Ember
Compassion and Pride for
the LGBTQIA+ Community in Death

LGBTQIA+ End-of-Life Guide

LGBT IRELAND
For Inclusion
For Equality
For Everyone

AIIHPC
All Ireland Institute of
Hospice and Palliative Care

Irish Hospice Foundation

An Roinn Leanaí, Comhionannais,
Míchumais, Lánpháirtíochta agus Óige
Department of Children, Equality,
Disability, Integration and Youth

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Introduction

Advance or Future Care Planning is thinking about, talking about, and recording your choices, values, and preferences for your care at end of life.

Discussing what you want with your loved ones, or with your GP or healthcare team, is an important part of advance care planning. It prepares you and others for a time when you may need assistance or are unable to communicate healthcare decisions.

We all value and prefer different things. So, it’s important to first reflect on your own values and preferences, and then to share those thoughts with your friends, family, advocate, and your healthcare team.

When other people know what kind of treatment and care you want, you are more likely to receive it. Advance care planning helps protect and communicate your choices, even if you are injured or ill and cannot express them. Think of it as a gift to loved ones to do this preparation before a crisis or health change. If your preferences aren’t known, your providers and loved ones are left to make tough decisions without knowing what you’d really want.

This guide aims to empower LGBTQIA+ people who may face specific challenges in the legal and healthcare systems. You may need to ensure your dignity and avoid conflict or discrimination.

In this guide, you’ll find information to help you think, and talk, about your wishes and plan for future healthcare decisions. This guide will also provide tips for LGBTQIA+ people who have advanced illness, including information on palliative and supportive care, caregiver advice and healthcare resources along with hospice services, memorial and burial options, and bereavement support for the LGBTQIA+ community.

Research suggests that sharing personal information — such as sexual orientation, gender identity, and sensitive health issues — makes it difficult for LGBTQIA+ people to do advance care planning. There are also challenges for LGBTQIA+ people, particularly transgender people, in accessing supportive healthcare providers.

This guide aims to make the advance care planning process easier, more approachable, and relevant to LGBTQIA+ issues by creating a checklist of helpful documents to complete, conversations to have, and decisions to consider.

As set out above, this guide provides general information only and is not a substitute for legal advice. You may also wish to consult with a community organisation - such as a local LGBTQIA+ support group - or a legal representative to make sure your sexuality, gender, health status, cultural, ethnic, economic, and racial identities are considered.

There are specific instructions about how these advance care planning documents should be completed, with advice from the Health Service Executive and from Citizens Information.

Who should do advance care planning?

Advance Care Planning is beneficial for everyone. Still, certain groups of people are encouraged to start planning ahead if they have not done so already.

- **People who are preparing for their retirement – or are already in retirement**
- **People who are caring for others**
- **People with life-limiting conditions**

Preparing for your life post-retirement is a practical step that can help you to feel ready and supported as you enter a new phase of life. Just like when you planned where to live, to have a child or get married, planning for what is coming next is a smart action.

People who are caring for others may find that they are looking into advance care planning for the person they are caring for. This is a great idea! Additionally, you may find that making your own plans for the future benefits both of you as well. It’s easier to do some planning with another person, so the two of you (and anybody else involved) can find it supportive to discuss and plan together. But you also might think about what would happen to the person you're caring for if something unexpected happened to you.

Ideally, people who are living with a life-limiting condition should consider their plans for the future alongside treatments. As you'll read in the next section, the earlier these conversations start, the easier the transition is if they ever become necessary.

What are the benefits in general? And, in particular, for LGBTQIA+ people?

There are many benefits to planning ahead. These include less stress, fear and anxiety around what the future might hold.

Through advance care planning, people of all ages and stages are more likely to be cared for where and how they want whether this is at home, hospital or hospice. This increases their involvement in care whether this is focused on quality of life or continuation of invasive treatments. Planning ahead may add voice, and reduce stress and anxiety about what the future may hold.

For LGBTQIA+ people, there are additional benefits to planning ahead. Advance care planning and planning ahead will ensure your wishes and preferences are maximised and recorded for those you want involved in speaking and caring for you at the end of life.

For many LGBTQIA+ people, families of origin may not be the people they trust, and they may want to nominate a Designated Healthcare Representative and register an Enduring Power of Attorney. Without doing so, it is possible that family of origin may, by default, end up advising on treatment and other decisions.

Planning

For many LGBTQIA+ people, there is the fear of 'going back in the closet' when you can no longer advocate for yourself. Moving to a nursing home can be a frightening option for some, but when you have made your identity, your personality, your pronouns, your sexuality, your spirituality and your health status known to others, you are more likely to receive the quality of care that matters to you.

For many LGBTQIA+ people, ensuring that your life is remembered, such as in a funeral or memorial ceremony, is extremely important. It may be important to those close to you that your life is celebrated in a way that honours you, too. Planning your funeral and giving those plans to the person responsible to see it through, can help others feel supported. Many people enjoy planning their funerals, surprisingly.

When should you start?

The sooner people start planning ahead, the easier it is in many ways. It's easier to think about what might happen in the future if you are still relatively well.

A common mistake is that people try to think too far into the future. It's important to think about what you would want now. You can always change your mind, and you very well might. But if your health were to suddenly worsen, or if you were injured, putting your plans in place can help you now.

Start with what you already know. These might be the songs you want played at your funeral. It might be naming a friend or loved one to help you with your finances. Or it might be what happens to a pet if you can no longer care for them. Thinking about what you already know or would want will help you start, and when you are ready you can decide on other available options.

What is decision-making capacity?

Some advance care planning requires a person to have 'capacity' to make those decisions. For example, a person must have capacity to make an Enduring Power of Attorney, an Advance Healthcare Directive (AHD), or a Final Will & Testament (a Will). However, the test as to whether a person has capacity will be different depending on whether they are making a Will, an Enduring Power of Attorney or an AHD.

As a general guide, having decision-making capacity means that you can do all of the following:

- **Understand information about the decision you have to make, at the time the decision is to be made;**
- **Hold the information long enough to make a choice;**
- **Weigh up information as part of the process of making the decision; and,**
- **Communicate your decision by writing it down, or by telling or showing someone what your decision is.**

For example, if a consultant recommends that a patient receive surgery, the patient must give their consent for the surgery to go forward. The patient would need to:

- **Understand any relevant information about going into surgery, including the benefits and drawbacks**
- **Remember that information while they think about their options for surgery**
- **Compare and contrast that information about their surgery**
- **And tell someone whether they consent or do not consent to surgery.**

If you are unable to do any of the above, you are said to "lack capacity". Among other reasons, this may be because of a brain injury, intellectual disability, mental health difficulty or dementia.

This can be confusing for people, because a person may have the capacity to decide some things and not others.

Since the introduction of the Assisted Decision-Making (Capacity) Act 2015, people are supported in making as many decisions as they can. The Decision Support Service supports and upholds the rights of people who need assistance in making decisions.

Somebody with cognitive impairment or cognitive decline - meaning they may not understand things as well as other people - might still have the capacity to make decisions. This varies from person to person. For example, the Alzheimer's Society of Ireland recommends that people start making their plans once they've received a diagnosis. They say this because it's likely that a person's cognitive function will worsen, so it's important to make plans while they are still relatively well.

Starting To Plan From Where You Are Now

Even when you are well, emergencies can occur. The human immunodeficiency virus (HIV) epidemic and COVID-19 pandemic have made us more aware of unexpected changes and health injustices for minority communities.

Some LGBTQIA+ people may experience challenges in their 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 guide and make updates to your documents.

Healthcare Planning

An Advanced Healthcare Directive (AHD) is a place to record your healthcare choices and appoint somebody to speak on your behalf, should you lack decision-making capacity to advocate for yourself through illness, accident, or mental distress. This document needs to be properly signed and witnessed.

An AHD is used to inform those who need to know about your treatment and care. As these decisions can be confusing or overwhelming, we highly recommend talking with your GP about your options and sharing your decisions with family and friends.

Some LGBTQIA+ people may not feel their GP can be their trusted source of information, due to lack of familiarity, understanding, prejudice or unavailability. It is important to remember that GPs are bound by law and by Medical Council guidelines not to discriminate on the grounds of gender or sexual orientation; however, in the event that the patient-doctor relationship breaks down, they are obliged to make arrangements for another doctor or service to take over the patient's care.

AHDs are normally written down but can include voice or video recording and speech recognition technologies: this is legally acceptable but it's recommended that these are written out or transcribed afterward. If you make an AHD in a language other than English or Irish, you should arrange to have it translated in case nobody is on-site who can translate it when needed.

