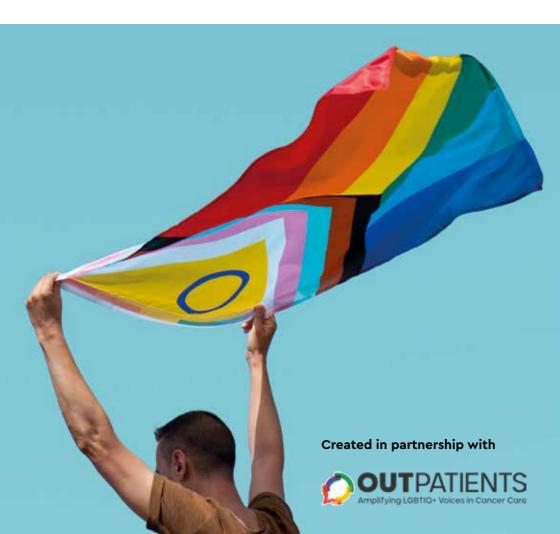


## LGBTQ+ people and cancer



### **About this booklet**

This booklet is for people who are LGBTQ+. It has information about:

- navigating healthcare
- cancer
- cancer treatment.

Sexual orientation and gender identity should not affect your access to the right healthcare. Your healthcare team should offer you care, support and information that meets your needs. But we know that sometimes LGBTQ+ people may face extra challenges in getting the right help.

We hope this booklet helps you deal with some of the questions or feelings you may have.

We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

We developed this information in partnership with OUTpatients (formerly called Live Through This). OUTpatients is a cancer support and advocacy charity for the LGBTIQ+ community (page 40). They provide a safe space for anybody who identifies as part of the queer spectrum and has had an experience with any type of cancer at any stage from testing, diagnosis, treatment, remission to long-term care.

In this booklet we talk about some subjects that may be upsetting. This includes mentions of gender dysphoria (distress caused by feeling the sex assigned at birth does not match your gender identity). If you need support or want to talk, contact the:

- LGBT Foundation helpline on **0345 330 3030** (page 51)
- Mindline Trans+ helpline on 0300 330 5468 (page 51)
- Switchboard helpline on 0800 011 9100 (page 52).

#### How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 5 to help you. It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 50 to 58, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (pages 60 to 63).

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.

#### Quotes

In this booklet, we have included guotes from people who identify as LGBTQ+, which you may find helpful. These are from people who have chosen to share their story with Macmillan or OUTpatients. To share your experience with Macmillan, visit macmillan.org.uk/shareyourstory

#### For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on 0808 808 00 00, 7 days a week, 8am to 8pm, or visit macmillan.org.uk

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using Relay UK on 18001 0808 **808 00 00**, or use the Relay UK app.

We have some information in different languages and formats, including audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit macmillan.org.uk/otherformats or call 0808 808 00 00



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## **Questions about**healthcare

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# Does my healthcare team need to know I am LGBTQ+?

There may be times when members of your healthcare team ask you about:

- sexual and romantic orientation
- sexual activity
- gender identity.

Your team may ask because they want to give the right care and support to you and the people close to you. They may also ask to collect some of this information for equality monitoring. This means the information is used to ensure that NHS services are accessible for everyone.

If you are unsure why you are being asked these questions, you can ask:

- why they need the information
- why they think the information is relevant to your care.

You do not have to give your team this information. But it may be an important part of who you are. It might be helpful for your team to know. And you may find it makes things easier or less stressful for you. Tell your team if the questions they ask do not fit with who you are or how you identify.

If your healthcare team have not asked, it is still important that you feel able to come out to them, if you want to. You may choose to do this when you first meet someone from your team. Or you may decide to wait until you find someone you feel comfortable with.

If a healthcare professional is wearing an NHS Rainbow Badge, you could start by asking them about it. The badge means they should be open to talking about LGBTQ+ needs and able to offer support. Some healthcare professionals wear rainbow lanyards or other items because they are LGBTQ+ themselves. Others do so to show they support the LGBTQ+ community.

It may also help your healthcare team to know the following things.

#### Whether you are out or not

Your team should treat all information about you confidentially. They may only share information with other healthcare professionals when it is needed for your care. If you are not out in all areas of your life, explain this to your team. They should not share your sexual orientation or transgender (trans) status without your permission.

#### Your name, title and pronouns

You can ask your team to make a note and use these even if they are different from those in your medical records.

#### People who are important to you

Your healthcare team needs to understand who supports you and your relationship to them. Tell your team who you give consent for them to talk to about your care.

#### What is important to you

Tell your team if they are offering you the wrong information or support. For example, some cancer treatments can affect your ability to get or make someone pregnant (your fertility). If you want information about this but have not been offered it, ask your team. If they talk to you about it but you do not want or need this information, tell them.

#### What you are worried about

You may be worrying about things your team are not aware of. Tell them if something is making you anxious so they can help. This could be anything, such as worries about hair loss or weight changes, or concerns about whether you will be able to continue with gender-affirming treatments. If there is something you are worried about, talk to your team. You can also tell them if they are offering you the wrong information or support.

