Marie Curie

Getting care and planning for the future when you're LGBTQ+

A guide for LGBTQ+ people living with a terminal illness and the people close to them

* Calls are free from landlines and mobiles. Your call may be recorded for training and monitoring purposes.

Introduction

If you're LGBTQ+ and you are living with a terminal illness, this booklet may be helpful for you. Your partner, family or friends may also find it useful.

Living with a terminal illness and getting the best care and support can be challenging for everyone. We all have individual needs and will have different experiences. Being LGBTQ+ may mean that you have specific concerns or questions about getting the care and support you need.

In this booklet, we explain the care and support that's available. We also answer questions you might have, such as how you can make decisions for the future.

There is more information on our website at **mariecurie.org.uk/information** For practical information or emotional support, contact the free Marie Curie Support Line on **0800 090 2309*** or at **support@mariecurie.org.uk**

Contents

The words we use in this booklet

We know that the words we use are important. Everyone will have different preferences and we respect people's right to choose their own words.

In this booklet, **LGBTQ+** is a term we use to include people who are lesbian, gay, bi, trans and/or queer or questioning. The '+' (plus) is inclusive of people who may describe their sexual orientation or gender identity in a different way.

When we talk about your **family and friends** in this booklet, we mean anyone who is important to you. This might be a partner or partners, husband, wife, spouse, civil partner, family of origin, chosen family, ex-partner, rainbow family, or your friends.

iStock

Palliative and end of life care

When you're living with a terminal illness, you might have lots of different worries and needs. Getting the right care and support can help with these things and make a difference to your day-to-day life.

You might have physical problems, like feeling tired, feeling breathless or being in pain. You might have lots of emotions or worries, which can be difficult to cope with. You might need support with things like money or housing.

Palliative care is treatment, care and support for people with a terminal illness and your family and friends. You can receive palliative care at any stage in your illness. The aim of palliative care is to help you to have a good quality of life – this includes being as well and active as possible.

End of life care is treatment, care and support for people who are nearing the end of their life. It's usually for people who are in the last 12 months of their life. It's an important part of palliative care.

What does palliative and end of life care involve?

Palliative care and end of life care are centred around you as a person – how you want to be cared for and what's important to you. Health and social care professionals will support your physical needs. But they are also there to help you with any emotional, social, financial and spiritual needs you have.

"The Marie Curie healthcare professionals saw David and I as individuals and were very compassionate."

Paul, whose husband David had a terminal illness

Who provides palliative and end of life care?

Different health and social care professionals might provide care and support. This can include doctors, nurses, physiotherapists, social workers, occupational therapists, counsellors, and chaplains. If you're living at home or in a care home, your GP is responsible for your care. But there may be other people who help co-ordinate your care, such as a district nurse, community nurse or social worker. The GP will sometimes involve a specialist palliative care or hospice at home team if you need more support.

How can I get palliative and end of life care?

Speak to your GP or another healthcare professional about palliative or end of life care. You can also contact your local hospice to find out what support they can offer. Marie Curie provides hospice care around the UK, in hospices and in your own home. You can find your local hospice on the Hospice UK website (**hospiceuk.org/hospice-care-finder**) or call the free Marie Curie Support Line on **0800 090 2309*** or email **support@mariecurie.org.uk**

What other support will I need?

When you're ill, you may also need help from the people important to you. There may be other people who can support you, including support groups, faith groups and online communities. Some organisations have specific LGBTQ+ or LGBTQ+-inclusive groups you could join. The organisations on page 42 may be able to help you find a support group online or near you. You could also ask your GP or local hospice if they know any local groups.

iStock

Return to contents page

Emotional needs and support

Emotional support is an important part of palliative and end of life care. After you've been diagnosed with a terminal illness, you may experience lots of different emotions including fear, denial, anger, regret, sadness and loneliness. This can be especially difficult if you also have self-esteem problems, anxiety, depression, or have experienced trauma in your life.

What can help

If you're finding it difficult to cope with your thoughts or feelings, there is support available. It may help to talk to your family, friends, a professional or a support group about how you're feeling. There are different things that may help, including talking to a counsellor, speaking to people in similar situations, or trying art or music therapy.