An AHD is made up of three key parts:

1. **Refusing medical and treatment options.**
2. **Consenting to medical and treatment options.**
3. **Appointing someone to carry out your choices and speak on your behalf.**

The Assisted Decision-Making (Capacity) Act 2015 sets out legal rules about how a person can create an AHD, how they can appoint a trusted person to act as their Designated Healthcare Representative, and how healthcare workers should apply a person's AHD to guide their care. For more information on the Assisted Decision-Making (Capacity) Act 2015, and how it can help you, visit the Decision Support Service.

An AHD only comes into effect if you cannot make decisions for yourself at the time when decisions have to be made, for whatever reason. If, for example, you have capacity to make decisions and you are able to communicate with your healthcare team then your AHD will not be used. However, a person with serious cognitive decline, a serious illness where they may not be conscious, and so on, are examples of why an AHD might come into effect if a healthcare treatment decision is needed.

An AHD should always be kept under regular review as your wishes and your health may change.

AHDs may take time to create, because it's important to think about what matters to you and to talk about it with others. You may have questions about your treatment options and may need to speak with a few people to find someone who would be comfortable being your Designated Healthcare Representative.

You may wish to speak with others, both professional or in your community, about what your future might hold. However, provided you comply with all of the requirements, you do not need to involve any medical or legal professional in order for your AHD to be legally valid. However, if you are in any doubt, a legal professional can ensure that all requirements have been met for a valid AHD.

Treatments

You may refuse or consent to any treatment: from preventative treatments to life-sustaining treatments, from medication to surgery, and everything in between.

Try to be specific as possible about the circumstances where you would or would not want treatment. You should be able to speak with your doctor about what options for treatment may exist if and when you may not be able to make decisions in the future. You might consider your quality of life and compare that with your quantity of life – meaning how you would like to live versus how long you would like to live. You should revisit this over time, because this comparison may change with time!

Refusing treatment and consenting to treatment are handled differently. Read on below to find out more.

Refusing treatment

Any refusals that you make in your AHD are legally-binding, so long as your AHD is legally valid. That means that while you can always change your mind or revoke your decisions, your healthcare team must follow them once the AHD is in effect. (For details on making, and potentially amending, your AHD, see ThinkAhead.ie)

Your healthcare team must follow your refusals in your AHD if you are unable to express your decision when it is needed. If you are unable to make or communicate a decision, your healthcare team would turn to your AHD and your Designated Healthcare Representative, as needed. If you have refused the treatment that they are offering, that refusal is binding. They cannot override that decision except under very specific scenarios.

Those scenarios include: 1) If they have evidence that you did not have capacity or were forced to make the AHD by someone else; 2) If you or your healthcare representative has not made your AHD available to your healthcare team; 3) If the AHD is not available when an emergency decision must be made.

Sometimes, people are not clear enough in identifying what treatments they refuse. In this case, the healthcare team would turn to next-of-kin or a designated person.

Consenting to Treatment

Any consent or request for treatment must be taken into consideration, but the final decision for these lies with your healthcare providers. For example, you may have given consent to a treatment like ventilation; but if you do not need ventilation, you will not receive it.

Templates for AHDs are available from Irish Hospice Foundation's Think Ahead programme at ThinkAhead.ie, by calling (01) 679 3188, or by emailing thinkahead@hospicefoundation.ie; or from the Decision Support Service at DecisionSupportService.ie

Nominating a designated healthcare representative

In your template AHD you will find the forms to nominate someone to be your Designated Healthcare Representative. This should be someone you know and trust to speak on your behalf for medical decisions. You may also appoint an alternate person to act for you if your original Designated Healthcare Representative is unable to do so.

Your Designated/Alternate Healthcare Representatives must agree to act on the decisions you have set out in your AHD if at some point in the future you lack capacity to make and/or express your choices. They must inform your healthcare providers about your decisions as you set them out in your AHD.

Situations may arise that you haven't foreseen, so you may also choose to give your Designated Healthcare Representative the power to interpret your wishes, including the power to refuse, consent to, or request treatments on your behalf. These decisions must be based on your wishes and preferences, not theirs.

The Designated/Alternate Healthcare Representatives must:

- **Be at least 18 years of age, and**
- **Agree to act for you in accordance with your will and preferences.**

The Designated/Alternate Healthcare Representatives must not be:

- **A person paid to look after you, unless that person is your spouse, civil partner, cohabitant, parent, child, or sibling;**
- **A person who owns, or works in, a residential or healthcare facility where you are living, unless that person is your spouse, civil partner, cohabitant, parent, child, or sibling;**
- **Someone who has been convicted of an offense regarding you or your child; or**
- **Someone who has a safety or barring order in relation to you or your child.**

Who should you choose?

When deciding who you would like to be your Designated/Alternate Healthcare Representatives, ask yourself a couple of questions. Which friend, relative, or person, do you trust, respect, and want to speak on your behalf? Who already knows you, and would understand and respect your choices at the end of your life? Who is willing to have these conversations with you? Who is likely to be available if and when this role is needed in the future? Remember, they must agree and commit to this role.

What if I do not have someone close to me that I trust to be my Designated Healthcare Representative?

If you do not have someone you would trust to name as a Designated Healthcare Representative, then you should be as clear as possible in your AHD. Clearly state under what circumstances you would want treatments, and under what circumstances you would not want certain treatments. The clearer you are, the less confusion or interpretation your healthcare team will have to make if you are unable to express yourself in the future.

Next of kin is a commonly used but misunderstood phrase. For making medical decisions, your 'next of kin' has no legal standing. That means that just because you are related or even married to someone does not mean that they have the power to make decisions about your medical care.

For some people, this is welcome news. For example, if you are estranged from your parents, siblings, spouse, or children, they are not entitled to make decisions on your behalf if you are unwell. For other people, this may come as unwelcome news, for example if you assumed that your partner, or a close sibling or child, would have that right. In reality, the only people who have this right are the one or two people you named in your **AHD** as your **Designated Healthcare Representatives.**

However, deferring to family members and consulting with them is common practice. Sometimes your healthcare team will follow the guidance of these family members, whether or not you think they should. Sometimes they won't follow the guidance of your family members, whether or not you think they should. To protect your wishes and decisions, it is important to name a **Designated Healthcare Representative.**

The best time to do this is **when you are well**, as there can be legal implications for your loved ones when you die. If there are legalities you have been putting off, now is the time to do them - for example, getting legally married, getting your Gender Recognition Certificate, or anything time-sensitive.

How should I ask someone to be my DHR?

Asking someone to be your Designated Healthcare Representative might feel intimidating or overwhelming for someone. Start with asking if they would be willing to talk with you about your wishes for the future, if you become ill, for example. Share with them what is important to you. If they are receptive, you might ask them to become a Designated Healthcare Representative and help to ensure that your wishes are carried out.

Television shows, movies, books, radio or any type of media featuring death or end-of-life scenarios can help to spark a conversation as well. If you've seen something that made you think about your preferences, ask a friend what they thought of the scene. You might say something like, "I wouldn't want that same thing to happen to me. What would you want?" You'd be surprised at the conversation that might follow…

"I'd like to ask you to be my Designated Healthcare Representative. That means you would be the person I'd trust to make my medical decisions and personal needs known if I'm unable to speak for myself. I'm going to write these down in an AHD so you'll have the information and wouldn't have to guess. I'd need you to speak up for my wishes, my safety, and my identity. Is this something you would be comfortable doing?"

Possible responses:

"I would be happy to!"

"Thank you! I'll make sure you have what you need in case you ever need it."

"I'm sorry. I won't be able to be your Designated Healthcare Representative."

"It is okay if you need to say no. Thank you for your honest response."

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." In this case, they may be listed as a "person who should have no authority" in the "in case of emergency" folder.

What to do with my AHD when it's done?

No register currently exists for AHDs, although it is expected there will be one in the future. Until then, it is your responsibility to make and share copies with important people, such as your Designated Healthcare Representatives and other close family or friends. Leaving a copy with a GP or other specialist is important as well. This helps to make sure that if your AHD is needed in the future, someone will have a copy.

Enduring Power of Attorney

Apart from an AHD, which legally binds healthcare teams to your previously recorded treatment choices, there are other legal documents which you may choose to put in place before they are needed. Remember, an AHD does not require a solicitor. However, if you are in any doubt on how to put a valid AHD in place, we suggest that a legal professional review the AHD to ensure it is valid. Other documents do however require a solicitor. These include an Enduring Power of Attorney and naming legal guardians for your children or dependents. Writing a Will does not require a solicitor, but it is highly recommended to ensure the Will is valid. Many Credit Unions also offer a free will-making service for members.

An **Enduring Power of Attorney**, sometimes called a **Living Will**, is an arrangement for how your affairs will be managed while you are living but you lack the capacity to take care of them yourself.

Within an Enduring Power of Attorney you can appoint a person, called an **attorney**, to make decisions as directed by you. An attorney is your agent and only has power to make decisions as directed in your Enduring Power of Attorney document.