My main difficulty being a queer person getting healthcare is that I feel like I'm walking on eggshells. I present as cis and straight, so heteronormativity plays in my favour. But it's quite humiliating to have to use that to get what I want. I never know if coming out will help me or will be used against me. \*\*

Charles, diagnosed with breast cancer

# Will I be treated differently because I am LGBTQ+?

Your healthcare team are there to support you and treat you in a way you feel comfortable with.

However, some LGBTQ+ people may worry about being treated less well. This may be because they have had difficult or negative experiences before. They may worry about:

- not getting the right information or support for their body or identity
- healthcare professionals making assumptions about sexual and romantic orientation or gender identity
- a partner being mistaken for a friend or family member, or being ignored.

#### **Discrimination**

By law, your healthcare team must not treat you less favourably because of your sexual orientation or sex or gender reassignment. This is called discrimination and is against the law.

Facing discrimination can be stressful and upsetting. It may be especially difficult when you are already dealing with cancer. If you are being treated unfairly, there are things you can do.

#### Talk to your healthcare team

Talk to someone from your team, if it feels safe and comfortable to do so. Sometimes they may not realise that there is a problem. Giving feedback about this may help your team make things right. Many healthcare professionals welcome feedback so they can learn and offer better care.

#### **Get support**

Start by talking to someone you trust. This may be someone close to you or a healthcare professional you know well. OUTpatients provides support specifically for LGBTIQ+ people with cancer, through peer services, advocacy and signposting (page 40). Switchboard, the LGBT+ Helpline (page 52) and the LGBT Foundation (page 51) offer safe spaces to talk by phone or online. Galop offers support to LGBT+ people who have experienced hate crime, domestic abuse or sexual violence (page 51). It also has a Trans Advocacy Service.

#### Give feedback or make a complaint

You can give feedback and complaints anonymously if you do not want to be identified. The process is different depending on where you live. You can find out more about how this works and the support available in your area:

- England visit england.nhs.uk/contact-us/complaint
- Scotland visit nhsinform.scot/care-support-and-rights/ health-rights
- Wales visit nhs.wales/hpb/contact-us
- Northern Ireland visit nidirect.gov.uk/articles/raising-concernor-making-complaint-about-health-services

"All the medical staff I came across were amazing - especially the nurses, but also the doctors and consultants too. They didn't have a problem with gay patients - and went out of their way to make my partner comfortable by finding pillows for him so he could stay close to me. ,,

Michael, diagnosed with leukaemia

## I am trans, non-binary or both. Where will I have tests or treatment?

Your healthcare team should offer you care, support and information that meet your needs. They should treat you as an individual and work with you in a way that respects your privacy and dignity.

They should always treat information about your transgender (trans) status and gender history confidentially. They may share this information with other healthcare professionals, but only when it is needed for your care. You do not have to give your team information about your gender identity and history. But you may find it makes things easier or less stressful. For example, some scans should not be used during pregnancy. If the gender on your NHS record is male and there is a chance you might be pregnant, it is important that the person doing the scan understands this.

#### Going to hospital or clinic

If you need to stay in hospital, your team should talk to you about where you will stay. Hospital wards may be single sex or mixed. Some rooms may have beds for several patients and shared bathrooms. Others may have single rooms with private bathrooms.

Where you stay should give you privacy and keep you safe. Tell your team what option or ward you prefer, and what feels comfortable and right for you.

Some health conditions are still often treated in clinics that are gendered. For example, if you have:

- a breast or chest lump, you may be offered tests at a breast clinic
- a problem affecting the vagina or nearby pelvic areas, you may have an appointment at a women's health clinic
- a problem affecting the prostate, you may be given an appointment at a clinic for men.

These clinics can be difficult to cope with if your gender identity does not reflect the sex you were assigned at birth. If your GP is arranging your appointment, you could ask them to explain this to the clinic. Or you may want to contact the clinic before your appointment and talk to them directly. They may be able to make things easier for you. For example, they may be able to offer an early appointment, when the waiting room is quieter.

I needed a mastectomy to treat breast cancer. I knew that going flat with no reconstruction was an option and could be done with very pleasant results, so I let my team know that this was my preference. But the surgeon left me with extra tissue 'for when you will want a reconstruction' which was clearly not what I wanted.

Charles, diagnosed with breast cancer



## Worried about cancer

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### **Cancer screening**

The NHS offers routine screening for cervical cancer, breast cancer and bowel cancer. Having screening can reduce your risk of cancer and may save your life.

Cancer screening uses tests to find people who may:

- have cancer so it can be treated early and effectively
- need treatment to stop cancer developing.

Whether or not you have screening is your choice. To help you make an informed decision, it is important to understand:

- which types of screening you can have
- what the screening tests involve
- the benefits and risks of having screening.

