basic health and legal paperwork to protect your wishes and values [at any age](#). As your life circumstances change, return to this toolkit and make updates to your documents.

Healthcare Planning

Advance directives are legal healthcare documents with instructions for medical decisions if you cannot speak for yourself. This includes:

1. a **health care agent (also known as your “proxy” or medical power of attorney)** names the person or people who would make healthcare decisions for you if you are not able to;
2. a **living will** describes your instructions and preferences for your healthcare decisions.

A lawyer is not needed to complete these advance directives — you only need to sign these forms in front of (usually two) witnesses. It is recommended to ask your trusted healthcare or social service providers to assist with and witness these forms, then have them keep a copy after signing.

In Case of Emergency

Keep the originals of all medical and legal documents for yourself in a folder labeled “In Case of Emergency” (see checklist for this folder on page 16).



HEALTH CARE PROXY

Naming someone to be your health care proxy is the most important part of advance care planning.

Who is your health care proxy and how can they be contacted?

Go to [caringinfo.org](https://www.caringinfo.org) to find your state-based Health Care Proxy form.

Health Care Proxy: Frequently Asked Questions

Who should I choose as my Health Care Proxy?

Select someone who knows you and will speak up for your wishes. If you had a surgery, head injury, or an emergency, etc, **who would you choose to speak for you if you are unable to speak for yourself?** Your health care proxy does not need to be your biological family or next-of-kin. They could be a partner, chosen family member, friend, or anyone who knows what is important to you and can stand up for you if you are too sick to communicate.

What resources are available for my Health Care Proxy?

Refer them to talk to your healthcare provider, or to read the [“Guide to Being a Health Care Proxy” by The Conversation Project](#) or [“Making Medical Decisions for Someone Else: A How-To Guide” by the American Bar Association](#). There is often a part on a health care proxy form where you can write specific advice to your loved ones and healthcare providers.

What happens if I don't name a Health Care Proxy? Who is my Health Care Proxy if I do not choose one myself before an emergency occurs?

Laws can vary by state, but generally the next-of-kin order to be your health care proxy is:

1. Legal guardian appointed by a judge (rare)
2. Spouse
3. Children (equal amongst biological and adopted, not stepchildren)
4. Grandchildren
5. Parents
6. Siblings and half-siblings
7. Extended family

Your first next-of-kin has the right to your money, health information, and to make decisions for you *unless you name another person to do so in your advance care planning documents*. For LGBTQ+ relationships, your state or institutions may not recognize your married or unmarried partner as your next-of-kin, even after the Supreme Court of the United States of America has recognized same-sex marriage as a constitutional right. Life partners and chosen family may not be given access to you if you become incapacitated in a facility. **For this reason, even if your next-of-kin is your health care proxy, it is a good idea as an LGBTQ+ person to complete a health care proxy form.**

What if I don't have someone who knows me well or whom I trust to be my health care proxy? Or what if I only know people who are not able to help me due to their own advanced age or illness?

If you don't choose a health care proxy because you can't think of anyone to choose, some state laws will have your healthcare providers ask a distant relative or non-family member to be your decision maker if no close family is available. Other states choose your doctors to make decisions for you when there is no available family and no health care proxy paperwork. If you do not have easy options for your proxy, refer to your state laws and discuss choosing someone who knows you with your trusted healthcare provider.

How should I make sure that all my loved ones are able to visit or support me in a healthcare setting?

Family of choice describes a (usually non-biological) bonded group of people chosen for sustained social support. If possible, tell your loved ones and next-of-kin when you have selected a health care proxy so that

HOW SHOULD I ASK SOMEONE TO BE MY HEALTH CARE PROXY?

"I'd like you to be my health care proxy. That means you would be the person I'd trust to make medical decisions for me if I can't make them for myself. I'd need you to speak up for my wishes, my safety, and my identity. As much as possible, I will tell you what I want, so you wouldn't have to guess. Is this something you would be comfortable doing?"

OR if you do not have any preferences, ask them if they are willing to make decisions *for* you.

"I don't have preferences for my care and would just like you to make decisions for me whatever happens based on what you and my healthcare team think is best. Is this something you would be comfortable doing?"

Other helpful phrases

"I was thinking about what happened to (friend/family member) when they got sick. It made me realize I would not want those things (to live in a care facility, to be in an intensive care unit, to have a feeding tube) to happen to me and I'd like to put some measures in place to make sure of that."

"My health is stable right now, but I'd like to talk to you about what I'd want if I got sick with the help of this advance care planning document."

"I would be happy to!"

Possible responses

"Thank you! I will make sure that you have support from my healthcare records, resources, and providers if you need to make a decision."

"I'm sorry. I won't be able to be your health care proxy."

"It is OK if you need to say no. Thank you for your honest response. Would you like to discuss your concerns with me? Do you have any thoughts on who might be a good alternative for me to choose? I would appreciate it if you support that person in this role."

Their concerns may be: "I do not agree with your care preferences." "I would never be able to tell doctors to disconnect you from a breathing machine." or "I would never be able to let them do CPR on you." See "person who should have no authority" on page 6 in this case.



they are not surprised or in conflict during an emergency.

A hospital or care facility visitation form gives loved ones who are not legally next-of-kin (for example unmarried partners, chosen family members, caregivers, etc.) first preference in visitation. This form can be found on the [Compassion & Choices website](#) and should be included in the “In Case of Emergency” folder.



HIPAA Waiver

Provided by your healthcare institution, a HIPAA waiver allows someone access to your medical information and lets them discuss your care with your healthcare team. You can say what medical information can be shared or kept private, such as HIV status or surgical history. This does not allow someone to make decisions for you, but it is helpful for communication. It is also important to have one person — usually your health care proxy — to be the contact for your healthcare providers, then report back to the rest of your loved ones.

Q How do I make it known if there is someone who I definitely don't want involved in my care?

If there is someone you do NOT want involved in your care or someone you do not want to be allowed to visit, write this clearly on the Health Care Proxy form as a “person who should have no authority.”

LIVING WILL

A living will is a document that tells your health care proxy and providers what treatments you would or would not want. [PREPARE for your Care](#) and [Five Wishes](#) are examples of a living will. They are national advance care planning programs to help you choose a health care proxy, medical treatments, comfort measures, and remembrance wishes. Leave flexibility for your personal agency and unknown situations in a living will by writing “unless I say or indicate otherwise” after your directions.

If you do not have strong preferences and want your proxy and/or healthcare providers to make all of your decisions, it is still helpful to write that in your will or on your health care proxy form!



Financial and Estate Planning

FINANCIAL POWER OF ATTORNEY

By selecting a [Financial Power of Attorney](#) (POA), you do not give up your own right to make your financial decisions as long as you are able to. Your financial power of attorney is someone else who you give control over your money to when you are ill. This can be a helpful document to complete with a trusted person in your life if you need help organizing care for yourself, paying bills, or managing your finances. If you want to limit the money available, you can ask your lawyer and financial advisor about making a trust. This is a state-specific document and should be notarized or filled out with a lawyer.

There are two types of POAs: a *non-durable* POA cannot be used until someone becomes unable to make their own decisions and a *durable* POA can be used as soon as it is signed until the person's death. **Both POA forms expire at death. The document that grants power over finances after someone's death is a person's "will" (last will and testament).**

LAST WILL AND TESTAMENT

A **last will and testament** is a written document describing what you want done with your money and any property after your death. The document is best written with the help of a lawyer, then notarized with your signature and the date on each page. **If your next-of-kin would not make the decisions you would want, it is especially important to choose your own will "executor" and write your wishes for your finances in your last will and testament. Without this document, your financial wishes may not be followed.** Even when your will "executor" (the person in control of the will) is named by you, be aware that notices to the next-of-kin are often legally required before the "executor" can move forward with financial control.

