

Palliative care

This information focuses on palliative care at the end of life. The aim of palliative care is to help you live as comfortably as possible. Palliative care can help to manage symptoms of lymphoma and improve your quality of life.

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What is palliative care?

Palliative care aims to enhance your quality of life. The term comes from the word 'palliative', meaning to provide relief or lessen pain.

Many people believe that palliative care only applies to those who are nearing the **end of life**. In fact, you should be offered it from diagnosis, throughout your **treatment for lymphoma** and during **follow-up**.

Palliative care should be tailored to your individual needs and can therefore mean different things to different people. It can help to address a range of needs.

Physical wellbeing

Palliative care for physical wellbeing can take the form of:

- pain relief
- symptom control
- supporting you to maintain your independence, for example through **physiotherapy** or **occupational therapy**.

Overall wellbeing

Palliative care can also address:

- your psychological and emotional wellbeing
- understanding what is happening and what to expect
- spiritual support, for example, in considering your beliefs, values and, if you have one, a religious faith
- supporting you to access **complementary therapies** (such as massage, aromatherapy and visualisation) to aid relaxation, lessen pain and reduce depression and anxiety.

Practical support

Palliative care can provide practical support in:

- accessing financial advice and support
- getting a referral to a hospice.

It is your right to receive good palliative care. Speak to your medical team about it if you haven't been offered it.

Palliative care is also available to the **people who care for you**, including your family and friends. This might be in the form of respite care (taking a short break from caring responsibilities). Sometimes, it includes pre-bereavement and post-bereavement support.

The NHS website gives more information about **what palliative care involves**, including videos on getting the most out of palliative care.

Palliative care at the end of life

At the end of life, palliative care 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 'individualised' (suited to your specific needs) and continue into the last days of your life.

Adults in the last days of life, and the people important to them, should be given opportunities to discuss, develop and review an individualised care plan.

National Institute for Health and Care Excellent (NICE), 2017

The Department of Health (DoH) aims to **support people in making decisions about their care**. They've pledged to end the variation in end of life care by 2020.

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*. Their 2017 publication, *One Year On: The Government Response to the Review of Choice in End of Life Care*, provides a review of progress and outlines ongoing efforts to improve end of life care for all.

Who provides palliative care?

Palliative care is provided by a wide range of professionals. The care you have depends on your individual needs and wishes. It also depends on the services available in your local area.

Regardless of who provides your care, the principles are the same: to help you to live and die as comfortably and peacefully as possible.

Many people have palliative care provided by their medical team and nursing teams. They might provide palliative care for you as an outpatient. For example, you may have **steroids** or low dose **chemotherapy** to help ease any **symptoms of lymphoma**. Sometimes, people have **radiotherapy** to a particular area where the lymphoma is causing discomfort.

Your GP is also an important contact if you need help or advice and can offer referrals to other appropriate services.

If you need more specialist palliative care, this can be provided by:

- community nurses
- a hospice
- your hospital's palliative care team
- palliative care nurses
- Marie Curie nurses
- palliative care social workers.

Community nurses

Community nurses visit you in your 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).

Community nurses often work with other people involved with your care to support you and the people who care for you at home.

Hospices

Hospices support and care for people who have a progressive and incurable disease and their loved ones. They are often funded by local charities. Hospice staff work closely with palliative care professionals in the NHS.

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**, chaplaincy and support groups.

A lot of hospice care is provided in your home or through visits to the hospice. Hospices also provide specialist care towards the end of life, which may 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, although some people do choose to die in a hospice, the average length of stay in a hospice in the UK is around 2 weeks. The person then returns 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. These teams are made up of professionals including consultants, specialist nurses, occupational therapists, chaplains and counsellors. The team assess your needs while you are in hospital and offer support to help make you as comfortable as possible.

Some hospitals provide palliative care at home. You might, though, still need to spend 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, both of which can require prompt medical attention. Hospitals are well equipped to provide any necessary medicines or blood transfusions at short notice.

Palliative care nurses

Palliative care nurses are experienced, 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.

You might have heard of 'Macmillan nurses'. There are different types of Macmillan nurses, for example Macmillan chemotherapy nurses and Macmillan palliative care nurses. Despite their title, 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 why they're called 'Macmillan nurses'. Some clinical nurse specialists do the same role but are not funded by Macmillan Cancer Support.

Macmillan nurses offer advice and support to people with cancer, their family and friends. This can include offering symptom and pain control, emotional support and information. Macmillan nurses work in the community (where they can visit you at home), in hospitals and hospices. They work with other professionals, such as those in your lymphoma medical team, your GP and district nurses, to offer you the support you need.

To receive support from a Macmillan palliative care nurse, you'll need a referral by your GP, your consultant, a district nurse or a hospital ward sister. If there isn't a Macmillan nurse available in your local area, you can be referred to a similar, alternative service.

Marie Curie nurses

Marie Curie nurses are funded by the charity [Marie Curie Cancer Care](#) and by the NHS. They are registered nurses who are trained and experienced in looking after people with terminal illness in their homes. They also support family members and friends who are caring for them. In some areas of the UK, Marie Curie nurses offer additional services. An example of this is staying overnight, usually for around 8 to 9 hours, in order to allow carers to get some rest.

The exact services offered depends on the needs set out by a particular local NHS. 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 specialist 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.

Palliative care social workers offer a range of practical and emotional support. This might include help at home, supporting you and your family to make decisions about your care, and providing financial advice. They might also signpost you to other services that could help you. Some palliative care social workers have additional specialist training, for example in counselling or bereavement support. In general, referrals to palliative care social workers are through a hospital or hospice.

FAQs about palliative care at the end of life

How can I access palliative care?

Speak to your GP or district nurse about your palliative care needs and requests. They can support you to get the help that best suits you.

Will I have to pay for palliative care?

Specialist palliative care is provided free of charge in your home, in hospital and in hospices.

Charges might apply if your care is provided by social services. If your care needs are primarily the result of a long-term, complex health condition, the NHS might pay the charges for you in a scheme called 'continuing care'. You can read more about the [NHS continuing care scheme](#) on the NHS website.

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

Do I have to have palliative care?

Palliative care supports you to live your life feeling as well as possible, physically and emotionally. It's your right to choose if you'd like palliative care and, if so, in which forms.

Generally, people prefer to have some form of palliative care, even if this is just to help ease their pain.

Some people choose to write an **advance decision** ('living will'). This allows you to write down treatments you would or wouldn't want in future, 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 statement**. This can include anything that's important to you, for example, how you'd like to dress or what music you enjoy listening to.

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.

References

The full list of references for this page is available on our website. Alternatively, email publications@lymphoma-action.org.uk or call 01296 619409 if you would like a copy.

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✓	Evidence-based
✓	Approved by experts
✓	Reviewed by users

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