In an Enduring Power of Attorney, you give the appointed attorney the authority to make decisions about your finances, property, and personal affairs, as set out in your Enduring Power of Attorney document. Generally, an attorney is someone close to you who you trust, such as a partner, friend, or a member of your chosen or extended family.

It's important you do so sooner rather than later as an Enduring Power of Attorney (EPA) needs to be prepared when you have capacity to do so. All EPAs are made through the Decision Support Service, although you may work with a solicitor to guide you through this process. Although you may choose not to hire a solicitor, you will need to seek a statement of capacity from one. The Legal Aid Board can help you make an EPA or provide you with a statement of capacity.

You will also need a statement of capacity from your GP or another healthcare provider to prove that you are able to understand and make these documents.

The Decision Support Service also offers guidance, including templates and videos, at Making an enduring power of attorney | Decision Support Service for making an Enduring Power of Attorney arrangement. An Enduring Power of Attorney must then be registered with the Decision Support Service. If in the future you lack capacity, your attorney will enact the EPA. That means they will get a statement from your GP that says you do not have capacity, and the decisions you previously made will come into effect. Most importantly, the person you named as your attorney will now be able to act on your behalf for financial, property and personal care affairs as you had previously decided.

What is the difference between an Enduring Power of Attorney and an AHD?

Generally speaking, an Enduring Power of Attorney is only used to grant a person control over your finances, property and your personal care. An Enduring Power of Attorney is not used for healthcare matters. For healthcare decisions, your wishes will be recorded in your AHD and you can also name a Designated Healthcare Representative to ensure that your AHD is complied with.

Making a Will

A will is a legal document, signed in the presence of two witnesses, that states what should happen to your **estate** (your **assets**) after you have died. It allows you to name persons (your executors) who will carry out your wishes after death. Your **beneficiaries** are the people who will inherit your estate. Remember, your estate is not only about property and money, but also your treasured possessions.

Whatever age you are, writing a will is the only way to make sure your wishes about your assets after your death are fulfilled. Many of us die without making a will and believe our wishes will be honoured anyway. This is not the case. A will can ensure your assets are distributed in the way you wish while avoiding any unnecessary taxation for your beneficiaries.

If you do not make a will, the law will decide on the distribution of your assets through a process called **probate**. Under this system, the law uses a prescribed beneficiary list which starts with family of origin. If you are estranged from your family, you may not wish this to happen.

In order to make a valid will, a person must have testamentary capacity. This will be a different test than the test for capacity to make an AHD. Generally speaking, you will need to demonstrate that you understand the nature and effect of the will, and the extent of your assets.

If you would like to make a will, it is recommended that you talk to a solicitor or contact your local Credit Union to see if they provide this service for free. You can find a solicitor by checking the Law Society's website.

Gender recognition

Since September 2015, trans people in Ireland can apply to have their preferred gender legally recognised by the State. This is set out in the Gender Recognition Act 2015.

In cases of extenuating circumstances, such as a terminal illness, a Gender Recognition Certificate can be issued on an expedited basis. This ensures that the preferred gender will be legally recognised on the death certificate and other relevant documentation. For assistance with the process, you can contact the Department of Social Protection at GRC@welfare.ie.

What if? Useful resources.

We do not always know when we will become ill whether through accident, chronic health condition or diagnosis of a life limiting condition. There are various resources you can use to make your wishes known and alleviate some of the administrative burden for your loves ones: In Case of Emergency Folder, Do Not Attempt to Resuscitate or DNAR, Personal Directive for Quality Living letter.

In case of emergency folder

Your Advance Care Plan will help to guide others whether health care staff, your family, trusted others or decision supporters, legal or Designated Healthcare Representatives. It is important that you share this document or alert them to its whereabouts in the event of an emergency.

In case of an emergency in the home, make sure that your AHD and important medical information is easy to find. You might put the Medical Summary Form on your refrigerator or behind the front door, for example.

If you call emergency services for yourself, make sure you unlock the front door so they can get in. If you have time, put your pets in a closed room. Take out your AHD and have it with you. Each of these steps will help you receive the correct treatments in a timely manner.

Do not attempt to resuscitate or DNAR:

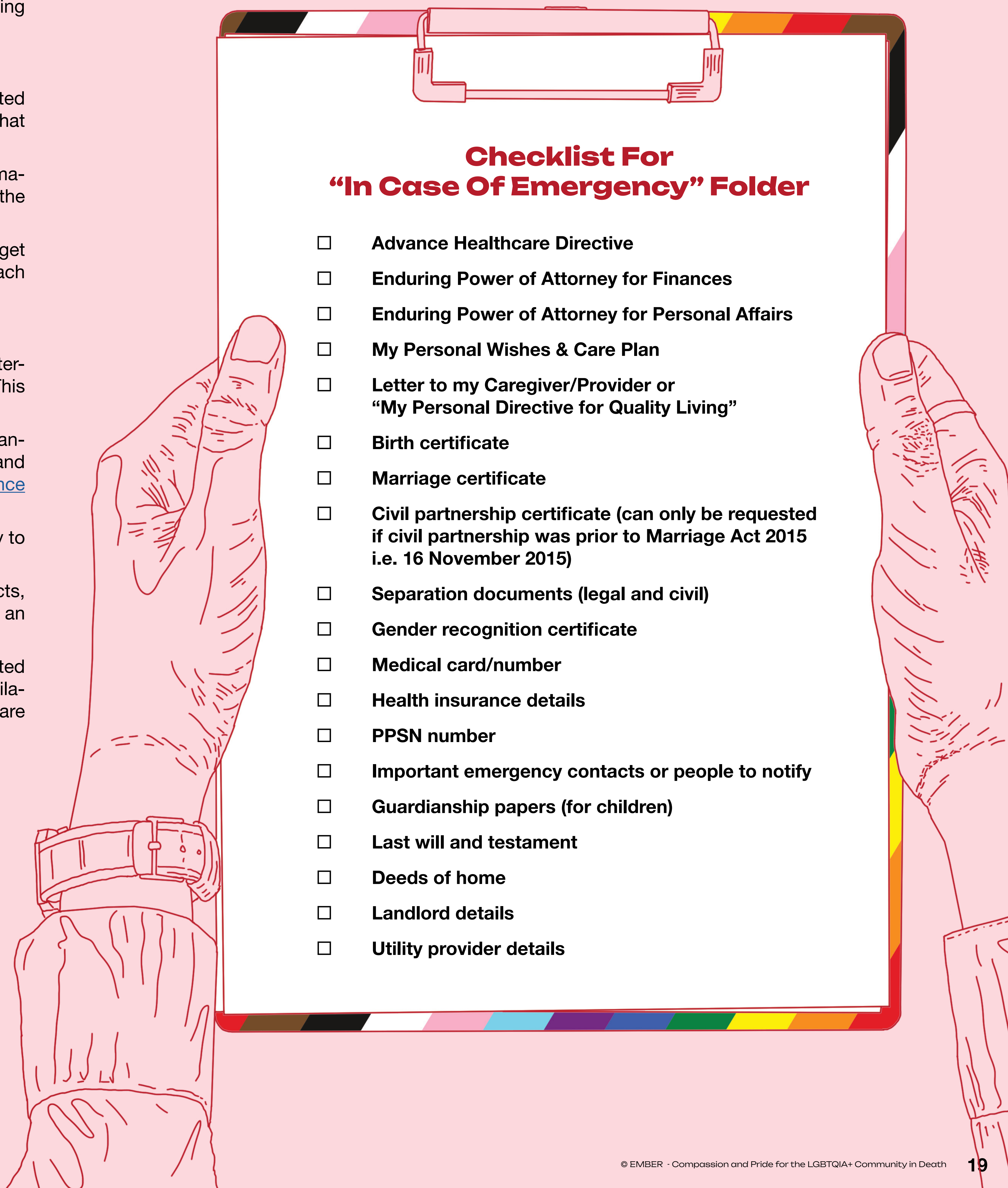
IIt is important to make advance care plans known, as well as decisions about appropriate interventions in the event that your condition, or that of the person you are caring for, deteriorates. This is to ensure that you or they do not receive inappropriate or harmful treatment.

This includes Do Not Attempt Resuscitation (DNAR) decisions. Normally, with advance care planning a medical professional will discuss your preferences including DNAR, other treatments and care that may be right for you in the event your condition deteriorates. The HSE offers guidance on making a resuscitation decision.

Do Not Attempt Resuscitation (DNAR) means that if your heart stops, professionals will not try to restart your heart using CPR (cardiopulmonary resuscitation) or a defibrillator.

A medical assessment on whether CPR is appropriate will be based on a number of core facts, including your current health, your expressed wishes around quality of life, and whether such an intervention would be beneficial to you or potentially cause harm.

