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Yorkshire Partnership**  
NHS Foundation Trust

A large circular graphic composed of many small, rectangular segments in various shades of blue and white, arranged in a pattern that resembles a woven basket or a decorative border. The segments are arranged in concentric circles, with the innermost circle being white and the outer rings being blue and white.

# **Palliative Care: Supporting Living and Dying Well**

With **all of us** in mind.

## What will we cover?

- A brief explanation of palliative care
- Supporting people to live well
- Conversations about dying
- A few cultural considerations
- Putting people at the center of their care

## Introductions

### Admiral Nurses

Registered nurses who have specialist knowledge of dementia care

Provide support to family carers and people living with dementia throughout the trajectory of dementia, particularly during complex periods of transition

Provide education, leadership, development and support to other colleagues and service providers





# What is Palliative Care?



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*“An approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-limiting illness, usually progressive. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems whether physical, psychosocial or spiritual”*

*World Health Organisation*

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# PALLIATIVE CARE ?



Palliative Care is a gentle & distinct approach to caring for people with illnesses that can't be cured (like advanced heart, lung, kidney and neurological diseases, and advanced cancer)

It doesn't mean that you have days to live! The earlier you have contact, the easier it is for you to access a range of services, equipment & expertise to make life more COMFORTABLE.



Palliative Care works **ALONGSIDE** your specialists to make sure all aspects of your illness are managed to best suit you.

## Quick definitions

- **Life-limiting illness** is a term used to describe an incurable condition that will shorten a person's life, though they may continue to live active lives for many years.
- **Terminal illness** sometimes used interchangeably with life-limiting illness or used to describe a life-limiting illness that is thought to have progressed to the final or terminal stage, likely the last 12 months.
- **End of life care** is support for people who are approaching death, usually those considered to be within the last 12 months of life, it is part of palliative care.

## What does it mean to people?

*“[palliative care nurse] has been the strength and support that we have needed since diagnosis and living each day with cancer. She is always on the end of the phone and no question seems silly to her and she helps us to face the future and realise that all the feelings we have are normal.”*

*“They are caring and understanding without being too overbearing. Everyone is treated and respected as an individual and yet you are made to feel like one of a large family.”*

*“I was glad of the support at [hospice] and they worked as a team to improve my confidence and lighten my anxiety. With their help, I recovered my mental, physical and emotional health.”*





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# Living Well



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‘Live in the moment, find joy when you can and accept that it’s a rollercoaster’

‘No excuse now for putting off doing things like going on ‘big’ holidays or sorting the house out. The clarity of not putting things off can be liberating!’

‘Make the best memories, take the photos, laugh and take it day by day’

## What do we need to live well?

- Management of symptoms
- Support for mental health and physical wellbeing
- Doing things we enjoy
- Practical support
- Information and advice / future planning
- Aids and adaptations
- Support for carers
- Peer support



## Moving to end of life care

- Gold Standards Framework
- Preferred place of dying
- Anticipatory medications / medication reconciliation
- Access to out of hours support
- Pre and post bereavement support for families



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# Conversations about dying



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## Let's not talk about dying

Passed away

Fell off the twig

Kicked the bucket

Slipped away

Lost them

Left us

Moved on

Popped their clogs

Pushing up daises

Gone to a better place

Cashed in their chips

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# Cultural considerations

## Brief thoughts to consider

- Diversity of beliefs and values
- Recognising impact of culture on treatment decisions
- Communicating with patients and families about end-of-life care choices
- Working with interpreters to facilitate communication
- Addressing spiritual needs at the end of life
- Considering legal/financial considerations for different cultures