To find an LGBTQ+ attorney or financial and legal resources go to: [LGBTQ+ Bar Association](#), [Lambda Legal's help desk](#), and "[Take the Power: Tools for Life and Financial Planning.](#)"



Sometimes, the last will and testament is not needed if a trust is made or beneficiary documentation (see details below in "In Case of Emergency" Folder section) is done to help loved ones with financial access. **If neither a will, trust, nor beneficiary is documented, a judge will often give your money to your next-of-kin. All of your belongings and money may be given to your biological family if you do not write your partner or chosen caregiver into your will.** Consider videotaping or recording your advance directive as another confirmation of your wishes.

Which will is which?

The *last will* and testament is about your financial plans. It is different from a *living will*, which is about your health-care plans.



FUNERAL PRE-PLANNING AND DISPOSITION RIGHTS

It may feel strange to plan for your own funeral. Funeral planning directives are helpful even if your next-of-kin agrees with your wishes for your body and the presentation of your memory after your death. For many LGBTQ+ people though, clearly choosing loved ones to protect and maintain your identity after death is essential.

A separate **funeral directive** lists instructions for memorial plans including:

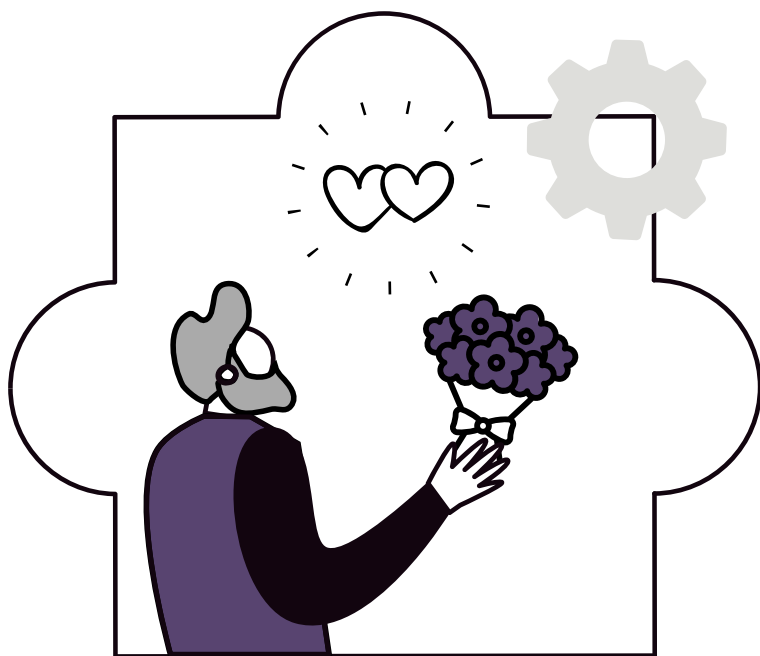
- **Funeral home choice** — find a LGBTQ+ experienced professional
- **Cremation vs. burial and anatomical gifts** — decide on your plan for your physical body
- **Burial clothing choices and body preparation** — give directions for an identity and gender-affirming appearance
- **Obituary content** — share your demographic information, identity, loved ones, and life story for the public
- **Headstone engraving or urn choice** — write your chosen name and how you want to be remembered

You can include information in this document about your [pre-payments](#) with a funeral home for your funeral too. Paying for a funeral ahead of time can save your loved one's money and tough choices while mourning. The funeral directive also chooses your **Funeral Proxy** who is in charge of the funeral and who should be in possession of your bodily remains (known as your **Primary Right of Disposition**).

If you do not record these wishes, your legal next-of-kin will be the decision maker and your chosen family may not have access to your body or to memorializing you. Sign and date your [state-based Funeral Proxy form](#) and directives with two witnesses or a notary. An **authorization of cremation form** is another state-specific form that can be self-completed during funeral pre-arrangements or done by your chosen primary right of disposition.

To summarize, the above documents and on our “In Case of Emergency” list are helpful for all adults, but they are especially necessary for LGBTQ+ individuals who may have specific concerns about their healthcare or have certain family members that are estranged or unsupportive.

It is also important to note that **advance care planning is not a one-time task** — it is an ongoing process, and these documents can be changed at any time! It is important to review your plans and talk to your loved ones about these decisions during major life and health changes.





2



Step 2

Prepare for Living with Serious Illness

Research has shown that using the following resources can improve how you feel and your healthcare experience when you have a life-threatening or advanced illness, especially for LGBTQ+ people.

Caregiver Resources

Whether your caregiver or home health aid is a loved one, hired professional, or a relative, writing a letter to your caregiver titled “How to Care for Me” can be helpful to provide understanding about your identities, goals, boundaries, and preferences. It is a gift to your caregiver to tell them in advance how to make you feel like yourself and more comfortable if you feel sick. See a sample letter on the next page.

Being a caregiver is a full-time job full of joy and satisfaction, as well as sacrifice and hazards. LGBTQ+ people have a long legacy of caregiving within their intergenerational community. Find support through your local community center or health system case management team, or through referring to the [“Caring For Those Who Care”](#) toolkit by the Diverse Elders Coalition.

Resources are also organized online by specific illness or issue (for example the American Cancer Society, Alzheimer’s Association, COPD Foundation, ALS Association, etc.).

Provide your healthcare provider with SAGE NRC’s tips for healthcare provider sheet: [“Identifying and Referring LGBT Caregivers”](#) to help them better meet your needs.



LETTER TO MY CAREGIVER OR PROVIDER

Nice to meet you!

My name is Elizabeth. Please call me “Eliza” and refer to me using the pronouns she/her/hers or they/them.

The important people in my life are my spouse and health care proxy George, my parents, my brothers, and my close friends, especially those who are also nurses and my foster dogs.

I enjoy spending my time doing outdoor activities, crafts, playing games, talking about reflective questions, and going to concerts and dancing. I have dedicated my life to palliative care nursing, LGBTQ+ advocacy, the outdoors, music, the Phillies, my loved ones, and learning about love.

My identity is a queer, white cis-gendered female from a catholic, episcopalian, and atheist middle-upper class American community and family.

Spiritually I believe in nature, interconnectedness and hopefulness, “all about love” by bell hooks as a sacred text, and humble atheism.

When possible, I prefer to have caregivers/providers who are empathetic, confident, gracious, calm, creative, and experienced with or in LGBTQ+ community.

Pain relief measures (medications, non-medication) that have worked/not worked for me in the past are lidocaine, heat, tylenol, NSAIDS, post-surgical oxycodone have worked; muscle relaxers like flexeril have not worked well for me.

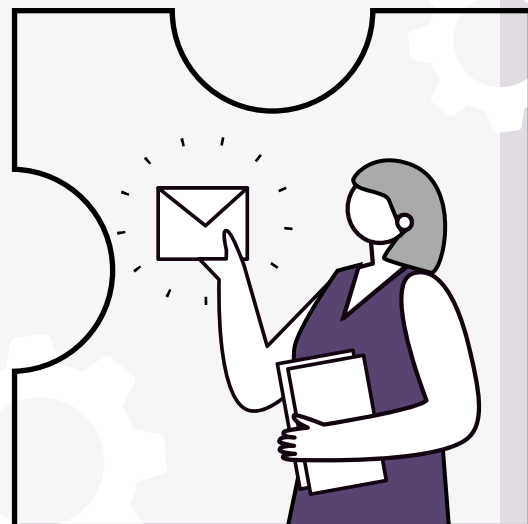
The best way to comfort me when I am feeling mentally or emotionally unwell is a hug, brushing my hair, patting my back or arms, fanning my face lightly; and physically unwell is: low lighting, favorite melodic instrumental music, a baseball game on, rain sounds, not being alone.

My diet restrictions and preferences are no olives and no garlic! More of a vegetarian diet. I love to drink soda water in warm weather and hot water in cold weather.

I feel most comfortable in/with: going for a walk and bathing daily; wearing a big t-shirt, mesh bra, and athletic shorts, only mascara on for makeup; near an open window, a lit candle or fireplace, and other people; I am an open book.

Thank you for your care!

Please refer to “[My Personal Directions for Quality Living](#)” form on the SAGE National Resource Center for LGBTQ+ Aging (NRC).



