

Getting care and planning for the future



Information for LGBTQ+ people and their family and friends



**Marie
Curie**

Care and support
through terminal illness

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 plan ahead and make decisions for the future.



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

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, including asexual, non-binary, gender non-conforming, or intersex.

When we talk about your **partner, family and friends** or **your loved ones** in this booklet, we mean anyone who is important to you. This might be a partner, husband, wife, civil partner, birth family, family of choice, rainbow family and/or your friends.

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

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Getting care and support

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.

It can sometimes feel difficult to know how to get the care you need, especially if lots of different people are involved. There is support available for you and your loved ones. If you're not sure how to get support, speak to your GP or a healthcare professional you trust.

Palliative and end of life care

Palliative care is treatment, care and support for people with a terminal illness and their loved ones. 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.

“Knowing that you can have specialist support without prejudice at your most vulnerable time is so important. Everyone deserves a good life and a good death with the people they love around them.”

Suzanne McArthur, Marie Curie Allied Healthcare Professional and LGBTQ+ ally

“I would say that I felt more self-conscious, being a gay couple on a ward that was open with other people from the public. I don't necessarily think that was because anyone said anything to us while we were on a ward. It was more to do with just life, just how things are.”

Gary, partner of someone living with a serious illness

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 and spiritual needs you have.

Different health and social care professionals might provide care and support. This may 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 coordinate your care, such as a district nurse, community nurse or social worker.

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 has nine hospices around the UK. You can find your local hospice on the Hospice UK website (see page 26) or call the Marie Curie Support Line on **0800 090 2309***.

You may also need help from your partner, if you have one, and your family or friends. 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. Stonewall (see page 27) may be able to help you find a support group near you.

Should I tell professionals that I'm LGBTQ+?

It's your choice whether you tell people that you're LGBTQ+ – there's no right or wrong decision. What you choose to tell people depends on what you are 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. Telling professionals about the people who are important to you means that they can involve them in decisions about your care and can support them too.

You might worry about telling health and social care professionals about your sexual orientation or gender identity. You might be hesitant if you've had negative experiences in the past. It might be especially difficult to know whether to say anything if you see different or new health and social care professionals. It can also be challenging if they've already made assumptions about your sexual orientation or haven't used your correct pronouns or name.

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

“We want everyone to feel comfortable and supported as who they are when they need our care. It's vital that people are given the opportunity to be themselves from the first conversation. Healthcare professionals can make it easier for you to tell them – they can ask ‘Who is important to you?’ and ‘What would you like to be called?’”

Lauren, Marie Curie Nurse who identifies as LGBTQ+

What are my rights?

You should be treated with dignity and respect, and your care should be centred around your needs and preferences. Your loved ones should also be supported.

You might worry that health and social care professionals will treat you differently because of your sexual orientation or gender identity. You may worry that they won't understand your needs or choices and you may have had negative experiences before.

It's also common to worry about how other people where you're staying or receiving care will treat you – for example other people in a hospital, hospice or care home.

Health and social care professionals should always treat you with dignity and respect. It's against the law for people to treat you less favourably than others because of your sexual orientation or gender identity. If you've been treated unfairly, you can report it directly to the person themselves, their manager or the organisation. Organisations should have a complaints procedure, and you might find it useful to see it. You can get support about discrimination and your rights from the Equality Advisory & Support Service (see page 26). We know that people don't always feel comfortable or able to report things – it's your choice what you do.

If you're not comfortable with the care you get from your GP, you can ask to change GP within the GP surgery or register with a different GP in your area.

It may also help to talk about your experiences with your loved ones or organisations who provide support (see page 26).

Emotional 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 denial, anger, regret and loneliness. This can be especially difficult if you also have self-esteem problems, anxiety or depression.

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. They can be a positive thing – you might want to share things from your life with others or get in touch people you haven't seen for a while.

If you're finding it difficult to cope with your thoughts or feelings, there is support available. It may help to talk to your loved ones or a professional about how you're feeling. There are different things that may help, from talking to a counsellor to trying art or music therapy. To get support, speak to a health or social care professional or contact a support organisation (see page 26).

“I was scared of the hospice to start with, but they made me feel very, very comfortable there. So, once I came to terms more with dying I then felt I could open up more about all sorts of things. Because life was so short, I could open up about my gender. And I actually offered information to the music therapist. I felt I could let go. I just felt this sense of being comfortable around him. And he asked nice questions.”

Louise, living with a life-limiting illness

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 help with some of these things. Social care or personal care is 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.

Some trans people say that they feel concerned about having this type of care. You may worry about other people seeing your body hair, your genitals or the clothes you wear. You may also have specific needs for your personal care. You can tell your health or social care professional what support you need and they should look at how they can best help you.



Image source

Where you can live

It can be helpful to think about where you'd like 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 coordinate your care and you might have help from nurses 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 have had an accident.