A DNAR decision does not affect your other treatment options, including keeping you hydrated using liquid through a tube (artificial hydration) or helping you breathe, sometimes called ventilation or intubation. This is why it is important that you are specific about what your preferences are based on your goals and quality of life.



Checklist For “In Case Of Emergency” Folder

- ☐ **Advance Healthcare Directive**
- ☐ **Enduring Power of Attorney for Finances**
- ☐ **Enduring Power of Attorney for Personal Affairs**
- ☐ **My Personal Wishes & Care Plan**
- ☐ **Letter to my Caregiver/Provider or “My Personal Directive for Quality Living”**
- ☐ **Birth certificate**
- ☐ **Marriage certificate**
- ☐ **Civil partnership certificate (can only be requested if civil partnership was prior to Marriage Act 2015 i.e. 16 November 2015)**
- ☐ **Separation documents (legal and civil)**
- ☐ **Gender recognition certificate**
- ☐ **Medical card/number**
- ☐ **Health insurance details**
- ☐ **PPSN number**
- ☐ **Important emergency contacts or people to notify**
- ☐ **Guardianship papers (for children)**
- ☐ **Last will and testament**
- ☐ **Deeds of home**
- ☐ **Landlord details**
- ☐ **Utility provider details**

Place this folder in an easy-to-find spot: your bedside locker, attached to the back of your front door, or even put it in a waterproof ziplock bag inside your refrigerator or freezer. Give copies as needed to your healthcare providers, lawyer, loved ones, and your Designated Healthcare Representative 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 Emergency Folder - discuss each decision with those people around you. 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.

If you cannot talk about your documents, at a minimum share them for review via email or mail with your health care provider, loved ones, or designated representative so that they can be available if needed.

Carer

A carer is someone who is providing an ongoing significant level of care to a person in need of care in the home due to illness, disability or frailty. The care that family and other carers provide involves looking after the needs of people with a wide range of dependencies across all age groups. Carer support enables the persons they are caring for to remain at home for as long as is safe and practical.

Your caregiver does not automatically have the authority to make decisions for you. Therefore, whether or not you have appointed your caregiver as your Attorney in an Enduring Power of Attorney, or as your Healthcare Representative in an Advance Healthcare Directive, it is recommended that you talk with your caregiver about your wishes and decisions.

You can share copies of the resources with your carer (Personal Directive for Quality Living letter, In Case of Emergency Folder and Do Not Attempt to Resuscitate or DNAR) which will help your carer to ensure that your decisions are followed, and your wishes are heard.

Supports for caregivers can be found through the HSE.

Letter to my caregiver or provider

It may be helpful to provide personal information to your caregivers. Below is a sample letter that might guide you thinking about what you would like others to know.

Nice to meet you!

My name is Charlie. Please 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, LGBTQIA+ advocacy, the outdoors, music, Mayo GAA, my loved ones, and learning about love.

My identity is a queer, white cis-gendered female from a Catholic and middle-class Irish 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 LGBTQIA+ community.

Pain relief measures (medications, non-medication) that have worked/ not worked for me in the past are lidocaine, heat, paracetamol, NSAIDS, post-surgical oxycodone which have worked; muscle relaxers like diazepam 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 when physically unwell, low lighting, favourite 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 sparkling water in warm weather and hot water in cold weather. I feel most comfortable: 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!

Adapted from "My Personal Directions for Quality Living" form on the SAGE National Resource Center for LGBTQIA+ Aging (NRC).

See an adapted template for an Irish context here.

My Personal Directions for Quality of Living Template

Name:

Pronouns:

Date:

To My Caregivers (paid and unpaid): I am writing down my personal preferences and information about myself in case I should need to be cared for. Please talk to me on a daily basis about what I want, as things may change, as time goes by. I hope the information below provides some help and understanding in proving my care.

I like to start my day by________________________________

People I enjoy having around________________________________

People I do not want around________________________________

Activities I enjoy________________________________

Things that I like to have in my room________________________________

Foods that I like for comfort________________________________

Foods that I like for fun________________________________

Things I do not like________________________________

I feel anxious when________________________________

Things that calm me________________________________

Things that make me laugh________________________________

I like to relax and finish my day by________________________________

My spiritual preferences are________________________________

For more information about me, you can talk to________________________________

At the end of my life I would like________________________________

Fair Deal and other housing supports

Fair Deal is a nursing home payment support scheme that helps you to pay for a nursing home when and if you are no longer able to care for yourself. Sometimes this process takes time, and you may choose to pay for the nursing home yourself whilst waiting. However, Fair Deal cannot be backdated.

Respite or Day Care

Fair Deal does not cover the cost of respite care or daycare. Check with your healthcare insurance company if access to these is covered.

Community support such as daycare may also be available in your area. Some daycare facilities are provided by the HSE, or independent care providers on behalf of the HSE. Although some provide meals and transport (charges may apply), others do not. If you want to be referred to daycare it is best to discuss this with your Public Health Nurse or GP.

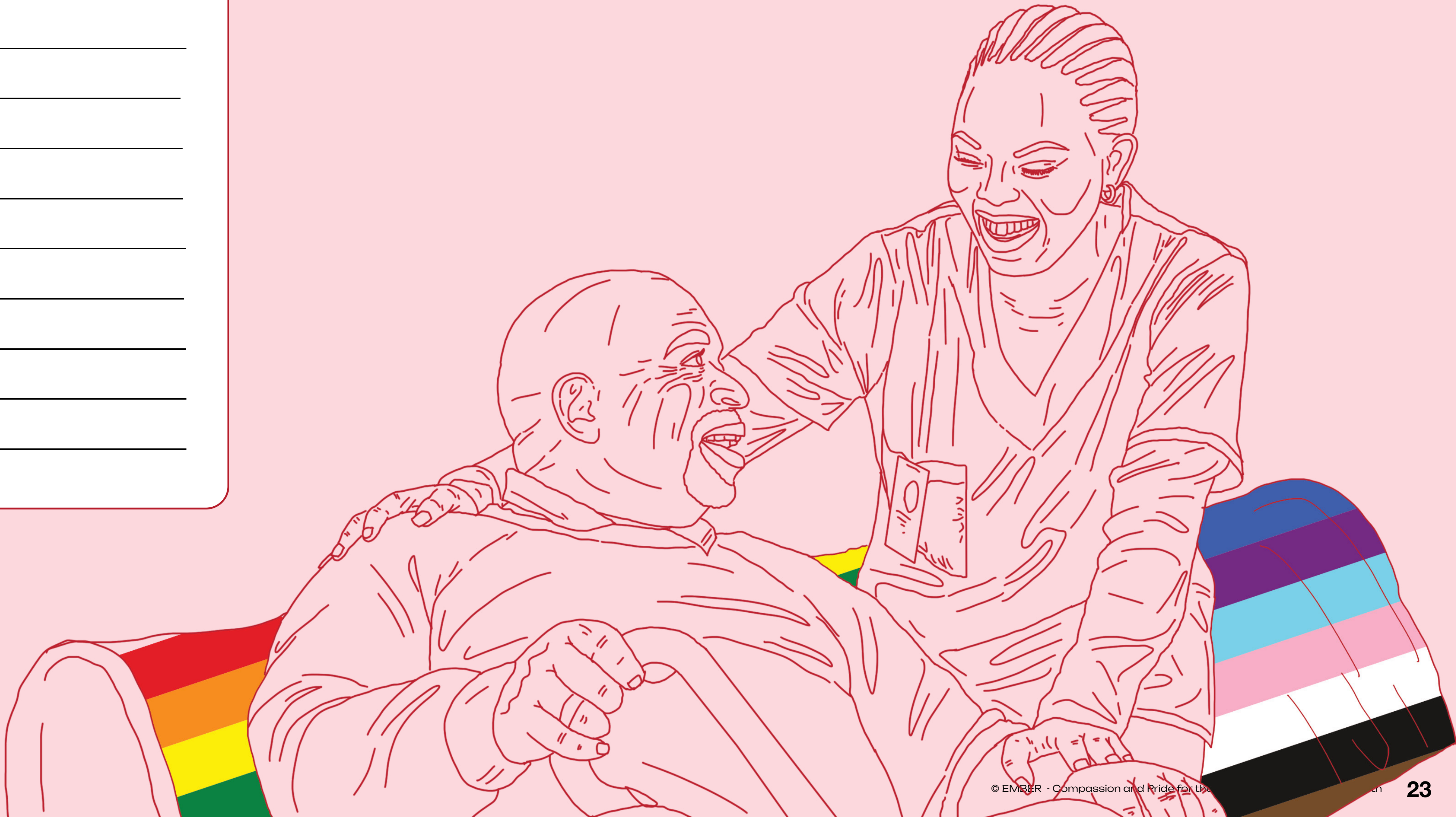
Citizens Information centres can also provide some useful and free information.

