



Palliative and End of Life Care

**Information for Patients
and Carers in Leeds**

www.leedspalliativecare.org.uk

Produced by



Leeds Palliative
Care Network

What is palliative care?

If you have been told your health may not improve or you have a life limiting illness, you may be offered palliative care. The healthcare professionals caring for you will offer to talk to you (and anyone else you would like to be involved) about what this means for you.

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, combined with supporting them and their family / carer practically and emotionally.

Professionals involved in your care may therefore ask about how you wish to be supported, what is important to you, where you might want to be cared for in the future and even types of care or treatment you might want to avoid.

Ideally these conversations happen when you are well, so that should you become unwell your care team is aware of any wishes you may have. Palliative care does not mean you won't be offered any treatment or care. Many patients receive palliative care for many months or years.

What is end of life care?

You may hear the term end of life care. This is care for people who are considered to be in the last year of life and to help people live as well as possible and to die with dignity. The last year of life can be difficult to predict as it will depend on the person and their underlying condition.



Who will look after me and talk to me about my care?

This will vary depending on your medical condition, current needs and what you want but typically may be your:

- GP
- Community nurse e.g. district nurse or community matron from your neighbourhood team
- Specialist nurse or doctor
- Social worker or Health Case Manager
- Carer
- Hospital team.

Your care team (i.e. the individuals listed left) want to support you and involve you in decisions wherever you are being cared for. With your involvement, they will record information about you in your healthcare record; including any wishes you may have about your future care. The person talking to you will be someone you know, like your GP or community nurse. If there are any aspects of your care you do not wish to discuss this will be respected. Should your wishes change at any time your records will be updated accordingly.

How will information about my palliative care be shared?

Where possible information recorded within your healthcare record is shared electronically with your care team. This enables your care team to make decisions with you at any time of day or night, especially when this information can be accessed by your GP, community nurses, palliative care nurse specialists and out-of-hours doctors. In future we hope all your care team, including hospital staff and social workers, will be able to view this information.

There are a number of additional ways you can make your wishes known, or nominate someone to speak on your behalf. Your care team can provide more information about the different options available to you and how information about you is shared.



What sort of information could be shared and how will it be recorded?

Information about your care is held in a clear, accessible format in your electronic patient record. You can request access to these electronic records. Depending who is involved in your care there may be some paper records in your home. Your care team will discuss with you whether you would like a written record of your wishes available, for example a ReSPECT form.

Typically, the information shared about you may include:

- who is involved in your care
- who you wish to speak for you if at any time you are unable to make decisions for yourself
- information about your medication and condition
- where you want to be cared for
- preferences or decisions you have made about your care, including resuscitation
- treatment plans about care you might require, should you become unwell.

Your patient record is confidential and only accessible to professionals involved in your care. Information about your care preferences can be updated should you change your mind.

What is ReSPECT?

ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment. The ReSPECT process creates a personalised recommendation for your clinical care in emergency situations where you are not able to make decisions or express your wishes.



What are the benefits of talking about my palliative care?

By giving you the opportunity to discuss your future care, it will be more co-ordinated and likely to reflect what you want should you become unwell and unable to make decisions for yourself.

If you do want to talk about your future care, it is important to have these conversations when you are well enough and to involve your relatives or carers if you wish to.

What are the disadvantages of talking about my palliative care?

In order to record and share your wishes, you will need to talk about your illness and wishes about your future care. This discussion may be sensitive, it can be difficult to know when the right time is and some of the questions asked may feel difficult to answer. You

may not want to talk about your illness or find it difficult to start a conversation about your future care. If you would prefer not to discuss your care this will be respected.



The following pages contain information on some of the palliative care services provided in Leeds



Services in Leeds

General Practitioner (GP)

As your care needs change over time, your GP may be your first port of call to discuss your wishes for your future care.

Your GP can help with discussing your advance care planning wishes with you and your family and help with symptoms, practical, emotional and spiritual support. Your GP is perfectly placed to co-ordinate your care needs working closely with the Neighbourhood Team community nurses and hospice team to ensure flexible and continuous support for you and your carers.

The level of care provided by Neighbourhood Teams can range from one visit per week, to one or more visits per day, plus support at night at the end of life. This all depends on a patient's individual needs.

Palliative and end of life care is provided by Leeds Community HealthCare's (LCH's) thirteen Neighbourhood Teams and Neighbourhood Night Service, working closely with GPs, Specialist Palliative Care Teams, community nurse specialists and Health Case Managers.

Our aim is to ensure that people's wishes are met and they can be cared for in their preferred place of care wherever possible. Our services providing palliative care include the following:

LCH Neighbourhood Teams

provide community nursing and therapy services to support people in their homes and care homes without nursing, over 24 hours a day 7 days per week. Neighbourhood Palliative Care Leads are senior nurses experienced in community nursing and palliative care and provide palliative care expertise within Neighbourhood Teams to support staff and patients.

LCH Neighbourhood Night Service

operates from 9.30pm – 7am, seven days per week to prevent unnecessary hospital admissions and to support patients with palliative care needs in their own homes.

LCH Palliative Care Discharge Facilitators

support the discharge of patients approaching the end of life whose wish it is to be cared for in their home or care home. These senior nurses work with hospital, hospice and community services to ensure a seamless transfer of care for patients between services.

LCH Palliative Care Facilitators for Care Homes

support staff within care homes with nursing. The team provides training and education and can offer clinical support where needed.

Leeds Health Case Management Service

Health Case Management Service provides case management for people aged 18 and over who are eligible for NHS Fast Track and Continuing Healthcare Funding and have a Leeds GP.