To get support, speak to a health or social care professional, contact your local hospice, or contact a support organisation (see page 42). You can also call the Marie Curie Support Line for free information and support on **0800 090 2309***.

Telling people you're ill

You might find it difficult to tell people that you have a terminal or life-limiting illness. This can be hard if you're not used to sharing information or asking for support, or if you've had bad experiences in the past. It can help to reach out to family and friends you trust at this time. Often people want to help if you ask. It can sometimes help to ask for specific things they can help with, like going to appointments, helping with shopping, or asking how you're doing regularly.

If you do not have family or friends that can help, speak to your health or social care professionals about what support is available.

Connecting with people from your past

You might want to get in touch with people you have not seen for a while. Some people may not know about your sexual orientation or gender identity, and you might want to share this with them. You may also want to try to reconnect with people from your past or resolve past problems.

Some people do not want to do this and want to focus on the things and people who are important to them now.

You should do what feels right for you. Everyone's responses can be different. It can help to have support from other family, friends or professionals to think through what is best for you.

Spiritual support

You may start to think about your life in a different way, and some people find themselves searching for meaning, hope and belonging. These things are sometimes called spiritual needs and affect people whether they're religious or not. You can get support from a faith leader, hospital or hospice chaplain, or spiritual advisor. Hospices can often provide this support.

Good Funeral Guide

Social care or personal care

You may need help with everyday activities like getting up in the morning, cleaning your home and making meals. This is sometimes called **social care** or **personal care**. Your health and social care professionals may arrange help with these things. Social care and personal care are sometimes arranged through your local council, authority or trust.

You might need help with things like getting dressed, washing and going to the toilet. Many people find it uncomfortable to have someone else help them with these things. It can sometimes help to say if you're nervous or worried. Health and social care professionals should always treat you with respect.

iStock

Return to contents page

Worries about personal care

Everyone has different concerns and needs. You may worry about other people seeing or touching your body.

You might worry that your gender identity will not be respected. For example, people not following your wishes if they are helping with your clothes, shaving, make up, hair style or wig. You may also have specific needs for your personal care that the professional does not know about – for example, vaginal dilatation after surgery.

You can tell your health or social care professional what support you need and they should look at how they can best help you. If they do not know how to support you, they should speak to their manager or get advice from a specialist if needed.

Having someone with you

You can ask for a family member or friend to be with you if this makes you feel more comfortable. You can also ask for a chaperone – this is usually another professional who will be in the room.

Worries about discrimination

You may have experienced discrimination or abuse in your life, including when accessing healthcare. These things can understandably make it difficult to go into new settings or meet new professionals.

You may worry that professionals will assume things about you. For example, they might assume a same-sex partner is a different family member or friend, or they might misgender you.

You may worry about how other people where you're getting care will treat you. For example, other people in a GP surgery, hospital, hospice or care home.

These are all valid fears and concerns. You might feel like you have to be compliant or extra polite with professionals. Or you might feel stressed by anticipating negative experiences.

You might have other protected characteristics – for example, you may be disabled, have a religion or beliefs, or be from a minoritised ethnic group. You may have experienced more discrimination in your life and have other concerns as well.

What can help?

It can help to talk to someone about how you're feeling.

If you're going into a new setting or meeting a professional for the first time, you might find it helpful to have someone with you.

Some staff and volunteers may wear rainbow lanyards or pin badges to show they are an ally. This might make you feel more comfortable to discuss things with them. But all professionals should provide good care and support.

What are my rights?

You should be treated with dignity and respect at all times. Your care should be centred around what you want and need. Your family and friends should also have support.

You can choose who should be involved in decisions about your care. This might be your partner, friends or family. See page 32 for more information.

You should never be treated badly or unfairly because of your sexual orientation or gender identity. This is called discrimination and it is against the law in the UK. Palliative care and end of life care services must stop people being treated unfairly and protect people's safety.

Negative experiences

Negative experiences can include things such as professionals or other patients or visitors:

- making comments or jokes
- misgendering you, either by mistake or deliberately
- making assumptions about your relationships
- reacting negatively to your partner
- not involving people who are important to you in updates or decisions.

You should not have to experience these things when accessing health or social care services.

What to do if you have a negative experience

If you have a negative experience, it's your choice what you do. If you feel safe to do so, you can give feedback to the person themselves, or you can tell their manager or the organisation. This can help to improve care and make it more inclusive for others.