Other housing supports

Age Friendly Ireland offers a variety of assistance in planning supports and home adaptations. Each county has an Healthy Age Friendly Homes Coordinator.

Occupational therapy services may be accessed through the HSE or your local health centre.

Local Authority Housing Department. To apply for local authority housing, download an application form from your local authority's website, or contact your local authority's housing department and ask for an application form. An Easy to Read Guide (pdf) to filling in the application form is also available.



Thinking Ahead

Palliative and end of life care involves family, friends and loved ones. And can raise numerous questions that often do not have straight or simple answers. Depending on the illness, a person's age and their life expectancy, the options and decisions to be made by a person and their family can vary hugely. It is important that you understand how palliative care can support your quality of life.

Palliative and End of Life Care

Palliative Care - what is it?

Palliative care is care that includes looking after your physical, social, emotional and spiritual well-being. It aims to support you and your family and carers to improve or maintain your quality of life when you are living with a life-limiting illness.

Palliative care manages symptoms, such as pain, breathlessness and nausea, so that you can continue to feel and to live as well as possible despite having a serious illness. It aims to improve your ability to participate in your daily activities and to keep doing the things that you enjoy.

Palliative care can be offered throughout your life-limiting illness, from the time of your diagnosis, during treatments and at the end of your life. It can help your family, friends and carers including in their bereavement.

Palliative care facilitates open and honest communication to ensure that decisions about your care, including treatment options, aligning with your preferences and what's important to you.

Palliative Care - when should I consider it?

Palliative care can benefit a person at all stages of a life-limiting illness. You may be experiencing symptoms and are worried about your illness, the treatments that might be available and what might lie ahead. The earlier you receive palliative care, the more it can help you, or someone close to you, who has been diagnosed with a life-limiting illness.

End-of-life care is care that is provided in the last months and weeks of a person's life and provides support to the person who is ill and those close to them.

Terminal care is care that is provided to a person and their family when the person is in the last days or hours of their life.

Some questions that may help you decide whether you need palliative care:

- **Do you need help with managing your symptoms?**
- **Is your illness making it hard for you to enjoy important parts of your life?**
- **Are you unsure about what to expect if your illness progresses or gets worse?**
- **Are you worried about how someone close to you is coping?**
- **Do you need support in how to communicate with a loved one?**
- **Do you need emotional, social or spiritual support to deal with how your illness has changed your life?**
- **Would you like the support of a carer in your own home?**

It is important to talk with your healthcare team about your concerns.

Palliative Care - who is it for?

Palliative care can affect a person at any age. And while most people associate palliative care with cancer, it is available for people with all kinds of life limiting illnesses including kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant tuberculosis.

Paliative Care - who provides it?

Palliative care can be provided by anyone who works in healthcare.

Palliative care is best provided by a team approach to planning and providing care that is tailored to meet the individual needs of a person, their family and those important to them.

This may include general practitioners (GPs), nurses, carers, hospital-based healthcare professionals, pharmacists, and allied health professionals (including physiotherapists, speech and language therapists, occupational therapists and dieticians).

Specialist Palliative Care (SPC) Teams can be hospital, hospice or community-based. Some community SPC Teams are based within local hospices and others are based within the community. Hospices provide a range of services focused on managing symptoms within community, outpatient day services and inpatient services as well as meeting peoples social, emotional and spiritual needs.

Levels of palliative care specialisation

Within a healthcare team are three levels of palliative care provision with increasing specialisation from level one to level three:

Level one: Provided in any location or setting by all health care professionals as part of their role and using a palliative care approach.

Level two: Provided in any location, using a palliative care approach by health care professionals who have additional knowledge of palliative care principles and use this as part of their role.

Level three: Provided by health care professionals who work solely in palliative care, and who have extensive knowledge and skills in this specialty (SPC).

Paying for hospice care

Palliative and End of Life Costs

Primary palliative care and specialist palliative care services are free for all patients and their families in Ireland. Where people have private medical insurance, their insurer may be asked to contribute towards the cost of their care.

Depending on the stage of your illness, you may be entitled to a medical card, which is applied for by your consultant, GP or social worker, who facilitates the application process to the HSE.

Be sure to check in with your GP and local primary care team about what other free services may be available in your local area.

Care settings

It is important that you express your wishes regarding where you would like this care to take place, and to have discussions about your preferred place of care with your family, and the health and social care professionals involved in your care.

This will promote shared decision-making and ensure those important to you are aware of your wishes. Palliative care is not only provided in hospitals and hospices; it can also be delivered in the community and your own home. Whether you live at home or in a nursing home, you can receive palliative care.

It is important to remember that palliative care is not just there for the person with the life limiting illness; it is also there for your family and carers. Seeing a family member or friend going through the stages of an untreatable illness can be tough, especially if you are a carer. Professionals are there to provide carers with support and advice to help guide them through their journey as a carer through to the bereavement.

Helpful links:

Information and resources regarding palliative care for adults www.adultpalliativehub.com
Information and resources regarding palliative care for children's and young people's: www.childrenspalliativehub.com
Information and resources regarding family carers www.carerspalliativehub.com
Online palliative care eLearning programmes and resources: www.palliativelearning.com

The following sites can also be found within the websites which may be useful:
All Ireland Institute of Hospice and Palliative Care www.aiihpc.org
Carers Alliance - http://www.carealliance.ie/
Central Remedial Clinic - http://www.crc.ie/
Cheshire Ireland - http://www.cheshire.ie/
Enable Ireland - http://www.enableireland.ie/
Irish Association for Palliative Care www.iapc.ie the site also includes a listing of local palliative care services.
Irish Cancer Society Night Nurses - https://www.cancer.ie/cancer-information-and-support/cancer-support/getting-organised/night-nursing
Irish Hospice Foundation www.hospicefoundation.ie
Family Carers Ireland www.familycarers.ie
Jack and Jill Children's Foundation https://www.jackandjill.ie/
National Clinical Programme for Palliative Care - HSE.ie

For further information on disease or condition specific organisations visit Adult Palliative Hub.

After a Death

This section provides guidance for your family, carer or designated healthcare representative on what is to be done after your death. This will be a distressing time for them, and having this information to hand may help them cope with your passing and ensure that your wishes are carried out.

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

If someone dies in hospice care, call the hospice team 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 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 you can call your primary care provider and/or 999/112, bearing in mind that emergency services are a different care pathway and that, if 999/112 are called, your loved one's body could be moved to a city morgue.

Tell the dispatcher about the circumstances of the death and, where possible, it can help to have any relevant paperwork available to help the emergency personnel respond appropriately when they attend. Based on the situation, the emergency personnel will tell you whether the person's body will need to be reviewed by the coroner before being transported to the funeral home. If someone dies at the hospital, the hospital staff will work with the person's designated healthcare representative or next of kin regarding the next steps.

If the death is expected: phone the hospice care team and/or GP or hospice doctor, as well as the funeral director. (Funeral directors can support & guide families, but cannot progress any care of the body until clearance from the doctor and/or coroner if relevant).

Body and organ donation

Almost all organ donations are done in hospitals when the person is on a ventilator at the end of their life, and their organs are deemed suitable for donation. If you want to be an organ donor, tell your next of kin. Your next of kin will be responsible for giving consent to organ donation on your behalf when you die. If you have discussed your wishes with them, they may find it easier to support your decision. Unlike medical treatments while you are still living, your Designated Healthcare Representative does not have authority to speak or act on your behalf for organ donation. Register your consent with the Irish Kidney Association or on your Driving License. The HSE describes your next of kin in this context as a 'designated family member' or a close friend who can consent to this decision. Designated family members are considered in the following hierarchy: the person's spouse/ civil partner, cohabitant, child, parent/guardian, sibling, grandparent, grandchild, uncle/aunt, niece/nephew, close friend who can demonstrate that they can determine and accurately convey the person's wishes.

In the context of palliative care, the option of organ donation depends on the individual case. Donors are generally required to be cancer-free for five years prior to donation.

At present, Ireland does not have a policy on organ donation for HIV+ people. We trust this will change in coming years and we look forward to updating this document accordingly.

A new law called the Human Tissue Act 2024 (Transplantation, Post-Mortem, Anatomical Examination and Public Display) will be in place soon. It will introduce an opt-out system of consent for organ donation. This means you can add your name to an opt-out register if you do not want to be an organ donor. If you are on the opt-out register, your next of kin will not be asked about organ donation. If you want to be an organ donor, you do not need to take any action with the opt-out register.

The opt-out register for organ donation is not yet in place. There is no change to organ donation at the time of publication. We will update this information when the new law takes effect. Find out more at: Human Tissue (Transplantation, Post-Mortem, Anatomical Examination and Public Display) Act 2024 – oireachtas.ie

If you want to donate your body for medical research, you must make arrangements with a relevant medical facility prior to your death. Currently, there are five schools in Ireland which accept donated bodies. Each medical school has its own procedures for entering into an agreement with you. See: Considering Body & Organ Donation on ThinkAhead.ie for details.