We have some information here. We have also included some useful organisations that can help if you need more information (pages 52 to 53).

We have more information about cancer risk and gender-affirming treatments on pages 22 to 25.

#### Who can have breast screening?

Breast screening is automatically offered to anyone who is registered as female with their GP, and aged between 50 and 70. If you are over 70, you can self-refer through your GP.

If you are transgender (trans), non-binary, or both, you may need to think about breast cancer risk and screening if you were either:

- assigned male at birth and take feminising hormone therapy
- assigned female at birth.

The NHS breast screening programme only automatically invites people who are registered as female with their GP. If you are registered as male and need breast screening, your GP can arrange screening for you.

#### Who can have cervical screening?

Cervical screening is for anyone between the ages of 25 and 64 who was assigned female at birth and still has a cervix. This can include cisgender women, trans men and non-binary people who were assigned female at birth.

Cervical screening is important for anyone who has ever been sexually active, whatever your sexual orientation.

If you are registered as female with your GP, you will automatically be sent cervical screening invitations. If you are registered as male and need cervical screening, your GP can arrange screening for you.

#### Who can have bowel cancer screening?

If you are registered with a GP, you will be sent your first home screening bowel test by post when you are aged between 50 and 60. The exact age depends on which UK country you live in. The screening programmes are based on research in each country and reflect the different needs of the populations.

## How can I reduce my cancer risk?

You can reduce your risk of cancer and improve your general health by making healthy lifestyle choices, such as:

- stopping smoking
- · keeping to a healthy weight
- eating and drinking healthily
- being physically active.

The World Cancer Research Fund has more information about making lifestyle changes to reduce your cancer risk (page 54).

Visit wcrf.org/diet-and-cancer/cancer-prevention-recommendations

## Symptoms of cancer

Different types of cancer have different symptoms. Many symptoms can be caused by things other than cancer. But it is important to understand your body and be aware of any changes. This includes the following:

- Ongoing symptoms this means a symptom that lasts for more than 3 weeks. This could be a cough that does not go away, a change in bowel function, a mouth ulcer that does not heal, or feeling bloated most days.
- Unexplained symptoms this means a symptom that does not have an obvious cause. For example, you may have a lump or bleeding without any injury.
- Unusual symptoms this means a change in your body that is not normal for you. It could be a change in a cough that you have had for a long time, a change to a mole or an unexplained change to the look or feel of your chest or breasts.

We have more information about what to look for, and when to get a symptom checked on our website. There are also tips for talking to your GP or practice nurse. Visit **macmillan.org.uk/signs-and-symptoms-of-cancer** You can contact your GP for advice about symptoms.

There may be parts of your body that you are less comfortable with or feel upset about. Thinking about any symptoms in these areas may be very difficult. Try not to let this stop you from getting checked if you have any changes or symptoms. If you go to a gender identity clinic, you can also talk to them. This may be helpful if you find it difficult to talk to your GP. A transgender (trans) and non-binary friendly sexual health and well-being service may also be able to help. Some even run trans and non-binary specific clinics. You can check if this is available in your area by visiting the websites for OUTpatients (page 40) or Tranzwiki (page 52).

## Do gender-affirming treatments cause cancer?

There is not a lot of research about gender-affirming treatments and cancer risk. Some treatments may slightly increase or lower your risk of developing some types of cancer. If you meet with a gender identity specialist, they can help explain what this means in your situation. For example, they may talk to you about any symptoms you should look out for or what screening you should have. If you do not have contact with a general identity specialist, your GP may be able to arrange this for you. OUTpatients also offers a booklet that helps explain cancer risk for transgender (trans) and non-binary people. Visit outpatients.org.uk/ tnbgd-screening to download the booklet.

#### If you take feminising hormone therapy

Feminising hormones increase your risk of breast cancer. If you were assigned male at birth and take feminising hormone therapy, your risk is higher than a cisgender man but lower than a cisgender woman. Cisgender means a person's gender identity matches the sex they were assigned at birth.

You should go for regular breast screening from the age of 50 to 71. Find out more about screening for trans and non-binary people from OUTpatients (page 40) or Cancer Research UK (page 55).

It is important to know how your breasts normally look and feel, so you can recognise any changes.

You can use the CoppaFeel Self-Checkout guide to help you learn how to check. Visit self-checkout.coppafeel.org/onboarding Tell your GP if you notice lumps or any changes to your breasts, nipples or armpits. CoppaFeel (page 54) and OUTpatients (page 40) also have gender-neutral information about chest-checking and changes during transition that may be useful.

Feminising hormones give you a lower risk of prostate cancer than a cisgender man. But it is important to remember that you do still have a prostate, and prostate cancer can develop in this area. There is no screening programme for prostate cancer. But tell your GP if you have problems peeing (passing urine). This includes needing to pee suddenly, pain when you pee, or blood in your pee. Prostate Cancer UK has information about prostate cancer for trans women (page 54).