Organisations should have a complaints procedure, and you can ask to see it. They may also have policies on providing a safe environment.

In a hospital, you can contact the Patient Advice and Liaison Service (PALS) for support with a complaint.

You can get support about discrimination and your rights from the Equality Advisory & Support Service (visit **equalityadvisoryservice.com** or call **0808 800 0082**).

It may also help to talk about your experiences with your family or friends or organisations who provide support (see page 42).

Changing your doctor

If you're not comfortable with the care you get from your doctor, you can ask for a different doctor. For your GP, you can change GP within the GP surgery or register with a different GP in your area. In a hospital or hospice, you can contact the doctor's secretary and ask if you can see a different doctor.

You can tell professionals about our website page on providing care for LGBTQ+ people. Visit **mariecurie.org.uk/lgbtq-care**

iStock

Marie Curie's work with LGBTQ+ people

Marie Curie is committed to better care and support for LGBTQ+ people. This includes funding research, training health and social care professionals, working with community groups, and supporting people through our national Information and Support service.

We want to know what's gone well and what we can do better. If you have any feedback about care from Marie Curie, speak to your healthcare professional or go to **mariecurie.org.uk/comments**

"We respect people as individuals, and we respect their choices and identities. People should feel that their identity and relationships are actively seen, valued and celebrated."

Andrew, Marie Curie Principal Social Worker

Where you can live or stay

It can be helpful to think about where you'd prefer to live, now and in the future. These may be different places and you might change your mind about where you want to live over time.

You might stay in:

- your home, where your GP will co-ordinate your care and you might have help from nurses, carers and other specialists
- a care home, where you can get extra care and support from professional carers or nurses
- a hospice, where you can get expert care and support
- a hospital, if you need tests or treatment or if you need urgent treatment.

It can be helpful to think about where you'd like to stay if you cannot be in the place you'd prefer. This might happen if you need extra care and support, for example.

You may worry about feeling safe and how you'll be treated. It can help to speak with your GP or another health or social care professional about the different options and any concerns you have. You can ask them about anything specific you're worried about. You may find it helpful to visit your local hospice or care homes to find out more about them.

Single-sex wards or facilities

You might be worried about what will happen if you're in a setting where there are single-sex wards, bays or toilets. That this can be stressful and upsetting.

It can help to think about your preferences and understand your rights, the setting's policy and how they would make decisions. You should always be treated with dignity and respect.

It may help if you or someone you trust, could approach the setting to ask them about these things in advance. Some services, hospitals or trusts will have statements on their websites with information about what to expect.

Facilities at Marie Curie

If you need care from Marie Curie, you can contact any Marie Curie hospice or building to ask about our facilities. All of our hospices have some private rooms with their own bathrooms. We will always try to meet people's needs and offer appropriate facilities. We want everyone to feel included, respected and supported when accessing our care.

You can find out more about our facilities at **mariecurie.org.uk/hospices**

Should I tell health and social care professionals that I'm LGBTQ+?

It's your choice what you tell people – there's no right or wrong decision. It depends on what you're comfortable with and what you feel is important.

Talking to professionals about your sexual orientation or gender identity can help to make sure care is centred around who you are and what's important to you.

If you tell professionals that you're LGBTQ+, they should continue to treat you with dignity and respect at all times.

Will professionals ask me about sexual orientation or gender identity?

Health and social care professionals might ask about your sexual orientation or gender identity. Sometimes this is part of a standard set of questions they ask everyone to find out more about who they are supporting. And sometimes it might be directly relevant to your care. It can help them to understand more about who you are and what your needs might be. They should only ask you about things that are relevant to your care.

You can ask them why they are asking a question and they should be able to explain. If you do not feel comfortable, you could explain that you'd prefer not to answer.

It's your choice what you share with people.

Telling professionals about the people important to you

Telling professionals about the people who are important to you, including a partner if you have one, means that they can involve these people in decisions about your care. It also means that they can support them too.

"We were open and proud. When meeting new nurses or doctors, I would just say, 'I'm David's husband'. We found it easier just to tackle things head-on."

Paul, whose husband David had a terminal illness

Telling professionals about your gender identity

Telling professionals about your gender identity can help make sure you get care centred around your needs.