It is recommended that you speak with your close family or close friends about your decision. Some bereaved people are surprised at how quickly the body is collected after a person's death. The remains will often not be returned to the family for a couple of years, so we recommend that you make funeral arrangements with your family ahead of time.

Registering the death

Every death in Ireland must be recorded and registered at a civil registration office. You should register the death as soon as possible. It must be registered within three months. You need a death notification form, which you can get from the doctor who certified the death. Normally, a partner or family member registers the death. If there are no relatives or designated healthcare representative available to do this, the death can be registered by anyone who has knowledge of the death. This is usually a close family member of the person who has died, but can also be a "Qualified Informant", specifically:

- **A relative of the deceased person**
- **Someone who lived with the deceased person**
- **The deceased person's personal representative**
- **A person who was present at the death**
- **An official of the hospital or institution where the person died**
- **A person who found the body or took charge of that body**
- **The person who arranged the funeral, including funeral director**
- **Any other person who has knowledge of the death and knows the details needed to register the death**

To register a death, you must bring a Death Notification Form stating the cause of death to any Registrar of Births, Marriages and Deaths Office, in any county in Ireland - it does not have to be the county they lived or died in.

You must complete Part 2 of the Death Notification Form and take it to the registry office. You will need to bring a photo ID with you. The registration is free, and there is a fee to obtain the certificate. Additional certificates can be obtained, and these may be useful if multiple agencies need to be notified.

You should register the death within 3 months of the date the person died. However, you have up to 12 months to register the death. If you need to register a death more than 12 months after the person died, you will need to contact the General Register Office.

Who should I notify about the death?

IIn due course, a number of State institutions should be informed that the person has died. For example, if the person was getting a State pension or another social welfare payment, you must inform the Department of Social Protection (DSP) that they have died. You must also inform the DSP if you were getting Carer's Allowance or Carer's Benefit for looking after them.

If the death was sudden or unexplained, the coroner may be appointed to hold an inquest about the circumstances surrounding the death. A post-mortem examination may be carried out to establish the cause of death in certain circumstances. In this case you will receive an interim death certificate for administrative use. Some agencies (e.g. insurance companies) will need the full death certificate to proceed with administration.

Death certificate

Once the death has been recorded, the death certificate can be issued.

You can get copies of the death certificate from the registration office when you are registering the death. To get a copy of a death certificate at a later stage, you can go directly to any civil registration office. You do not have to order a death certificate from a service in the area the death took place.

You can also apply for a death certificate:

- **Online**
- **In person at a registry office**
- **By emailing a completed form to GROonlinepayments@welfare.ie**
- **By phone**

Civil registration offices have different ways of handling requests for certificates. You can find details about your nearest civil registration office on the HSE website.

Legal requirements

You must get a legal order to give you the authority to administer the deceased person's estate. This is a legal document called a Grant of Representation.

If the deceased person left a will, the person who deals with the estate is called the deceased person's executor. The executor needs to take out probate. Taking out probate means having the Probate Office or the appropriate District Probate Registry certify that:

- **The will is valid**
- **All legal, financial and tax matters are in order**

Wills only take effect when the Probate Office accepts that the will is valid. The Probate Office may make some enquiries before making its decision, for example, it may ask for a sworn affidavit from one or both witnesses

If there is no will, the person who deals with the deceased person's estate is called an 'administrator'. An administrator may also be appointed if there is a will but:

- **No executor has been appointed**
- **The appointed person cannot act as executor**
- **The executor cannot or will not carry out their duties**

The administrator needs to take out a Letter of Administration (or a Letter of Administration with Will Annexed if there is a will).

Honouring Life

Choosing a funeral director

The Irish Association of Funeral Directors (IAFD) is the only representative organisation for funeral directors throughout the Republic of Ireland. Members must follow its Code of Practice and quality standards, this includes:

- **Providing professional and quality services in arranging and conducting the funeral**
- **Sensitivity, confidentiality and a commitment to leaving the client in control of decisions**
- **Care of the person from time of death until completion of final funeral arrangements**
- **Information, guidance and co-ordination of all services, service providers and documentation required throughout the funeral planning process**

Individual funeral arrangements vary widely and depend on, among other things, type of service, funeral location, the type of coffin and/or urn, and transportation.

The funeral director's job may include the following:

- **Discussing the deceased's and the family/loved ones wishes and ensuring that all the details are taken care of**
- **Care and presentation of the deceased person**
- **Providing the coffin, the hearse, and the transport of family members if required**
- **Organising and paying for the grave purchase/ opening, cremation charges, celebrant and musician fees, church offerings, newspaper announcements, flowers, music at the ceremony and catering*.**

*** These third party payments are known as "disbursements", and payment of these may be required in advance.**

Making funeral arrangements:

Funeral arrangements are usually made by the next-of-kin of the person who died. The deceased person may have left specific instructions about the funeral service they would like and where they would like to be buried or cremated. Designated Healthcare Representatives have no automatic authority over funeral arrangements.

However, you may pre-pay or pre-plan your own funeral with some funeral directors. Alternatively, you may include funeral directions in your Will. If you do this, make sure that your Executor is aware that your plans are in your Will, so they can access your Will straight away after your death.

While most people respect the wishes of the person who has died where possible, sometimes there are conflicts - which is why advance planning is so important.

If there is disagreement about who should make the arrangements, the personal representatives of the individual are entitled to make the decisions. The personal representatives are the executors of the will (if there is a will), or the people who are administering the estate if there is no will.

If there is dispute about who should have the final say on decisions in the time immediately after the death, in general it will fall to whoever is paying for the services provided. For this reason, some people pre-pay or make their own funeral arrangements before they die. Similarly, the 'estate' of the deceased often pays for the funeral. That is money that is left over from bank accounts or the sale of the house, and the remainder is distributed as described in the Will or by the Courts.

You can engage an undertaker or funeral director to deal with most aspects of the funeral. Sometimes there is limited choice based on location, but in general you can choose any funeral director. It is helpful to engage your funeral director in advance if possible.

A pre-funeral public event

Introduction

It is the custom in Ireland to have an activity where people can come to pay their respects to the person who has died, or to show support and solidarity with the people grieving the loss.

This provides the community with access to those who are grieving. Unlike a commemorative ceremony, these activities are not in place of a funeral; they generally take place before a funeral and are usually the first public appearance of the loved ones..

The days following the death can feel quite isolating so this can be an antidote to that, where everyone remembers that the person who died was part of larger communities and that those who are grieving are also part of communities.

Also, not everyone will be able to attend the funeral because it may be during the working day, so these other events give people a chance to sympathise and to show their support.

The three main types of activities are:

- **A wake**
- **A viewing**
- **A removal**

Wake

A 'wake' is a time for people to come together to commemorate the person who has died. It is usually held in the home of the person with their body on display in an open coffin in a bedroom or a room off the main kitchen or living room. A guiding time is usually given to those expected to attend. For example, a death notice may say that the person is 'reposing at home between 3pm and 6pm' - this will mean that, for those who know where the person lived, they can attend within those times.

It is customary that, during the wake, the family provides refreshments such as tea, coffee and sandwiches. Alcohol may also be available. Some people will drop in for a few minutes to sympathise with the family but most come and stay for a few hours. This is not as sombre as a funeral and can be quite a social activity.

Viewing

It is becoming more common that the body will remain at the funeral directors' premises, and a public room with the body will be opened for people to attend and pay their respects.

The funeral notice will provide the times when it is appropriate to attend. Space is usually tight in these rooms so it is less likely that people will stay at the viewing for very long.

This is usually less sombre than a funeral but not quite as relaxed as a wake. There is generally a book of condolence that you can sign so that people will know that you attended.

When the time is up, the funeral director will need to clear the room – to do this they may for example call for a final prayer, so it may be best to agree what is appropriate with them in advance.

Removal

For those being buried in a religious ceremony, it is possible that their body will be taken to the church the night before the funeral. This is called a 'removal' and will mean that there is a short prayer ceremony in the church or chapel at a time specified on the death notice. Once the prayer service is concluded, people generally form a line to sympathise with the family. Even if you know none of the family, it is acceptable to queue up and sympathise.

Planning a memorial or funeral

Anyone can hold a funeral or celebration of life. In Ireland, the funeral is usually held within the week of the death. This can be in a crematorium, a cemetery, a place of worship, or any venue that can accommodate a coffin. Your funeral director will guide you and will make all the arrangements. There is also the option of direct cremation.

Once the funeral is complete there can be an additional memorial service at a date in the future (scattering/interment of ashes, for example), which can be held anywhere, with or without the person's remains. This is important to know in a situation where there is conflict, as it is an opportunity for friends and chosen family to gather to mourn and celebrate their person in their own way.