#### If you take masculinising hormone therapy

There is not a lot of information about cancer risks of masculinising hormone treatment if you were assigned female at birth. But it is not thought to increase your risk of cancer.

It is still important to be aware of possible signs or symptoms of cancer. If you have a vagina, cervix, womb or ovaries, you should tell your GP if you often have a bloated or swollen tummy, or if it does not go away. Also tell your GP if you have unexpected or heavy vaginal bleeding. We have more information about the symptoms of cervical, ovarian and womb cancer in our booklets about those cancer types (page 46).

If you have a cervix, you should go for regular cervical screening. OUTpatients (page 40) has information about cervical screening for trans and non-binary people. Find out more at outpatients.org.uk/ tnbgd-screening

#### If you were assigned female at birth and have had chest reconstruction (top surgery)

This operation does not usually remove all the breast tissue. Ask the surgeon who did your operation to explain if you still have breast tissue. If you do, there is a risk of breast cancer. But this risk is less than before your surgery.

It is important to know how your chest normally looks and feels, so you can recognise any changes. You can use the CoppaFeel Self-Checkout guide to help you learn how to check. Visit self-checkout.coppafeel. org/onboarding Tell your GP if you notice lumps or any changes to your chest, nipples or armpits.

CoppaFeel (page 54) and OUTpatients (page 40) also have gender-neutral information about chest-checking and changes during transition that may be useful.

Ask your GP or gender identity clinic about breast screening. If breast cancer runs in your family, you may be offered regular breast screening using an MRI scan. The more commonly used breast screening test (a mammogram) is not usually possible after chest reconstruction.

#### If you were assigned male at birth and have had genital reconstructive surgery

If you have had surgery to make a vagina, the risks of cancer in this area are thought to be low. You do not have a cervix and do not need to go for cervical screening (a smear test).

But it is important to remember that you do still have a prostate, and prostate cancer can develop in this area. There is no screening programme for prostate cancer. But tell your GP if you have problems peeing (passing urine). This includes needing to pee suddenly, pain when you pee, or blood in your pee. Prostate Cancer UK (page 54) has information about prostate cancer for trans women. Visit prostatecanceruk.org/prostate-information/are-you-at-risk/ trans-women-and-prostate-cancer

#### If you were assigned female at birth and have had genital reconstructive surgery

You may still have a vagina, cervix, womb or ovaries. Ask the surgeon who did your surgery if you are not sure.

You should tell your GP if you often have a bloated or swollen tummy, or if it does not go away. Also tell your GP if you have unexpected or heavy vaginal bleeding. We have more detailed information about symptoms of cervical, ovarian and womb cancer in our booklets Understanding cervical cancer, Understanding cancer of the ovary, fallopian tube or peritoneum and Understanding womb (endometrial) cancer (page 46).

If you have a cervix, you should go for regular cervical screening. OUTpatients (page 40) has information about cervical screening for trans and non-binary people.

Find out more at outpatients.org.uk/trans-and-nonbinary



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## Planning cancer treatment

If you have been diagnosed with cancer, a team of healthcare professionals will work together to plan the treatment they feel is best for you. Together you make a decision about your treatment plan. Your team needs to understand what is important to you in making this decision. If there is anything you are worried about, tell them so they can help. They may not be aware of things that are difficult for you. By understanding more, they will be able to support you with your decisions.

It is usually okay to have a support person with you during appointments and during many types of tests and treatments. Contact the clinic or hospital to check if you can take someone with you to appointments. It can be helpful to have someone you trust listening and helping you cope with what is happening.

My brother and I weren't the best of buddies when we were younger, I think he had difficulty with my sexuality. But now that we've found out that he's a 100% match for the stem cell transplant, it's brought us together and bonded us.

Alan, diagnosed with Hodgkin lymphoma

## **Transitioning** during cancer

If you are in the early stages of transitioning when you are diagnosed with cancer, you may have additional questions or concerns you want to discuss. These may be about your social, medical or surgical plans for transition. If you have never talked about your gender identity before, you may not know how to start this conversation with your healthcare team.

If your cancer team need advice about how your cancer care may affect your transition related care, they can contact the UK Cancer and Transition Service (UCATS) - page 52. They should ask permission to share your information before they do so. You can also refer yourself to this service.

The most important thing is to get the right support for you. We have more information on pages 37 to 38.

## Side effects of cancer treatment

Most people will have some side effects during treatment for cancer. It can depend on the type of cancer and the type of treatment. Your cancer team will explain what to expect and how side effects can be managed. We have more information on our website and in our booklet Side effects of cancer treatment

Some side effects can be upsetting because they cause changes that do not reflect how you identify. For example, hair loss or a change in your weight or body shape may be upsetting if your appearance is an important part of your gender identity. Some treatments might change part of your body that you have worked hard to align with your gender. Other changes and side effects may not be visible, but may still affect how you feel about yourself.

It is important that your team understands how you feel about this as they plan your treatment. You can find more about coping with changes in our booklet **Body image and cancer**.