They may ask you specific questions about any hormone therapy you are taking or gender affirming surgery you have had. This may be important for your care. For example, they might ask about hormone therapy to check any medicines are safe to use and so they can understand test results accurately. Or they might ask about gender affirming surgery in case they need to drain pee (urine) from your bladder or support you with personal care. They can also support you to access services if you're considering future transition-related care.

You can ask them why they are asking a question and they should be able to explain.

Confidentiality

If you tell professionals that you're LGBTQ+, they should treat this information confidentially. They may need to share information with other healthcare professionals if it's relevant to your care. You can ask them if you have any concerns or questions about this. They should not talk about your sexual orientation or gender identity when it is not relevant to your care.

If some of your family or friends do not know about your sexual orientation or gender identity, it may help to tell your healthcare professionals. This can help to make sure that the professionals do not mention something that you would not want your family or friends to know.

iStock

Paying for care

Getting care in a hospital or hospice is free.

Most health care is free wherever you are staying. This includes doctors or nurses coming to visit you at home or in a care home. You may need to pay for things like prescriptions or dental care.

If you need social care or personal care at home or in a care home, you may have to contribute towards the cost. This includes things like help with washing, dressing and eating. Whether you need to pay will depend on where you live and how much income or savings you have.

Find out more at **mariecurie.org.uk/information**, or call or email the free Marie Curie Support Line on **0800 090 2309*** or at **support@mariecurie.org.uk**

iStock

Return to contents page

Benefits and finances

If you're living with a terminal illness, you and anyone who looks after you might be able to claim benefits. There are benefits that can help with the costs of having a health condition, or the costs of caring for someone who does. Some are not means-tested, which means they are not affected by any other income or savings you have. If you have a terminal illness, you may be able to get benefits more quickly and they might be paid at the highest rate.

Some charities and organisations offer grants to people who are ill and their partner, family and friends. And you may also be able to get help with other costs, such as energy bills, travel costs and prescriptions.

Find out more about benefits and finances at **mariecurie.org.uk/benefits** or contact our free Support Line on **0800 090 2309*** or at **support@mariecurie.org.uk**

Support for your partner, family or friends

Your family and friends might help with practical things like taking you to appointments, food shopping, dressing and taking medication. They may also provide emotional support and companionship. They might find these things challenging – physically, emotionally and financially.

Getting practical support

If a partner, family member or friend is looking after you, they can get a **carer's assessment** (in Scotland, an **Adult Carer Support Plan**). This will look at what help they need to support you. It might include respite care (breaks from caring), professionals to help with your care and information about local services.

To get a carer's assessment or plan, they can contact their local council, authority or trust. They may also be able to claim a benefit called Carer's Allowance or, in Scotland, Carer Support Payment.

Palliative care and end of life care also include supporting your family and friends. Their GP or one of your health or social care professionals should be able to tell them about local services and how they can get support.

Support from Marie Curie

The Marie Curie Support Line provides free information and support for anyone affected by terminal illness. We support partners, family and friends of anyone living with a terminal illness and people who have been bereaved. Contact us on **0800 090 2309***, email **support@mariecurie.org.uk** or visit **mariecurie.org.uk/information** for more information.

You, or your family or friends, can also get support from a Marie Curie Companion volunteer. They can provide practical and emotional support at home, in hospital or over the phone. For more information, call our free Support Line on **0800 090 2309*** or visit **mariecurie.org.uk/companions**

Phil Hardman/Marie Curie

If you do not have family or friends who can help

If you do not have family and friends you can ask for help, contact your GP, local hospice, or social services to see what support is available in your area. You can also contact the organisations on page 42 to see how they can help.

Bereavement support

Your partner, family and friends may need support, before and after you've died. They can speak to their GP, or a hospice or hospital where you receive care.

Marie Curie has a Support Line and a Bereavement Support Service (see page 40) that offers free support by phone. Call **0800 090 2309*** or visit **mariecurie.org.uk/bereavement** to find out more.

"As a gay couple, Terri and I didn't see ourselves represented in healthcare in lots of ways and that does have an effect. Before I rang the Support Line, I was nervous about calling. It's reassuring to know that Marie Curie supports everyone. People already see barriers in reaching out for help with their grief. Sexuality doesn't need to become an additional barrier to that."