Issues for LGBTQIA+ people at these events

Your role in these activities

If you were a partner of the person who died, you should be central to this activity. If there is a wake, you should attend the full wake. If there is a viewing, you should be with the coffin for the full viewing. If there is a removal, you should be in the front seat for the removal. Depending on your relationship with your partner's birth family, however, this may prove problematic and something that you will need to insist upon.

The people in attendance

Remember that these are usually less sombre, more social occasions so you may end up in conversation with a number of different people about a very diverse array of topics. Some will be extended family, some will be neighbours, some will be friends, some will be former work colleagues. There may be people there who never met the person who died, people who are there to sympathise with a family member. They may not even know that the person was part of the LGBTQIA+ community and may show surprise.

People may not know you

At events like this, it is usual that people will ask what your relationship was with the person who died. You can decide in advance how you will answer this. You may be introduced to others by family members who are unsure about how to characterise your relationship with the person who died as they may be uncertain about what you would like them to say.

Trans or non-binary status

For trans or non-binary people who have died, it may be possible that funeral guests may misgender them or use their birth name because they are unaware of their true gender or of their chosen name. A distant relative, who has not seen the person in many years, is likely to turn up at a wake so this situation would not be surprising.

Disagreements and discomfort

These events can also be a site for disagreements and for frustration to boil over. A wake, for example, can be a time when someone who is struggling with their grief drinks to excess and becomes angry. A removal can be a time where, because it is in a religious setting, an LGBTQIA+ partner can become side-lined because of anti-LGBTQIA+ teachings within that religion. It is useful to prepare for potential disagreements and discomfort.

Disenfranchised grief

There is no one correct way to grieve. People grieve in their own ways and the same person may experience multiple types of grief over their lifetime as they lose people close to them or lose an acquaintance or colleague suddenly, for example.

How we grieve and how other people recognise and acknowledge our grief, however, is guided by what is the norm. We are expected to cry without warning at a family funeral but not three months later. We are expected to talk a lot about the person who died on the days following their death but not six months later. There is an expectation that our grief will abate over time and that we will be able to deal with it in a way that we no longer share it with others.

This, however, is not always the case and, for people in same-sex relationships or in relationships that are not always recognised as having the same weight as others, someone may experience what is termed 'disenfranchised grief'.

What is disenfranchised grief?

Disenfranchised grief can occur in many situations – grief for a miscarriage, grief for loss of an object with deep meaning, grief by staff for someone in residential care who has died. People can feel grief but do not necessarily find the external support or validation that would be expected.

For members of the LGBTQIA+ community who are in relationships that are unacknowledged, hidden or unrecognised, the death of a partner may not come with the support or sympathy that can make a big difference during the early days of grief. Grieving the death of a 'friend' is not seen as equivalent to grieving the death of a partner, and so people may not recognise the need for support, they may not ask about how you are coping, and they may not understand the intensity of your grief and so may not provide you with the support you need.

For those people rejected by their birth family, they may have formed a chosen family with whom they have no blood ties but who are closer to them than their birth family. In a culture that identifies the primacy of birth families for bereavement leave, a death within someone's chosen family can leave peers nonplussed.

Where to start if you are struggling with grief

If you are struggling to come to terms with the death of someone, it is not your fault. How we grieve is individual to each of us and, while the way in which we are grieving might not be seen by others as 'the norm', that does not mean that it is inappropriate or a failing - it is simply how you are feeling and there is nothing wrong with that.

It is likely that you will benefit from speaking about your grief to someone who is more likely to understand it. One place to begin is the Bereavement Support Line, the Irish national freephone service on 1800 80 70 77 which is available from 10am to 1pm, Monday to Friday. LGBT Ireland also runs the National LGBT Helpline a freephone service on 1800 92 95 39 and an online instant messaging service on LGBT.ie which is available seven days a week;

Monday to Thursday: 6:30pm to 10:00pm,

Fridays: 4:00pm to 10:00pm,

Weekends: 4:00pm to 6:00pm

Outside of these times the Samaritans are available 24/7 and 365 days a year on 116-123

Planning how to share the news of a death

When someone close to you dies, figuring out how to share the news can feel overwhelming, but with some thoughtful preparation this difficult process can be made a bit more manageable.

The lives of LGBTQIA+ people can be structured very differently compared to others, sometimes involving a complex web of relationships across various communities. Due to this, traditional networks may not always be the best way to share this news.

Depending on their level of openness with their identity, LGBTQIA+ people may have kept different aspects of their lives, such as friends, colleagues, family, and "chosen family" *, intentionally separate. Therefore, extra care and consideration are needed to ensure that all those who were important to them are appropriately informed.

If time and circumstances allow before the person dies, talk to them about who is important in their life and check if they have a list of those they want contacted. Reach out to those who might not be aware of the person's declining health to prevent the news from being a complete shock.

It's a good idea to discuss with close friends or supportive family members who will be in charge of spreading the news. Delegating the task to others, to make sure everyone who needs to know is told in a timely and respectful manner, can provide a sense of support and ease the emotional strain during this tough time. Reaching out to local LGBTQIA+ community organisations can be a good way to ensure that news reaches those who need to know.

After the initial communication is done, a person's death can be announced in an obituary online (RIP.ie) and/or in print. A funeral director can guide you, and will submit the notices as required.

Usually, the death notice includes the person's name, date of death, list of primary mourners, and time, date and location of any funeral arrangements, sympathy preferences (flowers/donations) and a photo. If details of the funeral arrangements do not want to be publicized, a death notice or obituary can be created after the funeral has taken place, and to notify that the death has occurred.

Social media announcements

Some people choose to announce a death on social media. This can be a way to share the news widely. However, be mindful of the impact on those who might prefer to hear the news in a more personal way and the wishes of the individual who has passed away. Ensure extra care is taken to ensure all those who were important to the deceased are informed before posting to avoid catching anyone off guard.

Respecting identities

When discussing an individual who has passed away it's important to honour their identity. Use the pronouns, titles and gender markers they chose for themselves. Refrain from sharing details about their orientation or gender identity unless given permission or if it's essential.

**Chosen Family: A group of people who may not be related by blood or marriage, but who care about each other and fulfil the same kinds of functions as a family.*

Family and succession planning: key points

Understanding family and legal definitions:

- **Family Definition (Constitution):** The State recognises the Family is the fundamental unit of society with inherent rights.
- **Spouse:** In cases of intestacy (no will), the spouse receives the entire estate if there are no children, and two-thirds if there are children. With a will, the spouse is entitled to a legal share of half the estate without children, or one-third with children.
- **Separated Spouse:** The status of separation and any formal agreements affect succession rights. An Irish divorce provides certainty but does not revoke a will. Foreign divorces may have different implications based on jurisdiction.
- **Cohabitant:** Defined as two adults living together in an intimate relationship, not married or civil partners. Qualified cohabitants, living together for two years (with children) or five years (without children), may seek financial redress if financially dependent.

Children and inheritance:

- **Children:** Under Section 117 of the Succession Act 1965, courts can order provision for a child - including an adult child - if a will fails to do so adequately.
- **Additional Needs:** Consider setting up a discretionary trust for children with additional needs to manage their inheritance and maintain eligibility for means-tested benefits.

Property and estate considerations:

- **Excluded Property:** Trust property, jointly-owned property, life interests, and successfully nominated property (e.g., pensions, insurance) are not included in the estate. Foreign immov able property is subject to the laws of its location.