You can order our booklets and leaflets for free. Visit be.macmillan.org.uk or call us on 0808 808 00 00.





I think some of the female doctors found it difficult to understand that I didn't need to wear a wig or makeup to feel good about myself. I found losing my hair quite liberating. When I was younger I wanted to shave my head, but never dared.

Eileen (left), diagnosed with breast cancer

"I didn't feel like having sex while I was having treatment. Actually for a few months I felt really unattractive especially when I looked into the mirror and saw how thin or pale I was. So didn't feel very sexual at all. After treatment I started to gain my confidence again. Cancer deepened my relationship with my partner. ,,

## Cancer, sex and fertility

Cancer and some cancer treatments can affect many areas of sexual well-being. Sometimes, they can also affect your ability to get pregnant or make someone pregnant (fertility). Your cancer doctor or specialist nurse can explain before you start a cancer treatment if it is likely to cause sexual side effects or fertility problems. They can also give advice and information about this during or after treatment.

The side effects of cancer treatments are often the same whatever your sexual orientation or gender identity. But as an LGBTQ+ person, you may have some specific questions about how these will affect your sex life or your fertility options. And some side effects may be more of a problem depending on the type of sex you have.

Some people have already made decisions about fertility before being diagnosed with cancer. You may have decided you do not want to have children. Or you may have planned it for the future. Some people may have stored sperm, eggs, embryos or ovarian tissue. If you have questions about fertility before or after cancer treatment, talk to your cancer team. It might be helpful to write down your questions to take to appointments. Your team can give you information, or refer you to a fertility clinic for more support.

#### Finding more information

OUTpatients has information for LGBTQ+ people about sex with and beyond cancer (page 40). Macmillan also has information about cancer, sex and side effects for anyone before, during or after cancer treatment (page 46). You may also find our booklet **Cancer and fertility** helpful. This information is for you whether or not you are in a relationship or having sex, and whatever your sexual orientation or gender identity.

## Cancer treatment and gender-affirming treatment

Sometimes cancer treatment can affect or be affected by gender-affirming treatments. It may be useful for your cancer team to contact your gender identity clinic or the UK Cancer and Transition Service (UCATS) - page 52. You will need to give them permission to do this. If you have not been to a gender identity clinic in the UK, your cancer team can still get advice from UCATS.

#### Cancer surgery and gender-affirming surgery

Sometimes surgery to treat cancer is also gender-affirming. Surgery to remove the cancer may remove a body part that you prefer not to have anyway. Again, it is helpful if your team understands how you feel about this, so they can support you and plan your treatment well.

#### Cancer treatment and gender-affirming hormones

If you take gender-affirming hormones, it is usually fine to keep taking these during cancer treatment.

Your cancer team may talk to you about pausing, stopping or reducing hormone treatment. This is not common, but can be an important thing to talk about with your team.

Reasons for pausing, stopping or reducing hormones may include the following:

- If you have a high risk of blood clots, heart attacks, strokes or diabetes.
- If you are diagnosed with a type of cancer that is sensitive to hormones, such as breast cancer. Your team may suggest pausing your hormone treatment while they do tests to find out more about the type of cancer. In some situations, taking hormones long term may make the cancer more likely to come back after treatment.

It is not always clear how much gender-affirming hormones increase your risk in these situations. Your reasons for taking the hormones are also important and you may feel the benefits of continuing to take them may outweigh the risks for you. Talk to your team about the possible risks and benefits before you make any decisions about changing your hormone treatment.

#### Radiotherapy and gender-affirming genital surgery

Radiotherapy to the pelvic area (the area between the hips) can cause changes that may affect sexual well-being. We have more information about pelvic radiotherapy and possible side effects in our booklet Understanding pelvic radiotherapy (page 46).

If you have had genital surgery to make a new penis or vagina, pelvic radiotherapy may affect these areas. It is important to ask your radiotherapy team what to expect and whether there is a risk of long-term changes. This may depend on the exact area of the pelvis being treated and the way treatment is given. There are some examples on the next page.

# If you have had surgery to make a penis (phalloplasty or metoidioplasty)

Pelvic radiotherapy can usually be given in a way that avoids this area. If you also still have a vagina, radiotherapy may cause changes such as dryness, narrowing or bleeding. Your team may suggest using dilators regularly after treatment to prevent vaginal narrowing. This can be helpful if you still need to have cervical screening or want to use the vagina for sex.

## If you have had surgery to make a vagina (vaginoplasty)

Pelvic radiotherapy may narrow the vagina or make the skin more fragile and sensitive. You may need to use dilators more often to prevent the vagina closing.

## If you are planning to have gender-affirming surgery

If you are planning to have genital surgery in the future, talk to your team about this before having pelvic radiotherapy. Surgery is not always possible after an area has been treated with radiotherapy. Your team can explain what cancer treatment you need and how this may affect genital surgery in the future.

# **Getting support**

It can help to have people around you who can help or who understand what you are going through.