Michele, whose wife Terri had a terminal illness

Planning ahead for your care

You might want to think about how you want to be cared for in the future. This is sometimes called **advance care planning**, **future care planning** or **anticipatory care planning**. This is important to think about in case you become unable to make or communicate decisions about your care in the future.

What to include in an advance care plan

You can include any information that's important to you, including:

- your name and pronouns
- how you would like to be looked after, including personal care (see page 30)
- any preferences or needs for food or drink
- where you would prefer to be looked after or die
- any spiritual or religious beliefs you'd like taken into account
- who you want to spend time with
- any special days you celebrate, for example with religious or cultural meaning
- who your doctors or nurses should talk to if you're unable to make or tell people about your decisions
- how you would like practical matters dealt with, such as the care of a pet
- what you would like to happen to your body after you die
- if you've considered organ donation – read about donating organs and tissue at **organdonation.nhs.uk**

Having conversations with your healthcare team and those closest to you, will help them understand what's important to you. Talking to the people supporting you can also help you understand what your future care might look like.

How to make an advance care plan

There is no set template for making an advance care plan. You can record your wishes in a way that suits you. Some people choose to write their wishes in a document called an advance care plan, or advance statement. If you live in Scotland or Wales, this might be called an anticipatory care plan or future care plan. Writing down your wishes can make it easier for people to understand and follow them in the future. You can find templates to use at **mariecurie.org.uk/planning-ahead**

If you need help with this, speak to your healthcare professional or contact our Support Line for free information on **0800 090 2309*** or email **support@mariecurie.org.uk**

Keep your advance care plan somewhere safe. Share it with the people important to you and your healthcare professionals. Make sure it's recorded in your healthcare records.

Starting or continuing gender affirming treatment

You might have questions about whether you can start or continue gender affirming treatment when you have a terminal illness, including hormone therapy or surgery.

You may worry about whether you can continue this alongside treatment for your illness, if you become more ill, or if you need more support.

This depends on your preferences, your illness, your symptoms, your treatments, and your gender affirming treatment. It's individual to each person. You should be given information and support to help make the best decisions for you.

Speak to your GP or a healthcare professional you trust about continuing or starting treatment. They can help make plans for your future care. They may also be able to look into different options to meet your needs – for example, switching from tablets to a gel or patch if you have problems swallowing.

If your doctor or nurse does not have experience with this, they should speak to a gender identity specialist. They can record your wishes in your advance care plan with your permission, which will be looked at by professionals providing your care.

If you have cancer, you can contact the UK Cancer and Transition Service for support, advice and recommendations (**wearetransplus.co.uk/uk-cancer-and-transition-service**). Or you can ask your GP to refer you.

Your wishes for personal care

It can be important to make sure that your identity is respected when it comes to your personal care. This may include:

- choosing clothes
- doing make up
- hair or wig styling
- managing body hair.

In case you need help with these things in the future or cannot tell people what you want, you can record how these things should be done. You can also record who you are comfortable helping with them.

iStock

Return to contents page

You can record your preferences and any specific care you need as part of your advance care plan (see page 27). You can also include it in a 'This is me' or 'Care passport' document, which is used to tell healthcare professionals about you. They are sometimes used for people who have dementia, have a learning disability or are neurodivergent.

Deciding to refuse treatment or CPR

An **advance decision to refuse treatment (ADRT)** is a written decision to refuse a specific type of medical treatment, used in England and Wales. It's sometimes called an advance decision or living will. It will only be used if you lose the ability to make your own decisions about your treatment.

Some people decide they do not want to have cardiopulmonary resuscitation (CPR). CPR is not beneficial for everyone, and can sometimes cause serious complications. If you do not want to have CPR, you can tell your doctors or nurses. This is called a **do not attempt cardiopulmonary resuscitation (DNACPR) decision** or **DNACPR order**. If you have not made a DNACPR decision or order, your doctor or nurse will decide whether CPR is in your best interest.