Your Healthcare Team

Refer to SAGE's NRC guide "[Create Your Care Plan](#)" to learn more about your healthcare team members' titles and job descriptions. The [Coalition for Compassionate Care of California](#) and [Fair Health Consumer](#) sites have support to make decisions about certain illnesses when choosing treatment options.

SOCIAL WORKER AND SOCIAL SERVICES

Another resource for caregivers and patients is a social worker. Request a social work meeting through your provider's office or healthcare organization to get more resources. A social worker is another person on your care team that can speak up for you about advance care planning and help with setting up social services including:

- **Transportation:** resources are specific to city and state transit agencies, but often include a vehicle option for people with disabilities or limitations that are unable to take all public services. Please call your insurance company about signing up for a transportation benefit or refer to your local resources and access the [American Disabilities Association support line at 800-949-4232](#) for questions.
- **Veterans Benefits:** Veterans and their spouses receive specific healthcare and burial service benefits. Contact your local [Veterans Affairs department](#) or [SAGE NRC LGBTQ+ Vets resources](#) to learn more. One of the benefits of being VA-connected is having hospice services *without* ending your VA homecare or center services. Some states have also authorized access to state veterans' benefits for those who had an other-than-honorable military discharge on the basis of the unjust "Don't ask, Don't tell" era policy. Reach

out to [American Veterans for Equal Rights](#) and [Transgender American Veterans Association](#) for more support.

- **Financial Planning:** Healthcare is very costly in the United States, and it is often helpful to have a social worker, financial plan, understanding of insurance coverage, and billing advice from your healthcare provider. **Medicare** is the federal health insurance option for Americans age 65 and older or those with certain disabilities or complex health conditions. **Medicaid** is a federal and state health insurance option for individuals with limited income and resources. Additional insurance options to consider with your trusted provider include supplemental Medicare Advantage plans, disability, and long-term care insurance, which covers nursing home, rehabilitation therapy, and skilled in-home nursing care. **Call your insurance company number on the back of your insurance card with a loved one or social worker to understand all your benefits and the programs available to you.** State-based Senior Medicare Patrol (SMP) program, State Health Insurance Assistance Program (SHIP), and Medicare Improvements for Patients and Providers Act (MIPPA) offices can also provide counseling on Center for Medicare and Medicaid Services (CMS) benefits.

In the complicated American healthcare insurance system, finding the right health care provider that will be actively supportive of your LGBTQ+ identity can be a difficult task. It can be very difficult to get the best care if you are not comfortable in a healthcare system that has historically discriminated against LGBTQ+ people. Please refer to the SAGE NRC's ["10 Tips for Finding LGBTQ-Affirming Services"](#) for guidance on choosing LGBTQ+ affirming

providers and moving through the healthcare system with recommendations from LGBTQ+ friends, local HIV/AIDS providers, and [SAGE resource lists](#).



Download the [SAGE x HearMe Mental Wellness App](#) for compassionate support that is confidential and anonymous.

FIND THE RIGHT PROVIDERS

The best place to find an in-network primary or specialist provider is by first consulting your insurance company on their website or calling the number on the back of your insurance card. **Finding a trusted, accessible primary care office is one of the best things you can do for your health, rather than using urgent care or emergency departments.** It is best for easy communication to find a specialist provider (for example a heart, lung, brain, or cancer doctor) for your serious illness (for example heart failure, COPD, dementia, or cancer) that works at the same healthcare system as your primary care provider. Ask for a second opinion or the advice of your trusted primary care provider when making big decisions about your health or your specialist provider choices. Many LGBTQ+ people are less likely to have health insurance. If you do not have healthcare insurance, call your local 211 number or reach out to your local public health system to get assistance signing up for the healthcare marketplace or government programs with a social worker. When you search the names of in-network providers for a specialty, service, or long-term care facilities, experience, and reviews, look for and ask about visible and consistent LGBTQ+ inclusiveness:

- Ask if staff has received training on LGBTQ+ health and cultural competency or SAGECare training

- Look for nondiscrimination statements inclusive of sexual orientation and gender identity/expression
- Check for pronoun acknowledgment and safe space signs in the professional's emails and office
- Ask who to contact in patient advocacy or the Diversity, Equity and Inclusion office if you have an issue with receiving equitable, affirming care.
- Find out if the health organization collects sexual orientation and gender identity data
- Choose providers that ask about your identities, social life, cultural upbringing, and LGBTQ+ experience

When you find the right provider, it is time to make your appointment. At each appointment, come prepared to take notes and write follow-up questions. Ask for your caregiver to be present or on the phone to have a second set of ears or ask your provider if you can record audio of the visit to replay for yourself or your caregiver.

Use the teach-back method to summarize your appointment: repeat back your understanding of what the provider has said and ask the provider to repeat back to you their understanding of what you've said too.

Similar to the "Letter to my Caregiver," it may be helpful to create a letter to your provider outlining who you are, what your values are, and what they should know about you to take best care of you.

For more ideas for supporting care needs for independent living, access your [Area Agencies on Aging \(AAA\)](#) and your [ElderCare Locator](#) for assistance and resources.

Palliative Care for Serious Illness

Palliative Care is a healthcare service which focuses on supporting your quality of life, improving symptoms, and assisting with advance care planning for people with serious illness. It is provided at the same time as any other treatment as an extra layer of support with any symptoms and help with decision making about your illness or treatment options. The sooner it starts, the better it works — **if you are dealing with**

a serious illness, ask your provider for a Palliative Care consultation within your main healthcare organization. See the Goals of Care Worksheet on page 26 to prepare for a palliative care conversation. Search the [National Hospice and Palliative Care Organization care provider map](#), [getpalliativecare.org](#), and [capc.org](#) to find a palliative care provider or service near you.

Benefits of Palliative Care

SYMPTOM MANAGEMENT AND QUALITY OF LIFE

Palliative care providers are experts in supporting living life more fully with less discomfort. They can help you weigh the positives and negatives of treatments and help you determine your goals of care.

TREATING THE WHOLE PERSON AND CAREGIVER

Palliative care is made up of a team who works together to get you the care you need. Palliative care has a holistic approach to treating the person who has serious illness, as well as their loved ones and caregivers. For LGBTQ+ people who may have nontraditional family structure, identities, and relationship with religion, palliative care can go past standard options.



In Case of Emergency Folder

If you are someone who wants to be clear about what type of treatment you'd want in a crisis situation, it is important for you to discuss that with your health care providers, loved ones, and health care proxy then add the following documentation to your **"In Case of Emergency File."**

DNR AND MOLST ORDERS

- **Do Not Resuscitate (DNR) — Out of Hospital — Order:**
A state-based medical directive instructing to allow for a natural death and to not do CPR (cardiopulmonary resuscitation) in the event of breathing or heartbeat stopping. An in-hospital and

out-of-hospital DNR are not the same — make sure each time you are in a facility or when you get discharged the order stays in your medical chart or have a paper copy with you.

- **Medical or Physician Orders for Life Sustaining Treatment ([MOLST](#)/[POLST](#)):** This form is helpful because it has more instructions than just a DNR order. A MOLST/POLST form is a state-based medical directive documenting a patient's wishes regarding specific treatments commonly used in a medical crisis. This order to be completed by a healthcare provider writes out

wishes for treatment choices, such as resuscitation, intubation (breathing tube life support machine), artificial nutrition or hydration with a feeding tube or IV, and hospitalization.

Sometimes people — especially with LGBTQ+ concerns for other types of discrimination — worry that with a DNR order they will get less or worse care in general. Discuss your concerns with your healthcare providers and know that any withholding of other types of supportive care is illegal.

Without a visible out-of-hospital DNR order or MOLST/POLST showing DNR status, emergency responders are legally obligated to do CPR and intense life-prolonging treatment. It is very important to keep these papers accessible and visible. Put the

original in a “In Case of Emergency” file and a copy in an envelope labeled “DNR” or “for EMTs” by your home’s front door or on the refrigerator. In certain states, regulations allow for medical professionals to provide a [medical ID bracelet or necklace noting a DNR order](#). It is essential to have a copy of your documents — your health care proxy and living will and MOLST or DNR — in your medical chart at your healthcare provider’s offices and at your local hospital system.