# LGBTQ+ cancer support groups

Support groups are a way of meeting people in similar situations and sharing experiences. Many people find they help them cope with cancer and cancer treatment.

Each group is unique. There are groups for people affected by a certain type or stage of cancer, or having a particular treatment. There are also a small number of groups for LGBTQ+ people affected by cancer.

Some people find they try a few different groups before finding the right one for them. Or they may try a mixture of groups. Sometimes it might take a few meetings to feel comfortable and able to take part.

Ask your healthcare team about groups in your area, or call us on 0808 **808 00 00**. You can also search our database for groups in your area. Visit macmillan.org.uk/inyourarea

LGBTQ+ cancer support groups include the following:

- OUTpatients (page 40) runs peer support groups for LGBTIQ+ people affected by cancer, and for their carers and partners. Groups are open to people affected by any cancer type.
- LGBT Walnut (page 50) is a support group based in London for any LGBT person affected by prostate cancer.
- Out with Prostate Cancer (page 50) is a support group based in Manchester, aimed at gay and bisexual men and trans women affected by prostate cancer.

## Online groups

Online and social media groups can be a good way to find and connect with people. Online support may also feel safer or more comfortable for people who are not out or who want to be anonymous. Macmillan's Online Community offers a safe space to ask questions, share experiences and emotions. You can visit the LGBTIQ+ group at community.macmillan.org.uk/cancer\_experiences/lgbt-and**cancer-forum** or explore all the cancer support forums.

# LGBTQ+ support

It can be helpful and important to find wider support from the LGBTQ+ community when affected by cancer. The following organisations offer general support to LGBTQ+ people, rather than specific cancer support or information:

- The LGBT Foundation (page 51)
- Mindline Trans+ (page 51)
- Switchboard, the LGBT+ Helpline (page 52)
- Tranzwiki (page 52) and LGBT Consortium (page 51) have lists of groups that offer support for transgender (trans) and non-binary people. This includes national organisations and local support groups. Search by your area to find out what is available.



Being a gay man who knows and loves drag queens I came up with the idea of fundraising for financial support for people living with cancer. Cancer drags you down, so the name 'Cancer Is A Drag' is a bit tongue-in-cheek.

Alan, diagnosed with Hodgkin lymphoma

# **How OUTpatients** can help you

OUTpatients is the UK's only specialist cancer charity led by and for the LGBTIQ+ community. Through peer support, professional education, policy and partnerships, it works to improve the cancer sector's services to better support the LGBTIQ+ community.

Visit outpatients.org.uk to find out more, including:

- peer support groups for LGBTIQ+ people affected by any cancer types, and groups for their carers and partners
- breast cancer screening information visit the Best for My Chest section of the website
- cervical screening information visit the Remove the Doubt and My Cervix My Service sections on the website
- details of transgender and non-binary specialist clinics offering cervical screening
- cancer risk and screening information for people who are transgender, non-binary and gender diverse - visit the website or download the booklet at outpatients.org.uk/tnbgd-screening

"I noticed there was a trend of hospitals not having LGBT provision. The staff were excellent in helping us get things off the ground. We designed a peer support group and are now continuing to support patients, and share our knowledge with healthcare providers on how to make cancer care more inclusive.

Stewart, founder of OUTpatients



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# **About our information**

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

## Order what you need

You may want to order more booklets or leaflets like this one. Visit orders.macmillan.org.uk or call us on 0808 808 00 00.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

## Online information

All our information is also available online at macmillan.org.uk/ **information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

## Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets

- interactive PDFs
- large print
- translations.

Find out more at macmillan.org.uk/otherformats

If you would like us to produce information in a different format for you, email us at informationproductionteam@macmillan.org.uk or call us on 0808 808 00 00.

## The language we use

We want everyone affected by cancer to feel our information is written for them.

We try to make sure our information is as clear as possible. We use plain English, avoid jargon, explain any medical words, use illustrations to explain text, and make sure important points are highlighted clearly.

Macmillan is working to improve how our cancer information works for LGBTQ+ people. There are areas of our information that we are still working on to make more inclusive.

When we write or update our information, we think about the needs of all different audiences. This includes people of all sexual orientations and gender identities. We are careful about the language and wording we use. We include information about specific LGBTQ+ issues when needed. We offer other useful sources of information and support when this is helpful.

We welcome feedback on any of our information. If you have feedback, please contact us at informationproductionteam@macmillan.org.uk

You can read more about how we produce our information at macmillan.org.uk/ourinfo

# Other ways Macmillan can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

## Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

## **Macmillan Support Line**

Our support line is made up of specialist teams who can help you with:

- emotional and practical support if you or someone you know has been diagnosed with cancer
- clinical information from our nurses about things like diagnosis and treatments from our nurse specialists
- welfare rights advice, for information about benefits and general money worries.

To contact any of our teams, call the Macmillan Support Line for free on 0808 808 00 00. Or visit macmillan.org.uk/support-line to chat online and see the options and opening times.