Find out more about making decisions about treatments or CPR at **mariecurie.org.uk/planning-ahead**

Next of kin and choosing someone to make decisions

Tell your healthcare professionals who you want them to involve in decisions about your care or have as their main contact. This is sometimes called your next of kin. The person does not need to be a spouse or relative – it can be anyone you choose, including a partner or friend. It might help to write this down in your advance care plan and make sure your GP, district nurse, hospital or hospice are aware of this.

In England, Wales and Scotland, you can legally choose someone to make decisions about your health and social care for you. This will only be used if you lose the ability to make decisions yourself in the future. The legal document is called a **health and welfare lasting Power of Attorney** in England and Wales, and a **welfare Power of Attorney** in Scotland. It is not currently available in Northern Ireland.

The person you choose is called your attorney. This could be your partner, family member or friend. You can also ask a professional to be your attorney.

Find out more at
mariecurie.org.uk/power-of-attorney

Return to contents page

Making it clear who to involve in decisions

It can help to make it clear to professionals who is important to you and who you want to be involved in decisions about your care. This might be especially important if your healthcare professionals are not aware of the significance of your relationships. You might also want to let health and social care professionals know who you do not want to be involved in decisions about your care.

You can include this information in your advance care plan and a 'This is me' or 'Care passport' document (see page 27).

If you do not choose someone to make decisions

If you become unable to make decisions yourself and do not have a relevant Power of Attorney (see page 32) in place, the following will apply:

- Health and social care professionals should consider any wishes you've communicated in the past – for example, in your advance care plan (see page 27).
- They should involve anyone who you've said that you want to include in decisions about your care. They may also ask the people close to you what they think you would have wanted.
- Your partner, family member or friends can apply to legally make decisions on your behalf. This is sometimes called a deputy, controller or guardian. It can take time to put in place.

To find out more, speak to a solicitor or visit your government's website (see page 42). You can also visit **mariecurie.org.uk/advance-care-plan** or contact our free Support Line at **0800 090 2309*** or **support@mariecurie.org.uk**

Your partner, family or friends disagreeing

You may worry that your family or friends will not follow your wishes or will disagree with each other about your care.

It can help to make it clear who you want to be involved in decisions about your care in your advance care plan (see page 27). You can also legally appoint someone as your attorney (see page 32).

If there are disagreements, your health and social care professionals will speak to the people involved and try to resolve these. The professionals will do what's in your best interests, including following any wishes you've recorded where possible.

Planning your Will, funeral and other practical things

You might want to make decisions about your funeral, burial or cremation, and what will happen to your possessions after you've died. This can help to make sure that your wishes are understood and followed, and help your loved ones feel less worried about the future. You might not be ready to think about some of these things yet – and that's OK too.

If you have children, dependents or pets, you can also make plans for who will look after them if you are ill and when you die. You can record your wishes in your Will. If you're not sure what the options are for children or dependents, it can help to speak with a social worker.

It can help to talk about these things with your loved ones, and any relevant professionals. These can be difficult things to talk about – you can ask your doctor or nurse for help or contact our free Support Line on **0800 090 2309*** or at **support@mariecurie.org.uk**

Making a Will

A Will is your final way of telling the world who you are, what is important to you and what you want to happen after you have gone. It lets you decide what happens to your money, property and possessions – sometimes called your 'estate'. You can also use a Will to decide who should look after any children or pets you have.

If you do not have a Will, and are not in a civil-partnership or legally married, your estate will be divided using the rules of intestacy. The rules of intestacy refer to your biological family, not necessarily your chosen family.

Getting professional advice can help to make sure your Will is legally valid and reflects what you want. You can write your own Will, but you must use certain wording to make it legal and valid. If you are worried about costs, many charities have free Will-writing services.

Marie Curie has a free Will-writing service for anyone who is 18 years old or over. Find out more about making a Will at **mariecurie.org.uk/wills** or contact our free Support Line on **0800 090 2309*** or at **support@mariecurie.org.uk**

"Once Roger knew he had cancer he wrote a new Will, but it never got signed. I just presumed it had been done. The new Will was a split between his children and me – luckily, they are extremely good to me and we got it sorted. But it's those sorts of loose ends that needed tying up."

Peter, who cared for his partner, Roger, at the end of his life

Planning your funeral

You could put plans in place for your funeral by speaking to a funeral director, celebrant or faith leader. You could also write down your wishes and share them with your partner, family or friends.