Financial planning

In Ireland gifts and inheritances over certain thresholds qualify for Capital Acquisitions Tax, or CAT. This tax varies depending on the relationship between the person giving the gift or inheritance and the recipient. These amounts may vary from year to year **(check www.revenue.ie for most updated information).**

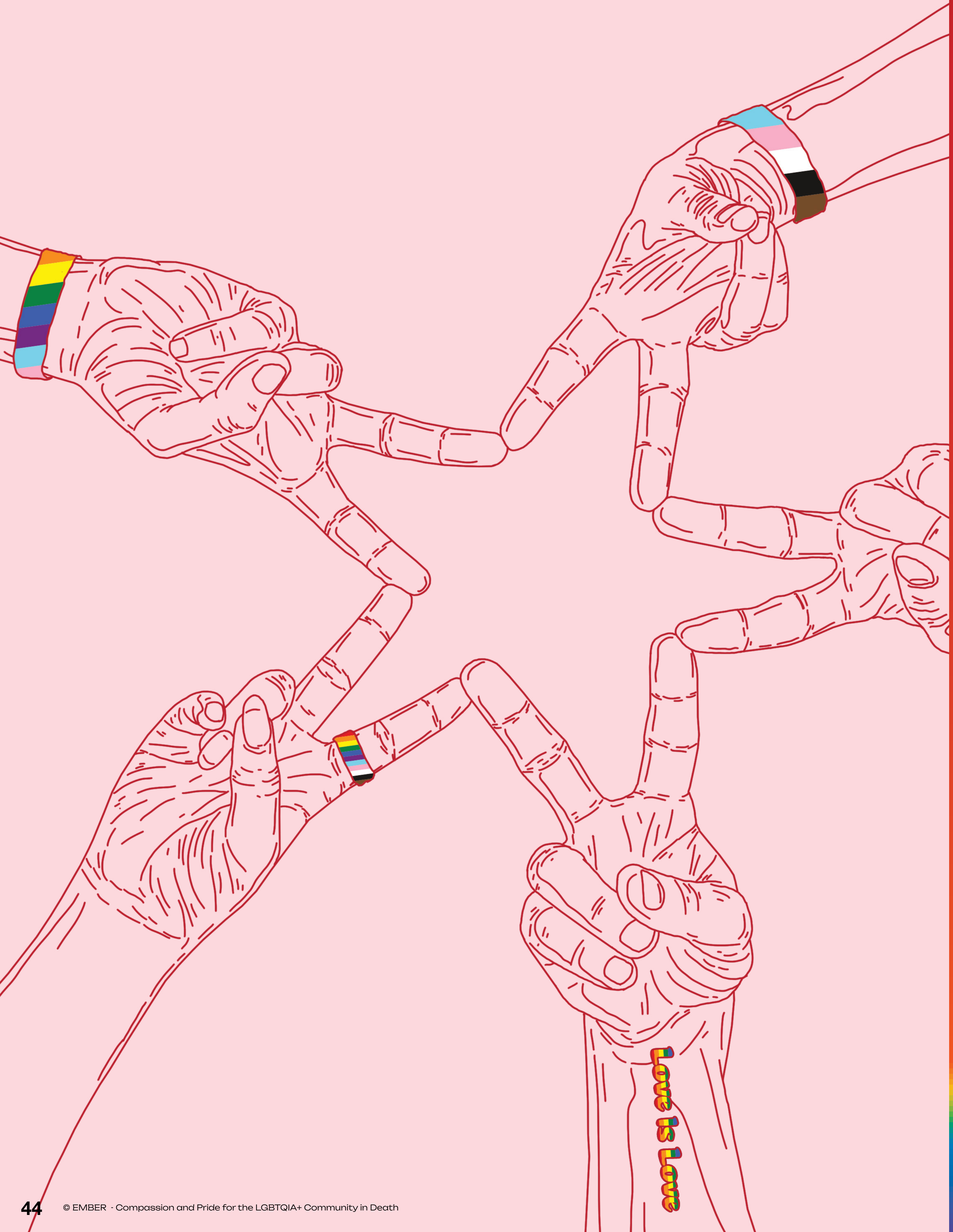
LGBTQIA+ individuals may still be in heterosexual marriages which can complicate legal recognition for new partners.

CAT Exemptions:

- **Dwelling House:** If you inherit a home and meet certain conditions, you won't have to pay Capital Acquisitions Tax (CAT) on it. Conditions include living in the house as your main home for three years before the inheritance and continuing to live there for six years after.
- **Small Gift:** You can receive up to €3,000 per year from any person without paying CAT. This applies to gifts, not inheritances.

Testamentary guardianship for lgbtqia+ families

For LGBTQIA+ families, testamentary guardianship can be a crucial legal tool to ensure that a non-biological or unrecognised parent maintains a connection and potential guardianship of the children they are raising. By appointing a testamentary guardian in a will, a biological parent can legally designate their partner as the guardian of their children in the event of their death. This can be particularly important in cases where the non-biological parent may not have legal recognition of parental rights under current laws. Testamentary guardianship helps secure the child's continued care and stability within the family structure they are accustomed to, providing peace of mind that their emotional and practical needs will be met by someone who has been actively involved in their upbringing.



Appendix A – Reference Group Bios

Daire Dempsey

Policy Lead at the Transgender Equality Network Ireland, working to make Ireland a safer and more equitable place for people of all genders. In this role they lead on research, policy and advocacy towards trans equality. They would like to continue in the cycle of life by being buried in a natural burial ground.

Karen Dempsey

Director of Entheos.ie, an inclusive organisation founded to serve people outside traditional faith paths; ensuring that everyone can have ceremonies to reflect their authentic selves, especially at End of Life. Karen's career includes both palliative care and obstetric nursing alongside psychotherapy and ceremonies, and she is a lifelong activist for equality, diversity and inclusion. She is passionate about challenging the heteronormativity of ceremonies and healthcare and is a firm believer in being the change we wish to see in the world.

Michael Foley

Civic Engagement for Societal Impact Manager in Trinity College Dublin. He promotes and encourages civic activity and partnership between the university, NGOs, public sector agencies and community groups. He is interested in ways to give voice to people with life-limiting conditions and those who are trying to support them. Knowing Irish people's love of funerals, he hopes that something unexpectedly dramatic happens at his funeral to give people a good story for their anthology of funeral lore.

Hayley Fox-Roberts

LGBTI+ activist, writer, consultant and community development worker with a focus on rural exclusion. She leads the Seeding the County Cork LGBT+ development project as part of her work with Cumann na Daoine CRC in Youghal. She has worked in LGBT+ community settings across the country for many years, providing training and development support at community and statutory level. Her research reports include LGBT+ needs assessments in Carlow and Cork and she is a Board member of NXF. Hayley lives in West Cork.

Ben Lucent

A multidisciplinary artist, theatre maker and Interfaith Minister in training. He lives in rural South Sligo in a house that increasingly resembles the set of a 90s children's TV show (including the puppets and slime). He would like to be buried in a woodland burial plot or in a tree pod.

Pradeep Mahadeshwar

A multifaceted visual artist and LGBTQIA+ activist based in Ireland. His work explores identity, migration, race, and sexuality through storytelling, illustration, filmmaking, and writing.

Pradeep is the founder of Queer Asian Pride Ireland and the Queer Spectrum Film Festival. He has created spaces for celebrating and amplifying queer narratives, especially those of Queer People of Colour (QPOC). His work focuses on themes of displacement, migration, and the impact of racism on mental and sexual health, making his voice particularly relevant to Ireland's multicultural LGBTQIA+ community.

Peter McGuire

Freelance journalist, writing primarily for The Irish Times and Noteworthy, the investigations unit at TheJournal.ie. He is a two-time GALA nominee.

Previously, he lectured in contemporary Irish folklore at UCD, where much of his work focused on death customs and beliefs. When he dies, he longs to return to the Earth and for his atoms to be recycled into many beautiful and ugly things.

James O'Hagan

Podcaster and activist passionate about giving voice to marginalised communities and exploring intersectional identities. His work with LGBT Ireland, the national support service for LGBTQ+ people in Ireland, focuses on ensuring older members of the LGBTQ+ community are supported and enabled to flourish and enjoy inclusive, healthy and fulfilling lives as part of their communities. When the time comes, he wants to be cremated to a soundtrack of Tom Jones' cover of Burning Down the House.

Julia Pakula

Executive Assistant at the All Ireland Institute of Hospice and Palliative Care living in Dublin, passionate about all thing's inclusivity, events and social media. When the time comes, she would like for her ashes to be turned into stones and for her family and chosen family to celebrate her life opposed to mourn her death.

Paula Pinto

Programme Manager for Policy and Engagement at the All Ireland Institute of Hospice and Palliative Care. Passionate about creating positive social impact and fostering honest connections and engagement with diverse communities. When she dies, she hopes to be cremated and be kept in an antique tea pot overlooking the sea.

Kathleen Quinlan

Lecturer/tutor in St Francis Hospice Dublin who work with individuals with a life limiting condition, their families, and significant others. She facilities palliative care education and training actively challenging herself and others to do better for all communities through knowledge, skill, and attitude change.

Ailbhe Smyth

Founding head of Women's and Gender Studies at University College Dublin where she lectured for many years and is a long-time LGBTIQ+, feminist and socialist activist.

Valerie Smith

Public Engagement Lead with Irish Hospice Foundation, managing the Think Ahead advance care planning programme. In her role, she trains professionals and communities on advance care planning and finds inventive ways to help people to talk about death, dying and grief. She would like to be buried in an eco-graveyard, when the time comes.

Ember

Compassion and Pride for
the LGBTQIA+ Community in Death

LGBTQIA+ End-of-Life Guide

LGBT IRELAND
For Inclusion
For Equality
For Everyone

AIIHPC
All Ireland Institute of
Hospice and Palliative Care

Irish
Hospice
Foundation

An Roinn Leanaí, Comhionannais,
Míchumais, Lánpháirtíochta agus Óige
Department of Children, Equality,
Disability, Integration and Youth