Our trained cancer information advisers can listen and signpost you to further support.

Our cancer information nurse specialists can talk you through information about your diagnosis and treatment. They can help you understand what to expect from your diagnosis and provide information to help you manage symptoms and side effects.

If you are deaf or hard of hearing, call us using Relay UK on 18001 0808 **808 00 00**, or use the Relay UK app.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to

## macmillan.org.uk/talktous

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call 0808 808 00 00 and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

## **Macmillan Information and Support Centres**

Our Information and Support Centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

Find your nearest centre at macmillan.org.uk/informationcentres or call us on 0808 808 00 00.

## Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

#### Financial advice

Our expert money advisers on the Macmillan Support Line can help you deal with money worries and recommend other useful organisations that can help.

## Help accessing benefits

You can speak to our money advisers for more information. Call us free on 0808 808 00 00. Visit macmillan.org.uk/financialsupport for more information about benefits.

## Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit macmillan.org.uk/work

## Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help bring people together in their communities and online.

### **Support groups**

Whether you are someone living with cancer or a carer, family member or friend, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting macmillan.org.uk/ selfhelpandsupport

## **Online Community**

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at macmillan.org.uk/community

You can also use our Ask an Expert service on the Online Community. You can ask a financial guide, cancer information nurse, work support advisor or an information and support advisor any questions you have.

## Macmillan healthcare professionals

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

# Other useful organisations

There are other organisations that can give you information or support. Details correct at time of printing.

## **LGBTQ+** cancer support

#### **LGBT Walnut**

## www.lgbt-walnut.org.uk

A support group based in London for any LGBT person affected by prostate cancer.

## **OUTpatients**

## www.outpatients.co.uk

A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. See page 40 for more information. OUTpatients runs a peer support group with Maggie's Barts.

#### **Out with Prostate Cancer**

#### Tel 0794 488 6043

#### outwithprostatecancer.org.uk

A support group based in Manchester, aimed at gay and bisexual men and trans women affected by prostate cancer.

## **LGBTQ+ support**

#### Consortium

## www.consortium.lgbt/member-directory

A directory of LGBT+ groups, organisations and projects across the UK.

### Galop

Helpline **0800 999 5428** 

## www.galop.org.uk

Provides support services for LGBT+ people who have experienced abuse or violence.

#### **LGBT Foundation**

Helpline **0345 330 3030** 

## www.lgbt.foundation

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

#### **Mindline Trans+**

## Helpline **0300 330 5468**

## www.mindinsomerset.org.uk/our-services/adult-one-to-one-support/ mindline-trans/

Has a confidential emotional, mental health support helpline and signposting service for people who identify as trans, agender, gender fluid, non-binary.

#### **Switchboard**

Helpline **0800 011 9100** 

## www.switchboard.lgbt/

LGBT+ helpline. Offers information and support for LGBT+ people.

#### **Tranzwiki**

## www.gires.org.uk/tranzwiki

Has a list of groups that offer support for trans and non-binary people. This includes national organisations and local support groups. Search by your area to find out what is available.

### UK Cancer and Transition Service (UCATS)

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

Is a new service for the trans and non-binary community for anyone with cancer or a history of cancer where they feel it interacts with their gender-affirming care. With your permission, your healthcare professional can refer you to UCATS. Or you can use a form on their website to self-refer.

## **Cancer screening information**

## **England**

www.england.nhs.uk/cancer/early-diagnosis/screening-and-earlierdiagnosis/

#### Scotland

www.nhsinform.scot/healthy-living/screening

#### Wales

phw.nhs.wales/services-and-teams/screening/

#### Northern Ireland

cancerscreening.hscni.net

## Cancer screening for trans and non-binary people

#### **Cancer Research UK**

www.cancerresearchuk.org/about-cancer/screening/trans-and-nonbinary-cancer-screening

## **Cervical screening**

#### **GOV.UK**

www.gov.uk/government/publications/cervical-screening-lesbianand-bisexual-women/cervical-screening-for-lesbian-and-bisexualwomen

## **Cancer awareness information**

## Coppafeel

www.coppafeel.org/breast-cancer-info-and-advice/how-do-i-check/ Has ilnformation about how to check your breasts, pecs or chest.

#### **Prostate Cancer UK**

prostatecanceruk.org/prostate-information/are-you-at-risk/transwomen-and-prostate-cancer

#### **World Cancer Research Fund**

## www.wcrf-uk.org

Has tools to check how healthy your lifestyle is and health information about reducing your risk of cancer. Also offers information for people going through cancer treatment.

## General cancer support organisations

## **Black Women Rising**

## www.blackwomenrisinguk.org

Aims to educate, inspire and bring opportunities for women from the BAME community. Shares stories and supports Black cancer patients and survivors through treatment and remission.

#### **Cancer Black Care**

#### Tel 0208 961 4151

## www.cancerblackcare.org.uk

Offers UK-wide information and support for people from Black and minority ethnic communities who have cancer. Also supports their friends, carers and families.

