

## Palliative care

Palliative care aims to help you live as well and as comfortably as possible. It can help to manage symptoms of lymphoma and improve your quality of life from the point of diagnosis onwards. Palliative care is relevant to **anyone** affected by lymphoma. This information covers palliative care from the point of diagnosis. This includes family and friends who are **caring for someone with lymphoma**. This information also covers palliative care for people who are nearing the end of life.

Our **helpline team** are here to support you if you would like to talk about any aspect of lymphoma, including about how you're feeling.

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We have separate information about the topics in **bold font**. Please get in touch if you'd like to request copies or if you would like further information about any aspect of lymphoma. Phone 0808 808 5555 or email [information@lymphoma-action.org.uk](mailto:information@lymphoma-action.org.uk).

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## What is palliative care?

Palliative care aims to improve your quality of life by addressing needs that are **physical, practical** and **emotional**.

**Some people associate palliative care with dying. It is in fact more about living, and helps people to preserve their quality of life and psychological health in spite of cancer and its treatment.**

Dr Monnery, Palliative Care Consultant

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Many people do not realise that palliative care can be used **alongside treatment for lymphoma**. A common belief is that palliative care only applies to people who are nearing the **end of life**. However, in reality, you should be offered palliative care from diagnosis, throughout your treatment and during **follow-up**.

Many centres in the UK now offer supportive care. Palliative care is a part of this and is for anyone with lymphoma. This includes people who are having treatment that aims to get rid of their lymphoma. These services aim to improve quality of life, manage symptoms and provide psychological support throughout treatment. Many centres also provide support in managing **late effects**.

**Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.**

World Health Organization

The palliative care you are offered should suit your individual needs. It can therefore mean different things to different people.

**Palliative care can mean anything from the management of lymphoma symptoms like itch or pain, to managing treatment side effects, or simply providing a source of psychological support and helping you navigate the healthcare system and find resources to support you. You can see the palliative care team once or many times, depending on what your preferences are and you can structure the support you receive around what suits you and your family best.**

Dr Monnery, Palliative Care Consultant

You might also hear about 'enhanced supportive care'. This is an approach to help prevent and manage the physical and psychological effects of cancer and its treatment. Find out about **enhanced supportive care and its role within the holistic management of lymphoma** in our podcast with Palliative Care Consultant, Dr Dan Monnery.

Below, we outline some of the ways that palliative care can support your **physical, practical** and **overall wellbeing**.

## Physical wellbeing

Palliative care for physical wellbeing can include:

- pain relief
- symptom control
- managing side effects of treatments such as **chemotherapy**
- supporting you to maintain your independence, for example, through **physiotherapy** or **occupational therapy**.

## Practical support

Palliative care can provide practical support such as helping with:

- accessing **financial** advice and support
- helping to arrange social support or caring services
- helping to arrange assessments of your home, to arrange for equipment to be fitted, for example, a stair rail
- getting a referral to receive **hospice care**.

## Overall wellbeing

Palliative care can help:

- improve your psychological and **emotional wellbeing**
- make sense of what has happened, what is happening now, and what you might expect
- you to consider your beliefs and values, which might include in relation to a religious or spiritual faith if you have one
- support you in accessing **complementary therapies** (such as **massage**, **aromatherapy** and **visualisation**) in order to bring relaxation, lessen pain and reduce **low mood** and **anxiety**.

The NHS website gives more information about **what palliative care involves**, who provides it, and has videos on getting the most out of palliative care.

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## Accessing palliative care

**Everyone** who is affected by cancer has a right to receive high quality palliative care.

Your medical team should speak to you about how palliative care could support you in any needs that you have. If you haven't been offered palliative care, or if there is any further support you would like, ask them about it.

### Support for family and friends

Palliative care is also available to the **people who care for you**, including your family and friends. This could be, for example, support to help with **the emotional impact of lymphoma**. Sometimes, it includes pre-bereavement and post-bereavement support.

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## Palliative care at the end of life

Palliative care at the end of life is given to make your final days as comfortable as possible, so that you can live and die with dignity.

The National Institute for Health and Care Excellence (NICE) say that **palliative care should be holistic**. This means that it should address any physical, practical, psychological, spiritual and social needs you have. Your care plan should be suited to your specific needs ('individualised') and continue into the last days of your life.

