



Leeds Palliative
Care Network



End of life care and support in Leeds

A guide for
patients
and carers



We can make this information available in Braille, large print, audio or other languages on request.

Introduction

If you're living with a life limiting illness, good care and support is an important part of getting the most from your life. This leaflet provides information about the different services that are available in Leeds, what care might look like for you and what you can expect. You can also find more information on our website at www.leedspalliativecare.org.uk

What is palliative care?

If you have been told that your health might not improve or you have a life limiting illness, you may be offered palliative care. The aim of palliative care is to maximise a person's quality of life by treating and relieving the symptoms and side effects of their illness, along with providing emotional and practical support for the patient, their family and/or carers. Palliative care is individualised to a person's needs, care preferences and what matters to them.

What is end of life care?

End of life care is the care provided for people who are approaching the end of their life, to help people live as well as possible and to die with dignity. For some people end of life care could be the last year of life and for others the last days, weeks or months. This can be difficult to predict as it depends on each individual and their condition.

Who provides palliative and end of life care?

The professionals involved in your care will depend on:

- Your medical condition
- What sort of care and support you need
- Where you are receiving the care and support
- Your current needs and wishes.

What can you expect from palliative care?

Palliative care should be:

- Based on a clear plan of care that's been agreed with you (this will be made with the professionals involved in your care and should be reviewed regularly).
- Kind and compassionate.
- High quality and safe.
- Considerate of all of your needs as a person.
- Based on what you need and what you want as an individual.
- Based on honest and timely communication.
- Provided in the place of your choice where possible.
- Designed to help you stay as independent as possible.
- Accessible, so you get the right care whenever you need it, day or night.

Talking to health professionals

It's important that you feel able to talk about your wishes and concerns with your healthcare team. Having open, honest conversations can help you get the best care. Think about what you want to say, and how you want to say it before the conversation.

Making decisions about your future care

If you're living with a life limiting illness, you may want to think about your future care and what is important to you. If you'd



like information about how your condition may progress – to help you think about this – please speak to your healthcare team.

You might want to think about such things as the place where you'd like to be cared for. For example, being near family or friends and being in familiar surroundings might be important to you, as well as being free from pain or discomfort. It may not always be possible to provide the care you need in the place that you would like.

Depending on your illness, your healthcare team may suggest different options, such as staying in your own home or moving to a care home or a family member or friend's home. They may also suggest staying in hospital or a hospice.

Some people change their mind about where and how they'd like to be cared for if their needs change. For example, you might want to be cared for at home, but then decide you would be more comfortable in a hospice. If you change your mind, or want to discuss this again, let your healthcare team know. They'll do their best to support you.

ReSPECT / Advance Care Planning

As part of planning for your future care, your healthcare team may talk to you about a ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) plan. The purpose of a ReSPECT plan is to outline the agreed care and treatment recommendations for you should you be unable to communicate or make decisions for yourself. Having this plan in place helps ensure that you will receive the appropriate care and treatment that has been discussed and recommended for you, including recommendations



ReSPECT
Recommended Summary Plan
for Emergency Care and Treatment

ReSPECT and You: Planning Together
Information for patients, families of patients
and members of the public

Version 2.0

What is ReSPECT?
ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment. ReSPECT is a PROCESS and a PLAN. It creates a personalised recommendation for your clinical care in emergency situations where you are not able to make decisions or express what matters to you.



How does it work?
The process consists of conversations between you and your healthcare professionals. These conversations produce recommendations about the types of care and treatment for which you would or would not want to be considered in an emergency. The plan is completed when you and your healthcare professionals are clear about what needs to be recorded. The aim of the process and its plan is to provide a summary of personalised recommendations to ensure you will receive the best possible treatment for your individual situation. This plan, stays with you and should be available immediately to healthcare professionals called to help you in an emergency, whether you are at home or being cared for elsewhere. Professionals such as ambulance clinicians, out-of-hours doctors, care home staff and hospital staff will be better able to make quick decisions about how best to help you in an emergency if they can see your ReSPECT plan.