#### **Cancer Focus Northern Ireland**

Helpline **0800 783 3339** 

## www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland.

#### **Cancer Research UK**

Helpline **0808 800 4040** 

#### www.cancerresearchuk.org

A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

#### **Macmillan Cancer Voices**

## www.macmillan.org.uk/cancervoices

A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

## Maggie's

#### Tel 0300 123 1801

## www.maggies.org

Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

## **Penny Brohn UK**

#### Helpline **0303 3000 118**

### www.pennybrohn.org.uk

Offers physical, emotional and spiritual support across the UK. using complementary therapies and self-help techniques.

#### **Tenovus**

#### Helpline **0808 808 1010**

#### www.tenovuscancercare.org.uk

Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

## General health information

#### Health and Social Care in Northern Ireland

#### www.northerntrust.hscni.net

Provides information about health and social care services in Northern Ireland

#### NHS.UK

#### www.nhs.uk

The UK's biggest health information website. Has service information for England.

#### **NHS 111 Wales**

#### 111.wales.nhs.uk

NHS health information site for Wales.

#### **NHS Inform**

#### Helpline **0800 22 44 88**

#### www.nhsinform.scot

NHS health information site for Scotland.

#### **Patient UK**

## www.patient.info

Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many healthand illness-related websites.

## Counselling

## British Association for Counselling and Psychotherapy (BACP)

#### Tel 0145 588 3300

## www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'How to find a therapist' page.

## **UK Council for Psychotherapy (UKCP)**

#### Tel 0207 014 9955

### www.psychotherapy.org.uk

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

## **Emotional and mental health support**

#### Mind

Helpline **0300 123 3393** 

## www.mind.org.uk

Provides information, advice and support to anyone with a mental health problem through its helpline and website.

#### Samaritans

Helpline 116 123

Email jo@samaritans.org

## www.samaritans.org

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

"Counselling has been a life-saver to me – to be able to tell someone how you feel each week and off-load your demons. Being able to reflect and to know that you are not alone is so important. "

Alan, diagnosed with Hodgkin lymphoma

# Your notes and questions



# Your notes and questions



#### **Disclaimer**

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

#### **Thanks**

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been developed in partnership with OUTpatients. It has been approved by Chief Medical Editor, Prof Tim Iveson, Consultant Medical Oncologist.

With thanks to: Dr Alison May Berner, Medical Oncologist; Julie Cain, Clinical Nurse Specialist; Charlotte Etheridge, Clinical Nurse Specialist; Ben Heyworth, Survivorship Network Manager/Consultant in LGBT and Cancer; Kirstie McEwan, Psychotherapist and Counsellor; Stewart O'Callaghan, Chief Executive, OUTpatients; and Rachael Webster, Radiographer.

Thanks also to the other professionals and the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact informationproductionteam@macmillan.org.uk

Cover photo 251018527 © Juan Moyano | Dreamstime.com

#### Sources

Below is a sample of the sources used in our information for people who are LGBTQ+. If you would like more information about the sources we use, please contact us at informationproductionteam@ macmillan.org.uk

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# Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

## 5 ways you can help someone with cancer

#### 1. Share your cancer experience

Support people living with cancer by telling your story, online, in the media or face to face.

#### 2. Campaign for change

We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

#### Help someone in your community 3.

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

#### Raise money 4.

Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

## 5. Give money

Big or small, every penny helps. To make a one-off donation see over.

Please fill in your personal details	Do not let the taxman keep your money		
Mr/Mrs/Miss/Other			
Name	Do you pay tax? If so, your gift will be worth 25% more to us -		
Surname	at no extra cost to you. All you		
Address	have to do is tick the box below,		
Postcode	and the tax office will give 25p for every pound you give.		
Phone	I am a UK tax payer and		
Email	I would like Macmillan Cancer		
Please accept my gift of £ (Please delete as appropriate)	Support to treat all donations I make or have made to Macmillan Cancer Support in the		
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support	last 4 years as Gift Aid donation until I notify you otherwise.		
OR debit my: Visa / MasterCard / CAF Charity Card / Switch / Maestro	I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.		
Card number			
Valid from Expiry date	Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use		
Issue no Security number	your details in this way please tick this box In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.		
Signature	If you would rather donate online		
	go to macmillan.org.uk/donate		
Date / /			







# Sexual orientation and gender identity should not affect your access to the right healthcare. But we know that sometimes LGBTQ+ people may face extra challenges in getting the right help.

This booklet is for people who are LGBTQ+. It has information about navigating healthcare. cancer, and cancer treatment.

At Macmillan we know cancer can disrupt your whole life. We'll do whatever it takes to help everyone living with cancer in the UK get the support they need right now, and transform cancer care for the future.

For information, support or just someone to talk to. call **0808 808 00 00** or visit macmillan.org.uk

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using Relay UK on 18001 0808 808 00 00. or use the Relay UK app.

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Patient Information Forum