IMPORTANT EMERGENCY DOCUMENTS

Below is a list of other documents that may also be important for you to keep in this folder depending on your preferences and circumstances:

- **[Organ and Body Donation Form:](#)** This information is included in most state or health system-based health care proxy forms. Write down specific instructions with the donation or medical organization’s contact information.
- **Updated Asset Ownership/Titles:** Discuss options for a transfer-on-death or trust accounts and estate taxes with a trusted financial advisor or estate lawyer. Document charities and loved ones who should receive certain valuables. Attempt to give away family heirlooms and non-essential belongings during your life to reduce waste and clear clutter for your loved ones.
- **Trusts and Beneficiary Forms:** These documents allow for easy transfer of your estate and financial account funds directly to individuals or charities of your choice without review of a will. You will often have to state a beneficiary for life-insurance policies — your next-of-kin will be your beneficiary if you do not choose one.
- **List of Accounts:** Carefully write down each account username and password

A note on CPR survival



CPR is compressions (pushing) on the chest and electrical shock to try to pump and restart your heart. CPR almost always results in broken ribs, an intensive care unit (ICU) stay, and high risk of brain damage. Discuss if you would have a meaningful survival from CPR with your trusted healthcare provider. Media sometimes shows CPR as easy, but it can be traumatic and [research](#) shows that between 20% to less than 5% of people survive with the ability to leave a hospital. CPR is more successful if it is done in the hospital and on people who are younger with fewer and less severe illnesses. Your providers will support whatever choice you make, and it is their job to help you make educated decisions if you want to understand the likely risks and outcomes.

for access as needed and account cancellation when necessary.

- **Online Legacy Plan:** Collect social media login information to facilitate communication after death and also mitigate hacking or identity theft risk. If available, appoint a [legacy contact](#) for your accounts.
- **Care of Dependents:** Stating a [guardian appointment](#) in your last will and testament is the best way to ensure your children (or minors) are cared for by the person or people of your choice, especially important in cases of adoption for LGBTQ+ families. If not written, care of the child is left to a court decision. Ask the guardian you choose so that they are aware of this plan.
- **Document Copies:** Copies of identity documents and certificates of marriage or civil union or domestic partnership registration and any other legal certification of relationships such as adoption paperwork and birth certificates are helpful to have on hand in case of emergencies, especially for non-biological family members and LGBTQ+ chosen families.
- **Care of Pets:** Written instructions based on planning with loved ones for care of pets and similar responsibilities can be signed and included in last will and testament papers.

ASSISTED LIVING FACILITY DOCUMENT

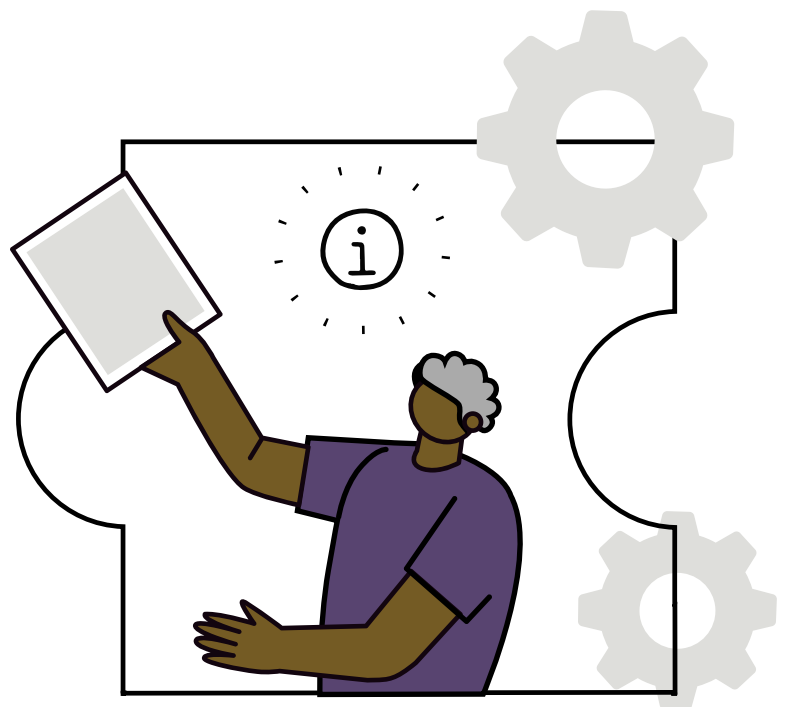
The [most common aging concern](#) for LGBTQ+ people — especially transgender and gender non-conforming adults — was losing the ability to care for themselves and needing to go to a nursing home or assisted living facility for fear of discrimination and dependence.

- A **Sectarian Healthcare Directive** makes sure that your wishes are followed even

if they are in conflict with institutional policies — especially in the case of religious or anti-LGBTQ+ convictions. It directs for assistance with a transfer of care to another chosen facility if needed. This form can be found via the [Compassion & Choices website](#).

- An **Assisted Living Facility (ALF) Rider** is a contract for people who live in an ALF who see the facility as their “home” and would like to stay there until their death. Form can be found via the [Compassion & Choices website](#).
- Discuss with an attorney and health care provider about if a supplement to a health care proxy with a **“[designation of pre-need guardian](#)” form or conservator form** is needed in your case. This form is to choose someone to control your medical and financial needs if you were to become incapacitated — with dementia or any brain issue — and need guardianship.

For more information review the [“\[Planning for Lifelong Care: Guiding Questions for Transgender & Non-Binary People to Plan for Dementia and Other Serious Illness\]\(#\)”](#) toolkit.



CHECKLIST FOR “IN CASE OF EMERGENCY” FOLDER

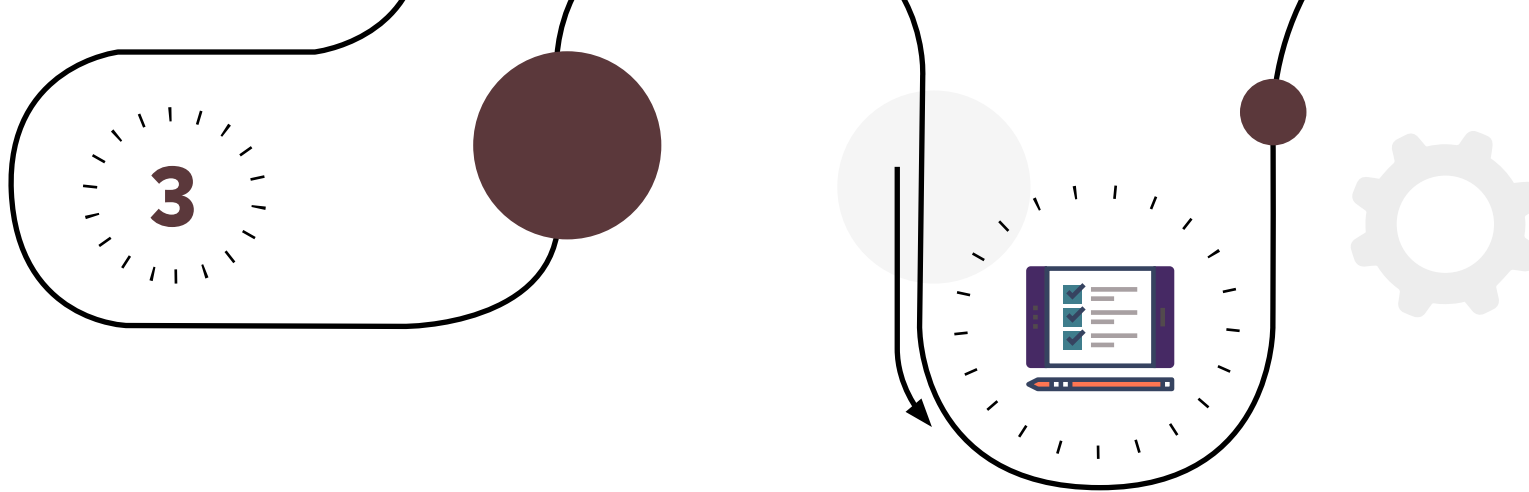
- Health Care Proxy/Agent/Power of Attorney form
- Living will (ex. PREPARE for your care, Five wishes forms)
- MOLST/POLST (Orders for Life-Sustaining Treatment)
- Out-of-hospital DNR
- Values and Goals of Care Worksheet
- Letter to my Caregiver/Provider or “My Personal Directive for Quality Living”
- HIPAA Waivers
- Hospital or Facility Visitation Forms
- “Person who should have no authority” list
- Copy of Certificate of Partnerships and Identity documents including insurance card and ID
- Assisted Living Facility Rider
- Sectarian Healthcare Directive
- Designation of pre-need guardian
- Financial Durable or Non-durable Power of Attorney Form
- Instructions for where to find your Last Will and Testament (usually with lawyer) and Will’s “executor” or “personal representative”
- Updated Asset/Estate/Property Ownership titles
- Trust and Beneficiary forms
- Instructions for the secure location or person who has the private list of your account and password information
- Online legacy plan
- Care of Dependents information
- Care of Pets information
- Organ and Body donation information
- Primary Right of Disposition
- Funeral Directives
- Funeral Proxy