You might want to think about who you want to make decisions about your funeral. Or you might want to decide on specific things, like whether you want particular songs, hymns, readings, poems or prayers.

You can choose a faith leader or celebrant to lead your service or memorial. You can choose someone who you trust to respect who you are. Some celebrants, funeral directors and faith leaders specialise in being LGBTQ+ affirming and inclusive. This includes using your correct name and pronouns, or including your partner or spouse appropriately. Find out more at **queerfuneralguide.co.uk**

Paying for a funeral

A funeral can cost a lot of money. You might want to pay in advance with a pre-paid funeral plan, organise insurance, or leave money in your bank account. You can check with your bank about how funds can be released for this. There may also be financial support available through the government.

For more information on planning and paying for a funeral, contact the free Marie Curie Support Line on **0800 090 2309*** or visit **mariecurie.org.uk/funeral-planning**

The name and sex on your death certificate

Some people worry that the name or sex assigned to them at birth will be used on their death certificate. It's important to speak to your partner, family or friends about your wishes and make it clear what you want. You can write down your wishes and share it with people you trust.

The person registering your death (usually your next of kin) will be asked to provide accurate information about you to register your death. The only official document they need to provide is the Medical Certificate of Cause of Death. This records your name, but not your sex or gender.

Sex on your death certificate

If you have a Gender Recognition Certificate, you must be treated as your affirmed gender for legal purposes, including on your death certificate.

If you do not have a Gender Recognition Certificate, the Registrar should still be able to register your death with your affirmed gender. But their approach can vary. You or someone you trust could contact them in advance to find out more.

Deaths are registered as male or female, so it's not currently possible to recognise non-binary identities on death certificates.

Name on your death certificate

Your name should be recorded as the full name you were known by at your death. This can be different from the name given to you at birth and you do not need a deed poll or Gender Recognition Certificate to prove this. If you think there may be disagreement, it may help to have a deed poll or other evidence of your change of name like a driving licence or bus pass.

The Registrar may record previous names on your death certificate. This can be helpful if you have bank accounts or property in a previous name. But the person registering your death can request that they do not include previous names on the register.

Name on your burial stone

The wording on burial stones or memorial plaques are usually chosen by the person organising them. Individual cemeteries may have policies about what can or cannot be included. It's important to speak to your partner, family or friends about your wishes and make it clear what you want.

How Marie Curie can help

Marie Curie is here for anyone with an illness they're likely to die from, and those close to them. Whatever the illness, wherever you are, we're with you to the end.

Marie Curie Support Line

0800 090 2309*

Our free Support Line is for anyone with an illness they're likely to die from and those close to them. Our team, including nurses and specialist Energy Support Officers, offers practical and emotional support on everything from symptom management and day-to-day care to financial information and bereavement support. Our Support Line is available in over 200 languages, or via webchat at **mariecurie.org.uk/support-line**

Marie Curie Companions

Companion volunteers focus on what's important to you and those close to you. It might be accompanying you to appointments, being there to listen to how you're feeling without judgment, or stepping in so family or carers can take a break. Companions provide the emotional and practical support you want – at home, in hospital or over the phone.
mariecurie.org.uk/companions

Marie Curie Telephone Bereavement Service

Get ongoing bereavement support over the phone from the same volunteer. You can access up to six sessions of 45 minutes. We can help if your bereavement was expected, happened recently or was some time ago.
mariecurie.org.uk/bereavement

* Your call may be recorded for training and monitoring purposes.

Marie Curie Online Community

Our Online Community is a space for you to share thoughts, feelings and experiences. It's moderated by the Marie Curie Support Line team, who can also help answer your questions.
community.mariecurie.org.uk

Marie Curie Hospice care where it's needed

Our hospices

Our hospices help people with any illness they're likely to die from, and the people close to them, receive the support they need. From medical and physical support to psychological and emotional care, whatever your illness, at whatever stage of the journey, we help you to live the best life possible, right to the end.
mariecurie.org.uk/hospices

Hospice care at home

Our nurses, healthcare assistants and other healthcare professionals bring the clinical, practical and emotional help you need to you, in the comfort of your own home. And we offer support to the people close to you too – from reassurance and practical information to letting them take a break.
mariecurie.org.uk/nurses

Looking for more information?