The Department of Health (DoH) aims to **support people in making decisions about their care**. You can read more about the Government's commitments in their 2016 paper **Our Commitment to you for end of life care: The Government Response to the Review of Choice in End of Life Care**.

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## Who provides palliative care?

Palliative care is provided by a wide range of professionals. Your GP is also an important contact if you need help or advice and can offer referrals to other appropriate services.

The care you have depends on your individual needs and wishes. It also depends on the services available in your local area. However, the principles are the same: to help you to live and die as comfortably as possible.

## General palliative care

General palliative care is provided by healthcare professionals who are part of **your medical team**. Many people have this type of care as an outpatient. For example, you might have **steroids** or low dose **chemotherapy** to help ease **symptoms of lymphoma**. Sometimes, people have **palliative radiotherapy**, where treatment is given to a particular area where the lymphoma is causing discomfort.

### District nurses

You might have support from district nurses, who visit you in your home. They work with other people involved with your care to support you and the people who care for you at home.

They offer a range of care, which might include:

- help with taking medications
- giving advice to help manage symptoms
- changing dressings
- taking care of urinary catheters (soft tubes put into the bladder to drain urine).

## Specialist palliative care

This type of care is provided by professionals who specialise in palliative care (palliative care doctors and nurses). Specialist care is also provided through:

- **hospice staff**
- **your hospital's palliative care team**
- **palliative care nurses**
- **Marie Curie nurses**
- **palliative care social workers.**

### Hospices

Hospices support and care for people who have an illness that cannot be cured. They also support family and friends. Most hospices offer a wide range of support to help you live well throughout your lymphoma. Their services often include **complementary therapies**, art and music therapy, **counselling**, support groups and chaplaincy (faith-based support).

You are usually allocated a hospice by your GP surgery. However, teenagers and young adults might be given an option between their local adult hospice or their local children's hospice. Sometimes, they can access support through both.

Often, hospices are funded by local charities. Some hospices are registered charities. Hospice staff work closely with palliative care professionals in the NHS.

Hospice care is provided in your home or through you visiting the hospice. Hospices also provide specialist **care towards the end of life**, which could be for a period of weeks or months.

If it becomes difficult for you to do things at home, your medical team might suggest a short stay in a hospice. Many people fear this means they will not return home. However, the average length of stay in a hospice in the UK is around 2 weeks before the person goes home.

**Hospice UK** gives more information about hospices. They also have a search tool to help you **find a hospice near to you**.

## **Hospital palliative care teams**

Many hospitals in the UK have specialist palliative care teams who can provide support tailored to your needs. These teams are made up of professionals including specialist palliative care consultants, clinical nurse specialists in palliative care, physiotherapists, occupational therapists, chaplains and counsellors.

Palliative care is offered in a variety of settings: at home, in **hospices** and to hospital inpatients. You might have short periods of time in hospital to help with symptom control or to deal with a particular problem. For example, if you have lymphoma in your bone marrow, you are at risk of bleeding and infection. Hospitals are well equipped to provide any necessary medicines or **blood transfusions** at short notice, to deal with problems promptly.

## **Palliative care nurses**

Palliative care nurses are registered nurses who specialise in palliative care or cancer nursing. They have additional qualifications, for example in pain and symptom management, and in providing psychological support.

## What is a Macmillan nurse?

Macmillan nurses give information and support to people diagnosed with cancer, their family and friends. They can help you to manage symptoms and side effects, offer emotional support, and give information about financial support, social care and support groups.

Macmillan nurses work with other professionals, such as those in your lymphoma medical team, your GP and district nurses, to offer you the support you need. There are different types of Macmillan nurses: Macmillan Clinical Nurse Specialists and Macmillan Palliative care nurses. Most Macmillan nurses are employed by the NHS. Their roles are funded by **Macmillan Cancer Support** for a fixed amount of time to start with, usually for the first few years. This is where the name 'Macmillan nurses' comes from. Some clinical nurse specialists are not funded by Macmillan Cancer Support but they do the same role.

You can find out more about **Macmillan nurses** and how to get access to one on the Macmillan Cancer Support website.