Who makes the decisions?
If you and your health professional have agreed a plan, it will be used to guide your emergency care and treatment. If you haven't, decisions will be made by health care professionals trying to act in your best interests and for your benefit. It is important to understand that the ReSPECT plan cannot be used to demand treatments that are not likely to benefit you and would not be offered.



about CPR (cardiopulmonary resuscitation). The ReSPECT Plan can be reviewed and updated if any changes are required. More information can be found at www.leedspalliativecare.org.uk/helping-you/planning-future-care

If you're not able to make decisions

The ability to make a decision is called 'mental capacity'. If you lose mental capacity, other people can make decisions for you. There is legal guidance that must be followed to make sure they act in your best interests. If you are not able to make decisions for yourself, you may wish to name someone who should be involved in discussions about your care or appoint a Lasting Power of Attorney for your Health and Welfare. More information about the different options available can be found here: https://www.nhs.uk/livewell/endoflifecare/documents/planning_your_future_care%5B1%5D.PDF

Who will pay for my care?

You may need to have a needs assessment to find out what support can be offered. You can:

- Contact Leeds adult social care to arrange: <https://www.leeds.gov.uk/adult-social-care>
- Ask your healthcare team for guidance.

The assessment can also cover adjustments to your home to make things easier for you. For example, you may need grab rails or an adapted shower.

Leeds City Council Welfare Rights team may also be able to provide advice and support and answer queries. Call **0113 376 0452** or visit: <https://www.leeds.gov.uk/benefits/welfare-rights>

If someone is living with a life limiting illness and is thought to be approaching the end of their life a doctor may complete an SR1 medical report form. An SR1 form can be used to apply for a number of benefits under what are known as special rules. For further

information visit: <https://www.gov.uk/government/publications/dwp-factual-medical-reports-guidance-for-healthcare-professionals/the-special-rules-how-the-benefit-system-supports-people-nearing-the-end-of-life>

You may also be entitled to a **Personal Independence Payment (PIP)**. For more information visit <https://www.gov.uk/pip/claiming-if-you-might-have-12-months-or-less-to-live>

How much does personal and social care cost?

Whether you pay some of the cost depends on what services are available in your area. It can also depend on how much money or savings you have. Your needs assessment will determine how much you need to contribute to your care.

Depending on your needs you may qualify for NHS Continuing Healthcare.

NHS Continuing Healthcare

NHS continuing healthcare is free healthcare provided by the NHS to individuals who have significant healthcare needs. Those eligible for NHS Continuing Healthcare will not require a financial assessment and no contribution is needed to meet assessed needs. If professionals agree you are approaching the end of your life and your condition is rapidly deteriorating, a Continuing Healthcare 'Fast Track' referral may be completed.

Leeds Health Case Management Service will support you with accessing the care you need. NHS continuing healthcare can be provided in a variety of settings outside hospital, such as in your own home or in a care home.

To be eligible for NHS continuing healthcare, you must be over 18, have a Leeds GP and be assessed by a team of healthcare professionals. You should be fully involved in the assessment process and have your views about your needs and support taken into

account. Carers and family members should also be consulted where appropriate to understand how they can help and support you. Your doctor or nurse can help you with the application process.

Leeds Health Case Management Service explores how services can be personalised to you, promoting individual choice and individual control to suit your needs. They can also provide advice and guidance on other care packages such as community packages and independent home care providers.



Help for people important to you

It's part of palliative care to support the person's loved ones. They may ask the people important to you how they're coping. They may also explain what support is available, now and in the future.

Support for carers

If you have a partner, friend or family member who is looking after you, they can get a carer's assessment. They will be given information about local services for carers including benefits, respite care (to care for you while they have a break from caring) and support groups.



At the assessment, the professional will ask questions to find out what effect caring is having on the person's health and wellbeing. If the assessment finds they need support, the council or trust will

provide it. For example, they might give the person training in how to provide care, or provide help with housework and transport.

More information can be found at www.carersleeds.org.uk

What will my care look like?

Health and care providers in Leeds are working together in partnership to make sure your care is well co-ordinated and meets your needs. Your care may include:

Care provided by your General Practitioner (GP) and GP Practice

As your care needs change over time, your GP is often your first port of call to discuss your wishes for your future care. Your GP can co-ordinate your care needs and ensure you access the services you may need. They will work closely with other care providers to ensure flexible and continuous support for you and your carers. Your GP along with others in your care team will help with discussing your advance care planning wishes with you and your family and help with symptoms, practical, emotional and spiritual support.

Community Pharmacists

Pharmacists are based in the community and can support you by giving out (dispensing) prescribed medication, answering any medication queries and working with the rest of your care team to help you get the right support.

Care provided in your home

Being cared for at home is an option that many people choose. The level of support people need often changes over time and the support provided can vary and be reviewed.