The service is available to people in hospital, a community bed or their own home needing support in arranging care to meet their complex needs. The Health Case Management team consists of Health Case Managers, Coordinators and Assistants who will assess a person's needs with their involvement, respecting their wishes and views. The team explores how services can be as personalised as possible, promoting individual choice and individual control to suit your needs.



The Hospital Specialist Palliative Care Team (HSPCT) offers assessment and advice on the management of complex physical symptoms, psychological, social and spiritual issues.

This service is available for patients with any advanced, progressive and life limiting disease. The team includes palliative medicine consultants and doctors, clinical nurse specialists and a pharmacist. We link closely with colleagues in clinical psychology, social work, chaplaincy, bereavement services and chronic pain management.

What we do

The HSPCT provides a service seven days a week to patients at all acute hospital sites across Leeds (Leeds General Infirmary, St James's University Hospital, Chapel Allerton and Wharfedale Hospitals). We work with the ward doctors and nurses to improve physical comfort (such as treatment for pain or sickness) and to help with any emotional, social or spiritual concerns you may have. We can support you through decisions about future treatment or place of care and offer a prompt referral to other professionals who will continue care in hospital, home, care home or a hospice if required.



How do patients and carers access the service?

You need to be referred by a member of the team on the ward where you are having treatment. If you feel palliative care services could help you please discuss with the doctors or nurses looking after you on the ward.



St Gemma's is a local, independent charity based in Moortown, Leeds, and is one of the leading hospices in the UK.

The Hospice provides the best possible care and quality of life for local people living with terminal illnesses. St Gemma's specialise in pain relief and symptom control to help people live as well as possible for as long as possible. This is known as palliative care.

The Hospice offers a wide range of expert services to support patients, their families and friends – not just in the Hospice building but also in homes, including nursing homes, across the Leeds community. Services include:

A 32 bed In-Patient Unit which provides specialist palliative and end of life care to hundreds of local people each year. Patients benefit from round-the-clock care, tailored to their individual needs and wishes.

St Gemma's Day Services, based at the Hospice, offers nursing and medical support and a range of daily clinics to people who need our care and expertise, but not as an In-Patient.

Most patients prefer to stay at home during their illness. So the St Gemma's Community Nurse Specialists, supported by doctors and the wider Hospice team, work with patients and their families to make this possible.

Patients' families and carers are also supported by the St Gemma's team. This includes bereavement workers who provide support to all, including children and young people.

St Gemma's Hospice welcomes and provides care for people from all faiths and those with no faith or religion. The staff focus care around the needs of the individual and are respectful of all beliefs, religions and cultures.

All our services are provided completely free of charge, thanks to the support of our local communities. For more information about St Gemma's Hospice please visit: www.st-gemma.co.uk



Located in Headingley, Leeds, Wheatfields Hospice is a Sue Ryder Hospice providing specialist palliative and end of life care every year to hundreds of people.

Sue Ryder Wheatfields Hospice is here for people aged 18 and over who have been diagnosed with a life-limiting condition be it cancer or a non-cancer.

Our focus is on quality of life – giving every patient the care and support they need to spend the time they have left in the way they choose.

We have respect for all beliefs, religions and cultures and tailor your care accordingly. We can offer a range of care services to support you and your loved ones whilst you are in our care:



- An 18 bedded in-patient unit which provides 24 hour expert care, 365 days a year
- Access to a variety of therapies such as physiotherapy, complementary therapies and occupational therapies
- Our Family Support Team provides practical as well as emotional support for you and those close to you, including children. This includes issues such as money concerns, social benefits, accessing equipment and services
- Our Community Nurse Specialist Team works closely with patients' GPs, families and community teams to ensure patients receive expert personalised care in their own home
- Our Day Therapy Service allows individuals access to care and support they need while continuing to live at home. This includes medical and nursing care, rehabilitation, creative therapies and complementary therapies.

We are a charity and all the services provided are completely free to patients and their loved ones, thanks to the generosity of our supporters. For more information about Sue Ryder Wheatfields Hospice please visit www.suerydercare.org

Carers Leeds is an independent charity that gives support, advice and information to unpaid carers aged 16 and over. Established in 1996, our team of expert support workers are dedicated to improving the lives of the 72,000 carers in Leeds.

A carer is someone who, without payment, provides help and support to a parent, partner, child, relative, friend or neighbour who could not manage without their help. This could be due to age, physical or mental health issues, substance misuse or disability.

We deliver confidential one to one and group support that helps carers keep on caring. We are based in the centre of Leeds, and also offer support in local communities, over the phone and online.

Carers Leeds works in partnership with community groups, local businesses and third sector organisations to give carers in Leeds a network of support that covers general and specialist carers issues.

For more details about our support and the specialist areas we cover, visit our website at www.carersleeds.org.uk or phone the advice line on 0113 380 4300

The 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. It aims to assist co-ordination between the different areas of the health service to enable you to be cared for and die in the place of your choice.

The ambulance is used seven days a week between 9am and 7pm, including weekends and bank holidays. The ambulance staff have all received additional training in caring for patients with palliative care needs.

The ambulance has been designed for comfort and relaxation, with the aim of reducing its 'clinical' look. There is also space for friends and family to travel with you.



Leeds Palliative Care Website

Your one-stop, online hub for palliative and end of life care services across Leeds:

www.leedspalliativecare.org.uk

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

Produced in partnership with Leeds Community Healthcare NHS Trust, The Leeds Teaching Hospitals NHS Trust, St Gemma's Hospice & Sue Ryder Wheatfields Hospice.