Place this folder in an easy-to-find spot: your nightstand, attached to the back of your front door, in your top drawer, or even put it in a waterproof ziplock bag inside your refrigerator or freezer. **Give copies as needed to your trusted healthcare providers, lawyer, loved ones, and your chosen health care proxy and tell them where the folder is in your own home.** You can also update your “In Case of Emergency” contact, documents, and medical alerts in your smartphone with copies of these documents. **Keep this sensitive information secure and password protected!**

Don’t just document and secretly put the documents in your “in case of emergency” folder... discuss each decision with your health care proxy! This next step in making your wishes and plans known is sometimes difficult because many of our loved ones would prefer never to discuss these emergency situations, but doing so calmly and considerately can avoid future conflicts and confusion. You can use April 16th — [National Healthcare Decisions Day](#) — as a way to start the conversation.

If you cannot talk about your documents, at minimum share them for review via email or mail with your health care provider, loved ones, or proxy so that they can be available if needed. You may also want to review [caringinfo.org](#) for support on how to talk to loved ones.





Step 3

End-of-Life Planning

The LGBTQ+ community has had to fight for equality in healthcare, and that equity of care should extend to the end of life with the help of the following resources and documents.

End-of-Life Planning and Hospice

[Hospice care](#) is for people who are in the end stages of a terminal illness and focusing on symptom relief and quality of life. In the United States, it is an insurance benefit that starts if you choose comfort-focused care when a qualified provider certifies that your illness could result in living six months or less.

Hospice care may be a good idea when treatments and therapies that make your life longer become more harmful than helpful. Hospice care is provided usually in the home with visits from a team of professionals: a social worker, physician, nurse practitioner, nurse, chaplain, volunteer, and bereavement counselor. There is 24/7 access via phone for nursing support and medical advice access with in-person visits as needed.

PAYING FOR HOSPICE CARE

Hospice Care is an insurance benefit that is 100% covered through Medicare or Medicaid. Private insurance coverage may have required copays. All aspects of hospice care — nursing and medical

support, a few home health aide hours, safety and care equipment, continence supplies, and medications related to the hospice diagnosis — are all covered by this benefit.

HOSPICE CARE SETTINGS

A helpful exercise can be to draw the room you would want your last living moments in to gain a clearer picture of your priorities and wishes for the setting. Many people who have difficulty and discrimination with the healthcare system prefer hospice care because it usually happens in the privacy of your own home.

Hospice care is usually done in the home or a home-setting like a nursing home, mostly by a nurse visiting for about an hour per week to provide assessment, education, and support. Hospice care provides medical equipment as needed such as a hospital bed, shower chair, oxygen concentrator, and wheelchair. Hospice care at home also requires having a 24/7 caregiver, such as a family member, partner, or friend. LGBTQ+ people are less likely to have children

or extended family as these caregivers and may need to gather chosen family to support. A paid home health aide can provide personal care support but is not able to be the primary caregiver due to rules around aides administering medication. If a break from caregiving is needed or if there are symptoms that cannot be managed at home (for example pain requiring IV medication or certain wound care) the patient may be able to get short-term respite or inpatient care at a facility. If you are looking into hospice companies, make sure to ask where this respite or inpatient option is.

HOSPICE AND END-OF-LIFE RESOURCES

Hospice can be accessed when your care provider makes a referral to a hospice agency. Find [hospice agencies that serve your area](#) and call to ask about agency-specific practices, training, and policies that are non-discriminatory and LGBTQ+ focused. Find more information about Hospice and Palliative Care through the National Hospice and Palliative Care Organization's LGBTQ+ [resource guide](#) and website at [caringinfo.org](#).



End-of-Life Doula

End-of-life doulas are privately hired and provide support, resources, and guidance for facing terminal illness and death. These professionals help with caregiver education, non-medical physical care advice, life and legacy review, ritual creation, funeral guidance, estate planning, companionship, respite, and emotional support. They can be found through the online [National End of Life Doula Association \(NEDA\)](#) directory for proficient doulas.

COMPASSIONATE END-OF-LIFE OPTIONS

As of 2023, death with dignity or medical aid in dying is allowed in 11 states in the United States. Please refer to the [Compassion & Choices](#) website for the most up-to-date information and end-of-life consultation options services at 800-247-7421. For adults who have an advanced terminal illness, [Voluntary Stop of Eating and Drinking](#) is another legal option to have more control over the timing of the end of their life by choosing not to eat or drink.

SAYING GOODBYE

When time is short, it can be difficult to know what to do or say. Some helpful things to do in the last days can be to listen to the dying person's concerns and life stories, look back at photos and videos, support their LGBTQ+ and other identities, and remind them they've made a difference in your life. Be the bridge to the outside world: share a taste of a favorite snack, bring in a bit of nature from outside, or sing a song... be present with them. In hospice teachings, there are six essential things to express — in your own way or words — at the end of your or your loved one's life:

*Please forgive me,
I forgive you,
I am proud of you,
Thank you,
I love you,
And "Goodbye" or
"Until we meet again."*

Ask for what help or information you need from your hospice or healthcare team. Remember that a natural death is not a medical emergency, it is a part of the cycle of life and a time to be present with the person during their life transition.

After a Death

When a loved one dies, our minds often race to what needs to be done and what calls need to be made. It is ok to slow down and take a moment of closure, which might include playing a favorite song, sharing a comforting reading aloud, or simply sitting in reflective silence with the person's body.

If someone dies on hospice care, call the hospice organization when you are ready. In most cases, a nurse will come by to support you and help to call the funeral home. The funeral director will bring the person's body to the funeral home whenever the loved ones are ready. Ask for assistance from the hospice organization or emergency personnel on how to dispose of medications properly and request to return or donate equipment.

If someone dies at home and is not on hospice care [AARP](#) recommends calling your primary care provider and/or 911. Tell the 911 dispatcher about the circumstances of the death and have the Advanced Directive documents (DNR form) available to help the emergency personnel respond appropriately while they certify the death. Based on the situation, the emergency personnel will tell you whether the person's body will need to be reviewed by the county Medical Examiner/Coroner before being transported to the funeral home.

If someone dies at the hospital, the hospital staff will work with the Primary Right of Disposition or Funeral Proxy chosen to coordinate organ or body donation and/or transport to the funeral home or to their own home for a home funeral.