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

Speak to your GP or other health or social care professional about your options and what might be suitable for you.

Paying for care

Health care is free – this includes staying in a hospital or hospice. But if you need social care or personal care at home or in a care home, you may have to contribute towards the cost. This will depend on where you live and how much income or savings you have.

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

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 aren't means-tested, which means they aren't 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 Support Line on **0800 090 2309***.



Phil Hardman/Marie Curie

Support for your partner, family or friends

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

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.

Palliative care and end of life care also include supporting your loved ones. 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.

There may also be support for your loved ones after you've died – they can speak to their GP, or a hospice or hospital where you received care.

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*** or visit mariecurie.org.uk/support for more information.

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** or **anticipatory care planning**. This involves thinking about what care you want, where you want to live, and who should be involved in decisions about these things.

You can talk about this with your GP, other healthcare professionals and your loved ones. You can also write down your wishes and share these with your healthcare professionals.

This is important to think about in case you become unable to make or communicate decisions about your care in the future.

Deciding to refuse treatment

You have the choice to refuse any particular treatments that you don't want to have.

You can make decisions now so that your wishes are followed if you lose the ability to make or communicate your decisions in the future. This is sometimes called an **advance decision to refuse treatment (ADRT)**, advance decision or Living Will. In Scotland, it's usually called an **advance directive**.

You'll need to state the specific treatments you wish to refuse and in what circumstances your refusal will apply. It's helpful to discuss your options with a doctor or nurse who knows about your medical history. They can talk you through different situations that you might be in.

To make sure your wishes to refuse treatment are followed, you'll need to record them in a particular way and share them with professionals.

To find out more, speak to your doctor or nurse. You can also visit mariecurie.org.uk/advance-care-planning or speak to trained staff or a nurse on our Support Line at **0800 090 2309***.

If you're on hormone therapy

If you're trans, non-binary or gender queer and are on hormone therapy, you might worry about whether you can have your hormone therapy alongside other treatment. You might also think about how you can take your hormones if you become more ill or if you're staying in a different place.

Speak to your GP or a healthcare professional you trust about any concerns you have around this. 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 doesn't have experience with this, they can 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.



iStock

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 doesn't need to be a spouse or relative – it can be 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 isn't 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

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 aren't aware of the significance of your relationships. You might also want to let health and social care professionals know who you don't want to be involved in decisions about your care.

If you don't choose someone to make decisions

You might think about what will happen if you become unable to make decisions yourself and you don't have a relevant Power of Attorney (see page 18) in place. The following will apply:

- Health and social care professionals will consider any wishes you've communicated in the past – for example, in your advance care plan (see page 16).
- They will 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.

To find out more, speak to a solicitor or visit your government's website (see page 26). You can also visit mariecurie.org.uk/advance-care-planning or contact our Support Line at **0800 090 2309***.

Your partner, family or friends disagreeing

You may worry that your loved ones won't 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 16). You can also legally appoint someone as your attorney (see page 18).

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



Elizabeth Cuthbertson/Marie Curie

“I’ve always been very scared of dying and I still am, but I think I feel better because I’m doing so well, I’m at home, and I can look after my boy. I can’t run, but I can walk and I can drive.”

Liz, living with a life-limiting illness

Planning ahead – finances and 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.

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 Support Line on **0800 090 2309***.

Making a Will

Making a Will lets you decide what happens to your money, property and possessions when you die. These things are sometimes called your ‘estate’. You can also use a Will to decide who should look after any children you have.

You can decide who you want to benefit from your Will (the ‘beneficiaries’) and what you want them to receive. You can also decide who you want to sort out your Will (the ‘executors’).

You can create a basic Will yourself. But getting advice can help make sure that your Will is legally valid. You can get advice from a solicitor, independent financial adviser (IFA) or professional Will writer. Many charities, including Marie Curie, offer free Will-writing services.

Find out more at **mariecurie.org.uk/makingawill** or contact our Support Line on **0800 090 2309***.

Planning your funeral

You could put plans in place for your funeral by speaking to a funeral director. You could also write down your wishes so that your partner, family or friends know what you'd want.

You might want to think about general things, like 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.

A funeral can cost thousands of pounds, so you might want to pay for your funeral in advance with a pre-paid funeral plan. You can also organise insurance to cover the cost. Or you can leave money in a bank account to cover the funeral cost when you die. Your bank may release funds from your account to pay for the funeral, but it's worth checking with them about how to do this. There may also be some financial support available through the government.

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

Choosing the name and gender on your death certificate

Some trans people worry that the name or gender assigned to them at birth will be used on their death certificate, at their funeral or on a burial headstone. It's important to speak to your partner, family and friends about your wishes and make it clear what you want.

If you have a Gender Recognition Certificate, you must be treated as your affirmed gender for legal purposes, including registration of death. If you don't have a Gender Recognition Certificate and you're concerned about this, you may want to seek further advice from a solicitor.

