

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 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.



## Useful websites

**Leeds Palliative Care**  
[www.leedspalliativecare.co.uk](http://www.leedspalliativecare.co.uk)

**Carers Leeds**  
[www.carersleeds.org.uk](http://www.carersleeds.org.uk)

**NHS**  
[www.nhs.uk](http://www.nhs.uk)

### Help us get it right

If you have a complaint, concern, comment or compliment please let us know by speaking to a member of our staff.

We learn from your feedback and use the information to improve and develop our services.

If you would like to talk to someone outside the service contact the **Patient Experience Team** on **0113 220 8585**, Monday to Friday 9.30am to 4.30pm or email [lch.pet@nhs.net](mailto:lch.pet@nhs.net)

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

# Palliative Care



**Information for patients and carers**



## 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.

## 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 above) want to support you and involve you in decisions wherever you are being cared for. To do this (and with your consent) they will share information about you, 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?

With your consent and where possible information recorded within your healthcare record is shared electronically. 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.

## 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. You may also wish to keep a written record of any wishes you have and keep it with you.

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