# Having conversations - REDMAP

Ready	Can we talk about what is happening with your health and care? Who else should be involved? Is there someone we should talk to?
Expect	How have you been recently? What has changed? What do you <b>know</b> about your health problems? What do you think is happening/might happen? Do you want to <b>tell/ask</b> me about anything?
Diagnosis	We <b>know</b> you are less well because... We <b>hope</b> you will improve, but I <b>am worried</b> that... It <b>is possible</b> you will not get better... I'm sorry but you <b>could die soon</b> with this illness. Do you have questions or worries we can talk about?
Matters	What is <b>important</b> to you and your family? How would <b>you like</b> to be cared for? Is there anything you would <b>not want</b> ? What would ( <i>person's name</i> ) <b>say</b> about this situation, if we could ask them? Can I ask <b>why</b> they would say that?
Actions	What we <b>can do</b> is... Options that <b>can help</b> are.... This <b>will not</b> help because.... That <b>does not work</b> when... I <b>wish</b> that was possible, let's talk about what <b>we can do</b> .
Plan	Can we talk about how we care for someone who is dying? We are <b>not sure</b> how quickly things will change. We can make a care plan for you ( <i>person's name</i> ) and your family.

# Having conversations

Talking about anticipatory care planning	
<b>Generalisation</b>	<b>Sometimes people</b> choose family members or close friends to help make decisions for them if they get less well in the future. Have you thought about that?
<b>Hypothetical questions</b>	<b>If you were less well</b> (like this) in the future, what do you think we should do?
<b>Sharing decisions</b>	Can we talk about what is <b>important</b> for you (and your family)? That will let us make good decisions together. Who <b>should be involved</b> in talking about your health and care? What would ( <i>person's name</i> ) <b>say</b> about this situation, <b>if</b> we could ask them? We <b>don't know</b> exactly what will happen or when, but <b>we can plan</b> for how to manage...
<b>Hope linked with concern</b>	We <b>hope</b> the (treatment) will help, but I am <b>worried</b> that at some stage, you will not get better.... We are doing our best to treat him, but <b>it is possible</b> he will die... I <b>wish</b> there was more treatment...Could we talk about <b>what we can</b> do if that will not help you?

# Having conversations

## Helpful language in anticipatory care planning towards the end of life

Poor word choice	Possible misinterpretation	DO SAY
What do you want us to do?	<i>Patient (and/or family) is responsible for making the decisions. People can choose whatever they want.</i>	What is important for you and your family in this situation? What would ( <i>person's name</i> ) say if we could ask them?
There is nothing more we can do. S/he is being 'made palliative'. Treatment is 'futile'.	<i>Patient and family are being abandoned by the clinical team. This person is not valued.</i>	We will do everything we can to make sure you ( <i>person's name</i> ) are cared for well, and are as comfortable as possible. We are focusing on care and treatments that will help you.
We are going to 'withdraw' treatment.	<i>Professionals will give less care and attention to the person now.</i>	We are continuing to care for you ( <i>person's name</i> ) while stopping treatments that are not working and may cause distress or discomfort.
The 'ceiling' of treatment or care is...	<i>A person is not being given treatment that could help them.</i>	This is what we can do. Some treatments do not help when a person has these problems with their health/is seriously ill or dying.

## **Advance / Anticipatory care planning: Things to include:**

- how you like spending your time
- important information about your identity
- your values, religious or spiritual beliefs
- important people in your life
- your lifestyle and habits
- your food preferences and allergies
- where you want to live and be cared for at the end of life
- information about your health

## Advance decisions v Advance statements

An Advance Care Plan / or Advance Statement describes a person's wishes but it is not legally binding. It can be used to support families, professionals and anyone with power of attorney to ensure the person gets the care they prefer.

An Advance Decision, sometimes known as a 'living will' is a legally binding choice to refuse certain treatments. It must be made while a person has capacity and to refuse life sustaining treatment it needs to be witnessed.

Some things, such as basic nursing care or food and drink cannot be refused. It is a good idea to put advance decisions in writing, however this isn't technically needed.