Palliative and end of life care is provided to people in their homes by Leeds Community Healthcare's Neighbourhood Services, over a 24 hour period depending on people's level

of need. The healthcare team works closely together and may include GPs, Specialist Palliative Care Teams, community nurse specialists, Health Case Managers and care agencies.

If Leeds Community Healthcare Neighbourhood Services are involved in caring for you at home you will be given numbers to call our Neighbourhood Hubs or Neighbourhood Night Service if you need support. Keep these to hand and share them with people close to you if needed. If contacted a clinician in our Hub or Night Service can provide advice, signpost to another service or request a visit. If a visit is needed, a decision is made on the level or urgency and priority. Neighbourhood services do not provide emergency care, however, they will prioritise urgent care visits such as those for symptom relief.



Care provided in your care home

If you are living in a residential care home the support and services involved in providing palliative and end of life care are similar to if you were living at home.

If living in a care home with nursing support is provided by registered nurses within the care home.

In both types of care home the healthcare team works closely together.

Care provided in hospital

The Leeds Teaching Hospitals NHS Trust have staff trained to deliver palliative and end of life care across all wards. The Hospital Adult Specialist Palliative Care



Team provides a seven day a week service, to support the care of patients in Leeds General Infirmary, St James's University Hospital and Chapel Allerton Hospital. The team includes specialist doctors and nurses that can help with complex physical symptoms as well as psychological, social and/or spiritual needs.

In order to access the service you will need to be referred by your Doctor on the ward. Please speak to them for more information or visit: www.leedsth.nhs.uk/a-z-of-services/palliative-care/

Care provided in a hospice

A hospice is a specialist centre that cares for people with a life limiting illness and their families in a welcoming, comfortable environment. They are staffed by specialist healthcare professionals including nurses, doctors and therapists as well as people who can support you and your family and friends. They are often run by charities and other organisations and you

do not have to pay to stay there.



There are two hospices in Leeds, St Gemma's in Moortown covering the East of the City and Sue Ryder Wheatfields in Headingley, covering the West of the City.

Both Leeds' hospices provide palliative and end of life care for local people with life limiting illnesses. They specialise in symptom control to help people live as well as possible for as long as possible.

Care is offered to patients and their carers in a variety of settings: in the Hospice's In-Patient Unit, in your own home supported by our hospice Community Teams and via Out-Patients facilities. Each GP practice and Neighbourhood Team, if involved, is linked to a hospice community team and staff work closely together to care for patients.

A wide range of support services are also available including physiotherapy, occupational therapy, complementary therapies and bereavement support. Bereavement support for children and young people is available at St Gemma's hospice only.

The hospices welcome and provide care to everyone regardless of people's age, gender, disability, race, religion or sexual orientation. For more information visit:

www.st-gemma.co.uk

www.sueryder.org

Support services

Yorkshire Ambulance Service

The Leeds Palliative Care Ambulance Service is operated by the Yorkshire Ambulance Service NHS Trust. The ambulance is used to transport

patients with palliative care needs in Leeds, seven days a week between 9:00am and 7:00pm, including weekends and bank holidays. The ambulance has been designed for comfort and relaxation, with space for friends and family to travel with you.



Bereavement Services

There are a range of services available in Leeds to support people through bereavement. More information can be found on our website at:

www.leedspalliativecare.org.uk/helping-you/bereavement-support

Help us get it right

If you have a complaint, concern, comment or compliment about the care you are receiving, you can share your feedback using the contact details below or speak to the healthcare professional providing your care.

Leeds Community Healthcare NHS Trust

Tel: 0113 220 8585 Email: Ich.pet@nhs.net

GP Practice

You can contact the Practice Manager or contact NHS England on:

Tel: 0300 3 11 22 33 Email: england.contactus@nhs.net

Care Home

You can contact the Care Home Manager or Leeds City Council if the care home is funded by them.

Tel: 0113 222 4405 Email: complaints@leeds.gov.uk

Yorkshire Ambulance Service

Phone: 0333 130 0549 Email: yas.patientrelations@nhs.net

Leeds Teaching Hospitals NHS Trust

Phone: 0113 206 6261

Textphone: 07468 753 025 (if you are D/deaf or speech impaired)

Email: patientexperience.leadsth@nhs.net

St Gemma's Hospice

Phone: 0113 218 5500 Email: postmaster@st-gemma.co.uk

Sue Ryder Wheatfields Hospice

Phone: 0113 278 7249 Email: wheatfields@sueryder.org

www.leedscommunityhealthcare.nhs.uk