BODY AND ORGAN DONATION

Almost all organ donations are done in hospital when the person is on a ventilator at the end of their life. Hospitals help with the organ donation process if chosen by the individual or their health care proxy. People

Primary Right of Disposition

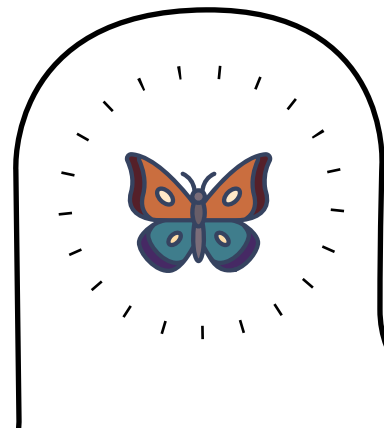
If the Primary Right of Disposition or Funeral Proxy paperwork has not been completed and given to the funeral director, then the funeral home will contact the next-of-kin.



living with HIV can now accept organs from donors with HIV since the [HOPE Act](#) was passed in 2023. If someone is registered to donate their body to science, call the university or healthcare organization where the person is a donor instead of calling the funeral home.

NOTIFICATION OF DEATH

Sharing the news of a loved one's death can be both helpful for expressing grief, and also overwhelming. It is important to decide who should be called directly, who can be asked to tell others, and who can be told in a group message. After direct communication is done, a person's death can be announced in an obituary online, on the funeral home's site for no additional charge, and/or in print as a short



notice by any interested party. Usually [the obituary](#) starts with the person’s personal, biographical, and death information. It also can include an honest, loving reflection on how they would want to be remembered, anecdotes of their life story, list of surviving loved ones — “who’s grieving” — as applicable, funeral information, sympathy preferences and a photo.

Perhaps not everyone in the person’s life knew everything about their personal life, sexuality, or gender identity. It is best to have written instructions or discussions with the funeral proxy form about the use of pronouns, listed loved ones, proper names, etc. If the individual did not make their wishes known before death, seek agreement in their trusted circle of loved ones about their wishes for what should be shared in their obituary. End-of-life planning can also include writing one’s own obituary and filing it with funeral directives forms or a funeral home.

REGISTERING THE DEATH

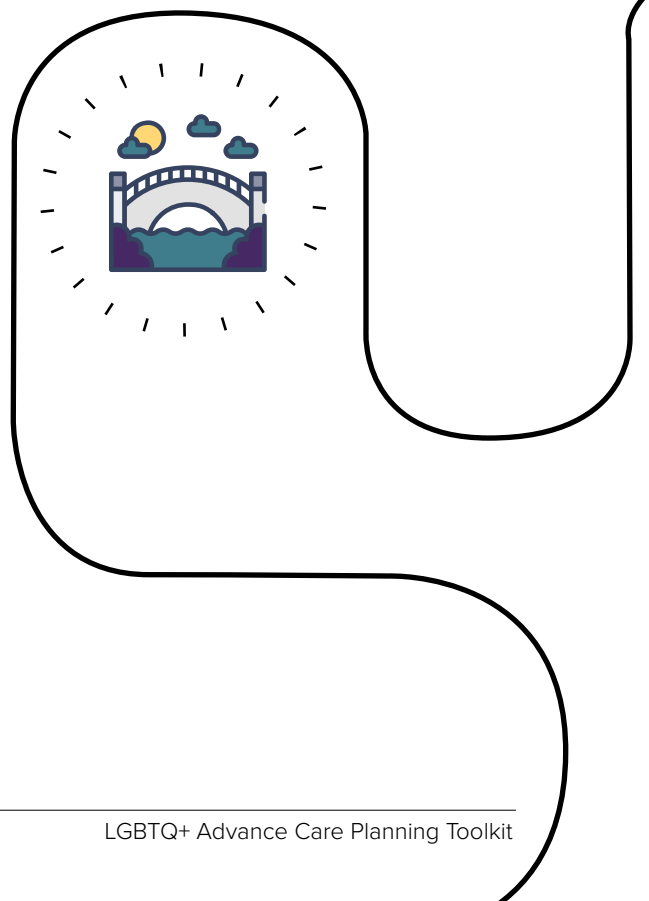
The next of kin, funeral proxy or Primary Right of Disposition is in charge of registering the death. The certificate of death is done by the last medical professional caring for the person at time of death. They can then order copies of the death certificate to close accounts, settle finances, and file paperwork. Contact the local Department Health Vital Records office or VitalChek.com for a death certificate for a modest cost — you may need multiple original copies depending on the size of the estate.

Depending on the state laws and regulations, coroners and funeral directors will record a person’s name or gender identity based on health records or driver’s license and funeral proxy decisions, instead of using the original birth certificate name and anatomical sex for the death certificate. In [some states there is now an “X” option](#) for undesignated gender on death certificates

with supporting legal documentation. **If you changed your name and gender marker consistently in legal and/or healthcare documents, the law directs funeral professionals to use current — not former — identifiers.** You should be allowed to have your chosen name on your burial marker whether you legally changed your name or not.

SETTLING AN ESTATE

The Consumer Financial Protection Bureau has a [“help for surviving spouses”](#) page and family members about financial and debt issues online or via their helpline at 855-411-2372. The resource includes advice to call local government (postal, voting, etc.) offices and the Social Security Administration, as well as, insurance, credit reporting and credit card companies to notify of the person’s death.





4

Step 4

Honoring Life

CHOOSING A MORTICIAN AND FUNERAL PROVIDER

Without a funeral proxy or next-of-kin, any available party who has the death certificate and can make payments for services can arrange a burial. If no one can pay for the burial, the state will arrange for burial through the coroner's office which unfortunately limits access to remains and place of interment.

It is important to be aware of the high and varied prices between funeral providers. Everyone is entitled to a free copy of any funeral home's price lists under the [Federal Trade Commission protections](#). You are also encouraged to ask about LGBTQ+ experience, cultural competency, eco-friendly options, and a written receipt of intended goods and services before purchases. A funeral provider cannot refuse or charge for the use of an "alternative container" or outsourced urn. Make sure the urn is TSA-compliant if travel is needed!

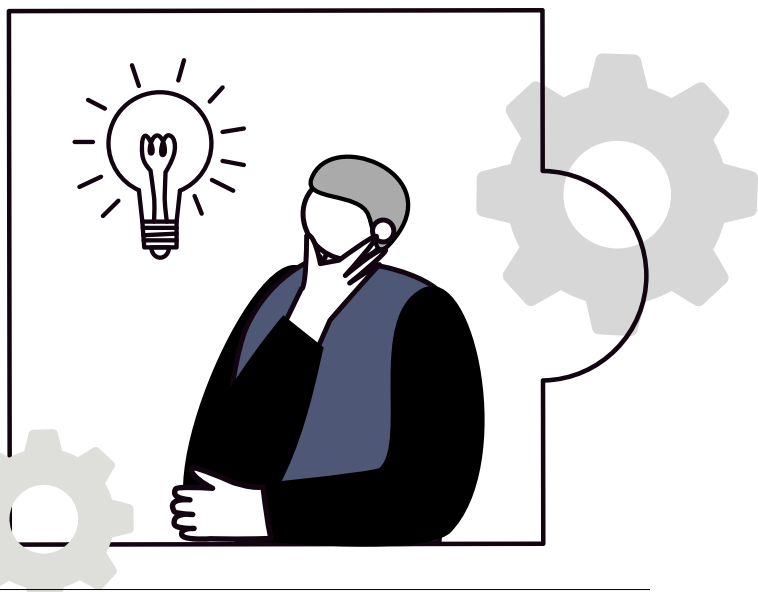
For a viewing, you can choose between embalming and "minimum preparation". Work with the mortician to make sure wishes for clothing choices and body preparation are followed. These important outward presentation options may include hairstyle, make-up, binding, and use of prosthetics. More guidance about cemetery specifications, cremation, green burial,

burial at sea, alkaline hydrolysis or "water cremation", Natural Organic Reduction, and alternative disposition options can be found in the [WAKE Louisiana LGBTQ+ and EOL Guide](#) followed by clarification in your state-based guidelines. Also review the [Environmental Protection Agency](#) and state-based or site-based rules on scattering ashes.

PLANNING YOUR MEMORIAL

After you die, what type of memorial or funeral do you want?