*This is someone with end stage COPD with severe dyspnoea and anxiety who wants to die at the earliest possible opportunity and who fears dying gasping for breath – end of life sedation has been discussed with him.*

I WOULD / WOULD NOT WANT	IN THESE CIRCUMSTANCES
I would NOT want any interventions that will prolong or preserve my life, for example antibiotics for a chest infection	Under any circumstances, including if I am likely to die without treatment
I WOULD want medication and other interventions to treat pain and other symptoms, as a priority.	At all times as long as those treatments will not prolong or preserve my life, and even if those treatments may hasten my death
I WOULD want to be sedated to the point of being completely relaxed, and unconscious if necessary, at the end of my life	If my breathlessness, anxiety, pain or other symptoms cannot be successfully treated with other measures within 24 hours, even if this means my death may be hastened
I would NOT want artificial fluids or nutrition	Under any circumstances
I would NOT want to be transferred to hospital	For any reason – please give treatment here in the facility, including sedation if necessary

## ReSPECT Plans

ReSPECT stands for the recommended summary plan for emergency care and treatment. The purpose is for individuals, families and professionals to discuss and record preferences, wishes and clinical recommendations that can be reviewed and updated if needed.

The ReSPECT process can be for anyone but will be increasingly relevant to those who are at risk of sudden deterioration in their health, have complex medical needs or are nearing the end of their life.

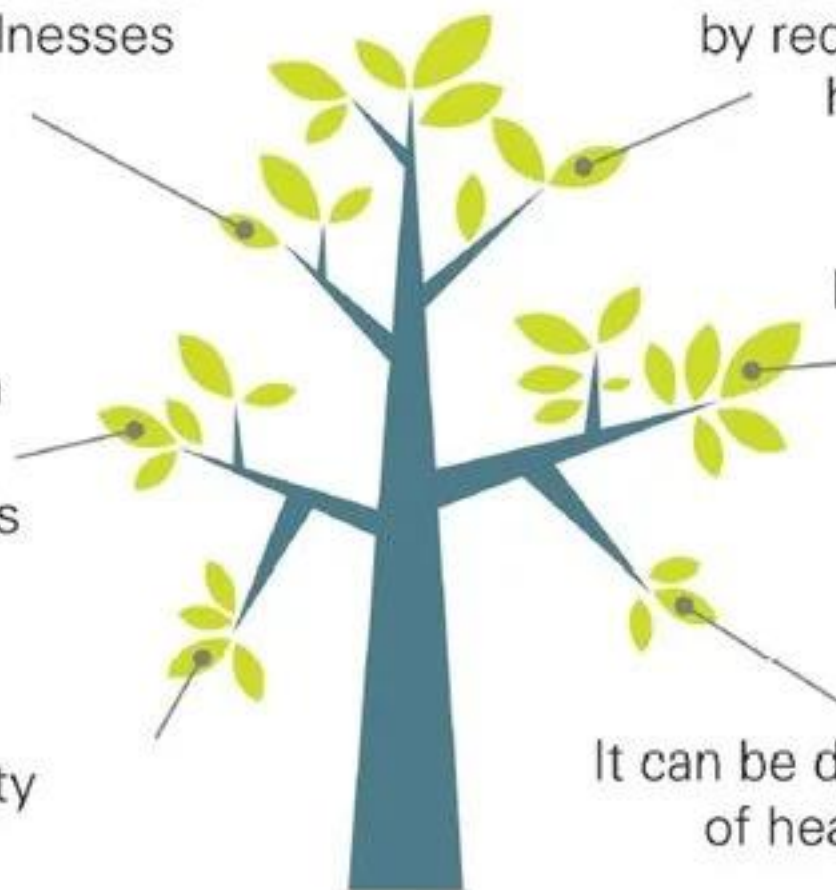
It includes discussion of CPR and preferences for if treatments should focus on quality or quantity of life. Specific wishes, such as admission to hospital can be included. If people do not have capacity their power of attorney, families and medical team can complete this.

## Recap and conclusion

It is care for patients with life-threatening illnesses & their families

It can be given in homes, health centres, hospitals and hospices

It improves quality of life



It benefits health systems by reducing unnecessary hospital admissions

It relieves physical, psychosocial & spiritual suffering

It can be done by many types of health professionals & volunteers



**Palliative care is the  
essence of medicine  
and nursing,  
the prevention  
and relief  
of human  
suffering**



**World Health  
Organization**

REGIONAL OFFICE FOR THE **Eastern Mediterranean**



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# Questions or comments?



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