

# Lymphoma and palliative care

Although palliative care does not treat your lymphoma, it helps you to live as comfortably as possible when you have cancer. This information page focuses on palliative care at the end of life and, as a result, you may find this content distressing.

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## What is palliative care?

Palliative care is a medical speciality, which aims to enhance your quality of life. To 'palliate' means to provide relief or lessen suffering. Many people believe that this type of care is given only at the **end of life**. In fact, it should be offered from diagnosis, throughout your **treatment** and during **follow-up**.

At the end of life, palliative care is given to make your final days as comfortable as possible, so 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 it should consider you as a

whole person; as well as addressing your physical needs, it should take into account any practical, psychological, spiritual and social needs you have. Your **medical team** should regularly discuss your needs and wishes with you to find out how they can best support you.

Palliative care may assist with:

- pain relief and symptom control
- explaining what is happening and what to expect
- psychological and emotional support with your feelings
- spiritual support, eg in considering your beliefs, values and, if you have one, your religious faith
- complementary therapies (eg massage, aromatherapy and visualisation) to aid relaxation, lessen pain and lower depression and anxiety
- guidance on financial support
- support to help you maintain your independence (eg through physiotherapy or occupational therapy)
- referral to a hospice.

Palliative care is also available to the people who care for you, including family and friends. This might be in the form of respite care. It may also include pre- and post- bereavement support to help them cope.

The Department of Health (DoH) aims to support people in making decisions about their care and to end the variation in end of life care by 2020. They have recently published 6 key commitments, to:

- offer opportunities for honest discussions
- enable people to make informed decisions about their care
- provide personalised care plans for all
- allow discussion of personalised care plans
- involve family members and carers
- provide a main contact for people at the end of life, available night and day.

You can read more about the DoH's commitments in their paper [Our commitment to you for end of life care](#).

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## 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 as comfortably, enjoyably and peacefully as possible. **Receiving good palliative care is your right.**

Many people have palliative care provided by their medical team and nursing teams. For other people, it is provided by their GP and community nurses. Please ask your medical team about palliative care if you haven't been offered it.

Specialist palliative care, if needed, can be provided by:

- a hospice
- your hospital's palliative care team
- community palliative care teams
- Macmillan nurses
- Marie Curie nurse specialists.

## GP and community nurses

Your GP is an important contact if you need help or advice. He or she can refer you to other services as appropriate.

Community nurses visit you in your home. They offer nursing care, which might include help with medications, dressings and care of urinary catheters (soft tubes put into the bladder to drain urine). They also work with other people involved with your care.

# Hospices

Hospices provide care for people who have a progressive and incurable disease. They work closely with palliative care professionals in the NHS.

Most hospices offer a wide range of support to help you live well throughout the course of your illness. Examples of services include complementary therapies, art therapy, counselling, chaplaincy and support groups.

Hospices also provide specialist care towards the end of life, which may be for a period of some months or weeks. Some hospices provide day care and care at home. 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 that this means they will not return home; this is not the case. 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 before the person returns home.

[Hospice UK](#) have more information about hospices.

## 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. They offer support to help make you as comfortable as possible.

Palliative care can also be provided by your usual lymphoma medical team. They might provide palliative care for you as an outpatient. For example, you may have **steroids**, or low dose **chemotherapy**, to help minimise any **symptoms of lymphoma**. Sometimes, people have **radiotherapy** to a particular area where the disease is causing discomfort.

Some hospitals provide palliative care at home. You may still need to spend short periods of time in hospital, though, 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 make you ill very quickly. Hospitals are well equipped to provide any necessary medicines or blood transfusions at short notice.

## Macmillan nurses

Macmillan nurses are experienced, registered nurses who specialise in palliative care or cancer nursing. They have additional qualifications, including in pain and symptom management, and in providing psychological support. Despite their title, most are employed by the NHS. Their jobs are initially funded (usually for the first few years) by **Macmillan Cancer Support**, hence the name 'Macmillan nurse' (there are Clinical Nurse Specialists who do the same role but are not funded by Macmillan).

Macmillan nurses offer advice and support to people with advanced progressive illness, their family and friends. As well as helping with symptom and pain control, they also offer emotional support and information. Macmillan nurses work in a range of settings, including hospitals, hospices and in the community, where they can visit you at home. They also work with other professionals, such as your lymphoma medical team, your GP and district nurses.

You need to have a referral to a Macmillan nurse by your GP, your consultant, a district nurse or a hospital ward Sister. If there isn't a Macmillan nurse team in your local area, you can be referred to a similar 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. Sometimes Marie Curie nurses stay overnight in order to allow the carers to rest.

To be referred to the Marie Curie nursing service, you need a referral from your GP, district nurse or specialist nurse.

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# Do I have to pay for palliative care?

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

If your care is provided by social services, charges may apply. In such a case, you may be entitled to help towards the costs. [Macmillan welfare advisors](#) can talk you through any sources of financial support that are available to you. If your care needs are primarily the result of your health problems, the NHS may pay the charges on your behalf in a scheme known as 'continuing care'.

You can read more about NHS continuing care on [NHS Choices](#).

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## Do I have to have palliative care?

Palliative care supports you to live your life feeling as well as possible, both physically and mentally. You can't be forced to have palliative care against your will. Most of the time, however, people prefer to have some form of palliative care, even if this is just to help control their pain.

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## Further information and support

We have listed a few national organisations that you might find useful if you, or a loved one, are reaching the end of life. You may also wish to use our online forums to get in touch with others affected by lymphoma. Your nurse specialist is a good person to ask about any local organisations that may be useful to you. You can also call our helpline on 0808 808 5555 for support or if you wish to talk through any aspect of lymphoma.

[Carers UK](#) offer support, advice and information for anyone who is caring for someone with an illness or disability.

[Dying Matters](#) is a coalition of members across the UK that aims to help people talk openly about dying, death and bereavement, and to make plans for the end of life. They have a range of resources on their website.

[Hospice UK](#) is a national charity that supports the work of hospices across the UK. Their website includes an [online search tool](#) to help you find a

hospice near to you.

**Macmillan Cancer Support** offer a range of information and support, including to help **support you at the end of life**.

**Maggie's Centres** provide practical, emotional and social support for people with cancer and their families and friends. They have a number of **centres across the UK** as well as an online community.

**Marie Curie Cancer Care** support people with a terminal illness and those close to them. Their website includes an **online directory of support** to help you find appropriate support.

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## References

These are a few of the sources we used to prepare this information. The full list of sources is available on request. Please contact us by email at [publications@lymphoma-action.org.uk](mailto:publications@lymphoma-action.org.uk) or phone on 01296 619409 if you would like a copy.

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# Further reading

- [Glossary](#)
- [Your medical team](#)

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## Acknowledgements

- We would like to thank the Expert Reviewers and members of our Reader Panel who gave their time to review this information.
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Content last reviewed: September 2016

Updated: April 2018

Next planned review: September 2019



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