**Regardless of who they are funded by, there is always access to a specialist nurse in the hospital. Similarly, there are always community nurses in your area. These are known as Community Specialist Palliative Care Nurses**

**Dr Monnery, Specialist Palliative Care Consultant**

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## Marie Curie nurses

Marie Curie nurses work in partnership with the NHS and are funded by both organisations (**Marie Curie Cancer Care** and NHS). They are registered nurses who are trained and experienced in providing one to one care for people with terminal illness in their homes. They also support family members and friends who are caring for them.

The exact offering of Marie Curie nurses depends on where you are in the UK. You can find out about Marie Curie nursing in your area through your district nurse or GP.

To be referred to the Marie Curie nursing service, you'll need a referral from your GP, district nurse or Clinical Nurse Specialist.

Find out more on the **Marie Curie website**, including about **how to get a Marie Curie nurse**.

## Palliative care social workers

Palliative care social workers are registered social workers who work alongside other professionals to support people living with a terminal illness and those close to them. Some are funded by the NHS; others are funded by adult and children's services, hospices and charities. Some palliative care social workers have additional specialist training, for example in **counselling** or bereavement support.

Palliative care social workers offer a range of practical and emotional support, either directly or through signposting and referrals. This might include practical help at home, supporting you and your family to **make decisions about your care**, offering individual or family counselling, and providing financial advice. They might also work with schools or employers to help support you.

In general, referrals to palliative care social workers are through a hospital or hospice palliative care team, although your medical team or Clinical Nurse Specialist can also refer you.

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## FAQs about palliative care

We answer some common questions people have about palliative care. Speak to your medical team for advice specific to your situation.

### How can I access palliative care?

There is a wide range of palliative care available. Speak to your GP or a member of your medical team about your palliative care needs and requests. They can support you to get the help that best suits you.

### When can I access palliative care?

Palliative care should be available to you, and those close to you, from the point of your diagnosis onwards. Some people see their palliative care team regularly throughout treatment, while other people have appointments when they need them. The type of arrangement you have is up to you. Palliative care services are available for patients with long term (chronic) conditions, so even if your lymphoma is manageable in the long term, palliative care services can still offer you support.



## Will I have to pay for palliative care?

If you receive palliative care in your home, in hospital or in a hospice, you do not have to pay for it.

However, you might need to pay for social care provided by social services. In some cases, the NHS might pay some of the charges for you through the [NHS continuing healthcare scheme](#).

If you are not eligible for NHS funding, you might qualify for a contribution towards the costs from another organisation, such as a charity. [Macmillan welfare advisors](#) can talk you through any sources of financial support that are available to you.

## Who decides if I should have palliative care?

Palliative care supports you to live your life feeling as well as possible, physically and emotionally. It is your right to choose if you'd like palliative care and, if so, in which forms. Many people choose to have some form of palliative care – even if this is just to relieve pain.

Some people choose to write a 'living will' ([advance decision to refuse treatment](#)), where you list in writing any treatments you wouldn't want in future. The purpose of this is to provide a legal record, in case you become unable to communicate your preferences when you need to. You are also entitled to set out any wider preferences about your care by making an [advance care plan](#) (though this is not a legally binding document) This can include anything that's important to you, for example, where you would like to be looked after, how you'd like to dress or what music you enjoy listening to.

## For people needing end of life care, when does this start?

People are considered to be nearing the end of their life if doctors expect that they are likely to die within the next 12 months.

End of life care can go on for days, months or over a year. The National Institute for Health and Care Excellence (NICE) have guidance on [care of dying adults in the last few days of their life](#). They also have guidance on [end of life care for infants, children and young people with life-limiting conditions](#). A key part of this is high quality palliative care.

## References

The full list of references for this page is available on our website. Alternatively, email [publications@lymphoma-action.org.uk](mailto:publications@lymphoma-action.org.uk) or call 01296 619400 if you would like a copy.

## Acknowledgements

- Dr Dan Monnery, Consultant in Palliative Medicine, The Clatterbridge Centre NHS Foundation Trust.
- We would like to thank our Helpline team and the members of our Reader Panel who gave their time to review this information.

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Content last reviewed: October 2022

Next planned review: October 2025

LYMweb0217PalliativeCare2022v3



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