If you found this booklet useful, we have free information online at **mariecurie.org.uk/information** or to order at **mariecurie.org.uk/publications**.

Useful organisations

Equality Advisory & Support Service

equalityadvisoryservice.com
0808 800 0082
Organisation that provides advice on discrimination because of disability, sexual orientation and gender identity. Supports people across England, Wales and Scotland.

Gender Identity Clinic

Your nearest gender identity clinic can provide advice for you and your healthcare professionals.. Ask your GP or search online for your nearest clinic.

Government websites

GOV.UK (England and Wales)
mygov.scot (Scotland)
nidirect.gov.uk (Northern Ireland)
Information on benefits, Power of Attorney and getting a Gender Recognition Certificate.

Hospice UK

hospiceuk.org
020 7520 8200
Charity representing more than 200 hospices. Information on palliative and end of life care, bereavement support, and how to find hospice services in your area.

LGBT Health and Wellbeing (Scotland)

lgbthealth.org.uk
0300 123 2523
Charity working to improve the health, wellbeing and equality of LGBT people in Scotland.

LGBT Foundation

lgbt.foundation

0345 3 30 30 30

Charity delivering advice, support and information services to LGBT communities.

Queer Funeral Guide

queerfuneralguide.co.uk

This guide provides tips and information on registering a death and organising a funeral.

OUTpatients

outpatients.org.uk

LGBTIQ+ cancer charity, providing online and in-person support groups for LGBTIQ+ people affected by cancer.

Stonewall

stonewall.org.uk

0800 050 2020

LGBT equality charity, providing help and advice to individuals and organisations, and a map to search for community groups and local support.

Switchboard

switchboard.lgbt

0300 330 0630

LGBT+ helpline run by LGBT+ volunteers, providing confidential advice and understanding.

UK Cancer and Transition Service

wearetransplus.co.uk/uk-cancer-and-transition-service

NHS service offering review and recommendations of care for trans and non-binary people with cancer.

About this information

This booklet was produced by Marie Curie's Information and Support team. It has been developed with people affected by terminal illness, and health and social care professionals. Thank you to the following experts, organisations and community groups who have been involved in producing this booklet:

- Birmingham LGBT
- Gender Identity Research and Education Society (GIRES)
- Hospice UK
- LGBT Foundation
- Marie Curie health and social care professionals
- Marie Curie volunteers
- Marie Curie's LGBTQ+ Network
- No Barriers Here
- OUTpatients
- Queer Funeral Guide
- UK Cancer and Transition Service.

If you'd like the list of sources used to create this information, please email **review@mariecurie.org.uk** or call the free Marie Curie Support Line on **0800 090 2309***.

Notice

The information in this publication is provided for the benefit and personal use of people with a terminal illness, their families and carers.

This information is provided as general guidance for information purposes only. It should not be considered as medical or clinical advice, or used as a substitute for personalised or specific advice from a qualified medical practitioner. In respect of legal, financial or other matters covered by this information, you should also consider seeking specific professional advice about your personal circumstances.

While we try to ensure that this information is accurate, we do not accept any liability arising from its use. Please refer to our website for our full terms and conditions.

Did you find this information useful?

If you have feedback about this booklet, please email us at **review@mariecurie.org.uk** or call the free Marie Curie Support Line on **0800 090 2309***.

Your notes

Your notes

Your notes

Marie Curie

Marie Curie is the UK's leading end of life charity. Whatever the illness, wherever you are, we're with you to the end.

0800 090 2309*

Marie Curie provides free support over the phone in over 200 languages, and via webchat, to anyone with an illness they're likely to die from and those close to them. Our team, including nurses and specialist Energy Support Officers, offers practical and emotional support on everything from symptom management and day-to-day care to financial information and bereavement support. Visit **mariecurie.org.uk/support**

We also have an Online Community where you can share thoughts, feelings and experiences at **community.mariecurie.org.uk**

We can't do it without you

Our free information and support services are entirely funded by your generous donations. Thanks to you, we can continue to offer people what they need, when they need it. To support us, visit **mariecurie.org.uk/get-involved** or use the QR code.

* Calls are free from landlines and mobiles. Your call may be recorded for training and monitoring purposes.

Trusted Information Creator
Patient Information Forum