Anyone can hold a funeral or celebration of life — you do not need to involve a funeral home unless an uncremated body is present. Memorial events can be any size



Rituals, Grief, and Directives

Grief is felt with any loss, and bereavement is specific to the death of a loved one. Described in the book *A Beginner's Guide to the End* it is “a place with its own weather and terrain.” Bereavement is not always what it seems and is different for everyone.

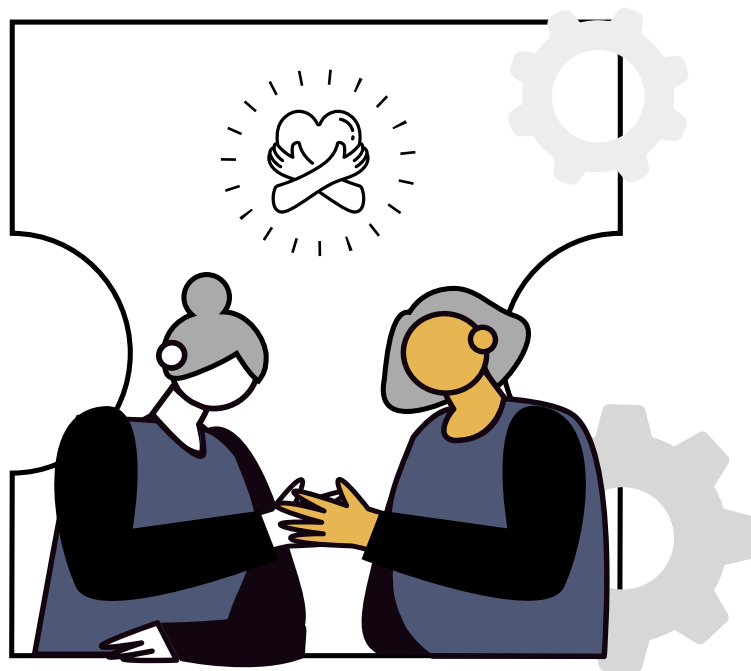
Research shows that rituals from cultural, ethnic, religious, or community traditions create space for and even help with grief's pain. Whether you make your own kinds of LGBTQ+ gatherings and bereavement practices or use existing ceremonies and expressions of mourning, they can help you explore your continued connection with the person who has died.

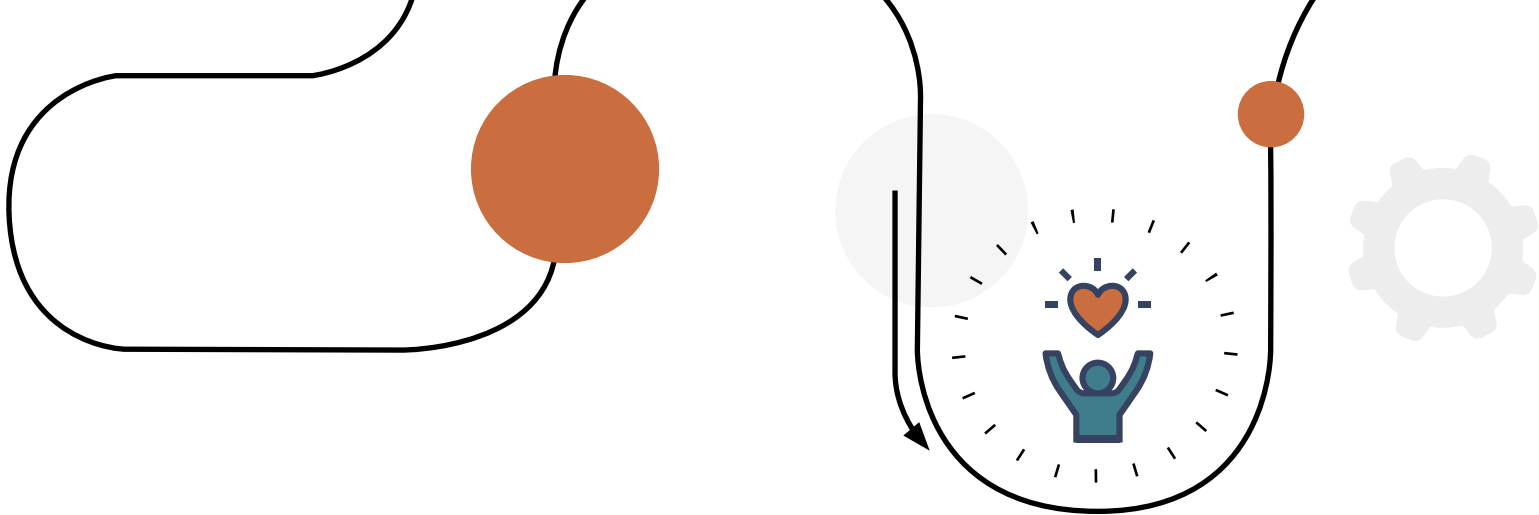
Give yourself and others around you grace and room for mistakes in your grief; however, also be aware of the harmful signs of complicated grief. Some examples include a long time without regular functioning, painful repeated thinking, and changed thinking about reality. Find professional mental health support if you are having destructive thoughts or coping behaviors too. All hospices must include bereavement services through the year after the death and will make referrals for more grief support as needed. You can reach out to a hospital system or funeral home grief counselor support too.

Another difficult type of bereavement that is common in the LGBTQ+ community is “disenfranchised grief” — when someone is not able to socially or publicly mourn and be supported, especially in the case of unacknowledged chosen family members or loved ones. Look into your local LGBTQ+ organization, affirming faith communities, and healthcare organization for a grief support group. Consider calling your local 211 number for a listing of grief support programs.



and planned creatively and thoughtfully as a gathering. Consider what the person enjoyed and incorporate their favorite food, drink, and activities, such as a walk, singing, or opportunity for loved ones to verbalize favorite memories. Feature the person's work or passions. A memorial can take place in a public place such as a park, restaurant, bar, event venue, community center, place of worship, or a private home. It can be hosted by the person's loved ones or a community leader. You can also honor your loved one at joyous annual events, like pride celebrations and annual remembrances with a cause important to that person.





Conclusion

Top three things to do after reading this guide:

1. **Complete a Health Care Proxy form** (p. 3)
2. **Make an “In Case of Emergency” folder** containing whichever documents *you* need and put it in a safe, known, easy-to-find place (p. 13)
3. **Don’t do it alone** — make an appointment with a trusted healthcare provider to talk about these documents and your wishes.

Thinking about the future can be overwhelming — these are sensitive topics that may feel like the last things on your mind.



Your Rights

If your documented wishes are ignored and you are confronting discrimination or the threat of legal action, reach out to the Lambda Legal help desk at 866-542-8336 to review the best course of action. A good first step may be to speak to an administrator or supervisor, the organization’s legal team, or — for a healthcare issue — reaching out to federal compliance for CMS or Office of Civil Rights of the US Department of Health and Human Services.

Taking one hour to do at least these three essential tasks now will save you from worrying and suffering in precious time later. We make better decisions in calm contemplation and conversation than in unexpected crisis and avoidable conflict.

Our hope is that these documents will make sure that you are surrounded by professionals and people who know how to make you feel safe, comfortable, and cared for when you need it most. It is important for you to have the tools to help yourself — for LGBTQ+ people especially, this type of planning protects your identity, loved ones, and legacy.

The last words of the book [A Beginner’s Guide to the End](#) are:

“Our advice is just this: participate. Resist the notion that you have total control; resist the notion that you have none. However you can, with whatever you’ve got, participate in your care, in your dying, in life.”

And with that, thank you for reading, considering, and participating in protecting your life, your death, and your care.

Appendices

Resources

Following is a list of the resources referenced throughout this toolkit.

SAGE

[SAGECents — Plan with Pride](#), information on Powers of Attorney and other financial planning resources.

[SAGEVets | SAGE NY \(sageserves.org\)](#) — for New York State veterans age 50 and older.