How Marie Curie can help

We help everyone affected by a terminal illness get the care and support they need, whether you have an illness yourself or you're a partner, family member or friend.

Marie Curie Support Line

0800 090 2309*

Ask questions and find support. Speak to a trained member of staff or a nurse for free confidential information on all aspects of terminal illness. Open 8am to 6pm Monday to Friday and 11am to 5pm Saturday. Your call may be recorded for training and monitoring purposes.

Marie Curie Online Chat

You can talk to our trained staff and get information and support via our online chat service.

mariecurie.org.uk/support

Marie Curie Community

Share experiences and find support by talking to people in a similar situation.

community.mariecurie.org.uk

Marie Curie Information

We have a range of free information available to view online or as printed booklets.

mariecurie.org.uk/support

Marie Curie Hospices

Our hospices offer the reassurance of specialist care and support, in a friendly, welcoming environment, for people living with a terminal illness and their loved ones – whether you're staying in the hospice, or just coming in for the day. Our hospices also support people who have been bereaved, and some offer support for children.

mariecurie.org.uk/hospices

Marie Curie Nursing Services

Marie Curie Nurses and Healthcare Assistants work in people's homes across the UK, providing hands-on care and vital emotional support. If you're living with a terminal illness, they can help you stay surrounded by the people you care about most, in the place where you're most comfortable.

mariecurie.org.uk/nurses

Marie Curie Helper Volunteers

We know the little things can make a big difference when you're living with a terminal illness. That's where our trained Helper Volunteers come in. They can visit you regularly to have a chat over a cup of tea, help you get to an appointment or just listen when you need a friendly ear.

mariecurie.org.uk/helper

Marie Curie's work with LGBTQ+ communities

At Marie Curie, we believe that everyone affected by terminal illness should get high quality care and support. We are committed to better care and support for LGBTQ+ people. This includes funding research, training health and social care professionals, working with community groups and organisations, and supporting people through our national Information and Support service.



"In our hospice, we've been doing training with staff about LGBTQ+ inclusivity. The response has been really positive and we're now doing more across the UK."

Lauren, Marie Curie Nurse who identifies as LGBTQ+

Useful organisations

Equality Advisory & Support Service

Organisation that provides advice and assistance on issues relating to equality, including discrimination because of disability, sexual orientation and gender identity. Supports people across England, Wales and Scotland.

equalityadvisoryservice.com

0808 800 0082

Gender Identity Clinic

Your nearest gender identity clinic can provide advice and support for issues related to gender, and specialist support for professionals around end of life care. Ask your GP or search online for your nearest clinic.

Government websites

Information on benefits, Power of Attorney and getting a Gender Recognition Certificate.

[GOV.UK](https://gov.uk) (England and Wales)

mygov.scot (Scotland)

[nidirect](https://nidirect.gov.uk) (Northern Ireland)

Hospice UK

National charity providing hospice and palliative care. The website includes a database where you can find a hospice near you.

hospiceuk.org

020 7520 8200

LGBT Foundation

Charity delivering advice, support and information services to lesbian, gay, bi and trans (LGBT) communities.

lgbt.foundation

0345 3 30 30 30

Opening Doors London

Charity providing information and support to LGBTQ+ people over 50, and training and quality standard for health and social care professionals throughout the UK.

openingdoorslondon.org.uk

020 7239 0400

Stonewall

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

stonewall.org.uk

0800 050 2020

Switchboard

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

switchboard.lgbt

0300 330 0630

About this information

This booklet was produced by Marie Curie's Information and Support team. It has been reviewed by health and social care professionals and people affected by terminal illness.

Thank you to the following experts, organisations and community groups who have been involved in producing this leaflet:

- Marie Curie health and social care professionals
- Marie Curie volunteers
- ACCESSCare Research Project, King's College London
- The London Gender Identity Clinic
- LGBT Foundation
- Opening Doors London
- Stonewall
- TrAC (Trans Ageing and Care) project, Swansea University

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

Notes

This image shows a single page of white paper with horizontal blue lines. The lines are evenly spaced and run across the width of the page, typical of notebook or ledger paper. There are no margins, text, or other markings on the page.

Marie Curie – who we're here for

We're here for people living with any terminal illness, and their families. We offer expert care, guidance and support to help them get the most from the time they have left.

Marie Curie Support Line

0800 090 2309*

Ask questions and find support from trained staff and nurses.

Open 8am to 6pm Monday to Friday,

11am to 5pm Saturday.

mariecurie.org.uk/support

You can also visit **community.mariecurie.org.uk** to share experiences and find support by talking to people in a similar situation.

We can't do it without you

Our Information and Support service is entirely funded by your generous donations, so the work we do would not be possible without your help. Thanks to you, we can continue to offer people the free information and support they need, when they need it.

mariecurie.org.uk/donate

*Calls are free from landlines and mobiles.

Your call may be recorded for training and monitoring purposes.



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through terminal illness**