[SAGE X HearMe — Mental Wellness App](#)

[SAGECare Training and Credentialing](#)

National Resource Center on LGBTQ+ Aging

[My Personal Directions for Quality Living](#)

[Identifying and Referring LGBT Caregivers](#)

[Create Your Care Plan](#)

[LGBT Aging Center.org — Resources — LGBTQ+ Veterans](#)

[10 Tips for Finding LGBT-Affirming Services](#)

[Planning for Lifelong Care: Guiding Questions for Transgender & Non-Binary People to Plan for Dementia and Other Serious Illness](#)

National Hospice and Palliative Care Organization - CaringInfo.org

[Health Care Proxy Forms by State](#)

[How to Prepare, Plan, and Be Present](#)

[Searchable Care Provider Map](#)

[LGBTQ+ Resource Guide](#)

Center for Advance Palliative Care

[Palliative Care Provider Directory](#)

AARP

[State by State Advance Directive Forms](#)

Compassion and Choices

[Advance Directive and End-of-Life Planning Resources](#)

[Hospital Visitation Form](#)

[Sectarian Healthcare Directive](#)

[End-of-Life Consultation Options including Voluntarily Stop Eating and Drinking \(VSED\)](#)

The Conversation Project

[Your Guide to Being a Health Care Proxy](#)

[National Healthcare Decisions Day](#)

The American Bar Association Commission on Law and Aging

[Making Medical Decisions for Someone Else — A How to Guide](#)

The HIPAA Journal

[HIPAA Waiver](#)

Prepare for Your Care

[Advance directive resources](#)

Five Wishes

[Digital and paper advance planning resources](#)

LGBTQ+ Bar

[State resources for LGBTQ+ and ally legal resources](#)

Lambda Legal

[Help Desk](#)

[Take the Power — Tools for Preparing Wills and Trusts](#)

Funeral Consumer Alliance

[State-based funeral proxy form\(s\)](#)

Diverse Elders Coalition

[Caring for those Who Care](#)

Coalition for Compassionate Care of California

[Decision Aids for Healthcare Providers](#)

Fair Health Consumer

[Decision Aids for Healthcare Providers](#)

Americans with Disabilities Act National Network

[Help line 1-800-949-4232](#)

U.S. Department of Veterans Affairs

[VA LGBTQ+ Health Program Patient Education, Resources, & Outreach Materials — Patient Care Services](#)

AVER

[American Veterans for Equal Rights. We Are You!](#)

TAVA

[Transgender American Veterans Association](#)

National POLST

[Portable Medical Orders](#)

The New York Times article

[The CPR We Don't See on TV](#)

National End of Life Doula Association

[Online directory for doulas](#)

American Medical ID

[DNR Medical Idea bracelets](#)

Health Resources & Services Administration

[Organ Donor Registration](#)

Death with Dignity

[Life File: How to Safeguard Your Digital Legacy](#)

MAP (Movement Advancement Project)

[Identity Document Laws and Policies](#)

Consumer Financial Protection Bureau

[Help for Surviving Spouses](#)

VitalChek

[Online ordering of vital records \(birth, death, marriage and divorce certificates\)](#)

Social Security Administration

[Report death of loved one and information on survivor benefits via phone at 1-800-772-1213](#)

Federal Trade Commission

[The Funeral Rule](#): learn about rights to compare provide among funeral homes.

WAKE

[Louisiana LGBTQ+ End of Life Guide](#)

Grief Support

A number of local resources provide grief support. Here are places that may have information on support in your local community: [LGBTQ+ Community Centers](#), [SAGECollab Partners](#), [Eldercare Locator](#) hospitals, hospice organizations and faith/spiritual based communities.

Goals of Care Worksheet

Questions to ask and expect in a Palliative Care consultation, family meeting, or “goals of care” conversation.

- How much detail would you and your loved ones like to know about your illness and plan?
- What is your understanding of the current situation of your health?
- What does a good day look like for you?
- What makes your life meaningful? What are your spiritual beliefs? What is important to you? Who are the most important people in your life?
- Facing serious illness, what gives you strength?
- What do you hope for most? ... If that hope isn't possible, what else would you hope for?
- Facing serious illness, what concerns you most? What are you most afraid of?
- What is bothering you most — about your health, your quality of life, or your situation?
- What do you hope to learn or understand from this conversation with palliative care?
- What is the goal or intent of your current and future treatment? Is it to cure your illness completely or to make your life more comfortable or longer — and by how much time?
- What abilities are so critical to you that you can't imagine living without them?
- What is the prognosis — or how long you may have to live in days to weeks, weeks to months, months to years, or years +? Would your provider be surprised if you died from your illness within the next year?
- What does the future look like if you continue to do the treatments you're on now? What are the other options or paths?
- Some people want to be clear about what types of treatment they'd want or would not want in a crisis situation. Do you have preferences about CPR, breathing on a ventilator machine, feeding tubes and other life-prolonging measures?
- What decisions need to be made today? What decisions can wait and how long?
- Will palliative care continue to be involved in care in the next step? How and with who?

Check out resources on [caringinfo.org](https://www.caringinfo.org) for how to speak to providers about your care.

Letter to a Caregiver

Nice to meet you!

My name is _____.

Please call me “_____” and refer to me using the pronouns _____.

The important people in my life are _____ (*person/relationship*) _____.

I enjoy spending my time doing _____.

I have dedicated my life to _____.

My identity is _____ (*cultural/communities*) _____.

Spiritually I believe in _____ (*religion/atheism/community*) _____.

When possible, I prefer to have caregivers/providers who are:
_____ (*characteristics/preferences*) _____.

Pain relief measures (medications, non-medication) that have worked/not worked for me in the past are: _____.

The best way to comfort me when I am:
feeling mentally or emotionally unwell is _____;
and physically unwell is: _____ (*sounds, lighting, presence of people*) _____.

My diet restrictions and preferences are: _____.

I feel most comfortable in/with: _____ (*clothing, environment, surrounded by, appearance upkeep, privacy considerations, bodily care*) _____.

Thank you for your care!

About Me and Honoring Me

To be placed in the secure “In Case of Emergency” folder or a separate location told to your trusted funeral proxy due to the sensitive nature of the information.

1. What biographical information (name, pronouns) and important points should be used in your obituary? at your service? and on your headstone?
2. Helpful information for my memorial:
SSN:
DOB and place of birth:
Current Mailing address:
Citizenships and dates of immigration:
Occupation, employer, employer contact:
Level of education/schools/degrees/certifications:
Marriage/Partnership information and status:
Next of Kin:
Parents' Names, DOBs and place of birth:
Military Service:
Location of deeds/titles:
Landlord name/contact info:
Location of birth, SSN, and marriage etc. certificates:
Retirement accounts and numbers:
Financial planner name and contact info:
Bank account numbers and transfer on death designations:
Last will and testament location:
Life insurance policies:
Long-term care insurance policies:
Emails and passwords:
Online accounts and passwords:
Electronic passwords/access codes:
3. Draw the room you would want your last living moments in.
4. What rituals would you like to be performed around the time of death?
5. What are your body boundaries and directives for how my body should be cared for after my death?
6. My wishes for the disposition of my body post-death are:
7. Do you want organ/body donation? Where?
8. Who to and not to notify after my death?
9. My funeral agent is:
10. What is your vision and wishes for your funeral? What rituals and elements would celebrate me and my life at my memorial?

This guide was written and created by [Eliza Giles](#), MSN, RN, AGPCNP-BC, CHPN in collaboration with professionals in the fields of nursing, law, healthcare, and LGBTQ+ advocacy. Thank you to Dorothy Wholihan at [NYU Rory Meyers](#), Sherrill Wayland, Irene Tsiktas, Taisha Aguilar, Morgan Van Vleck, Sadiya Abjani, and Elise Hernandez at [SAGE](#), Kate Muehlemann Cataldo at [Constellations of Care](#), Osha Towers and Alyson Lynch at [Compassion and Choices](#), and Amber Christ at [Justice in Aging](#).

This project was supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$281,734 with 74% percentage funded by ACL/HHS and \$71,924 amount and 26% percentage funded by non-governmental source(s). The contents are those of the author(s) and do not necessarily represent the official views of, nor are an endorsement, by ACL/HHS, or the U.S. Government. All Rights Reserved.

© SAGE 2024

