

The last weeks and days of Life: A guide for families and carers



Regional Hospice details...

Saint Catherine's Hospice Scarborough, Whitby & Ryedale

Call: 0800 808 1677

www.saintcatherines.org.uk

St. Leonards Hospice York, including Pocklington

Call: 01904 708553

www.stleonardshospice.org.uk

Dove House Hospice Hull and East Riding

Call: 01482 784343

www.dovehouse.org.uk

Complaints

If you have any concerns about the care you have received, you can contact our Complaints and Feedback Team to discuss your concerns and for information on our complaints process.



(01482) 303930



HNF-TR.complaints@nhs.net

About this booklet...

This booklet has been written to support you as you care for someone in the last weeks and days of their life.

We understand this can be an emotional and uncertain time. You may notice changes that feel unfamiliar or worrying and you may have questions about what is happening.

The information in this guide explains common changes that can occur, what they might mean and how you can keep your loved one comfortable. Not everyone's experience will be the same but this guide outlines what is typical and when to seek advice and reassurance from healthcare professionals.

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What to expect in the last weeks

As someone becomes more unwell and may be approaching the last weeks of life you may notice gradual changes. These changes can happen slowly or over a shorter period. Not everyone will experience all of them and they may not happen in the order below.

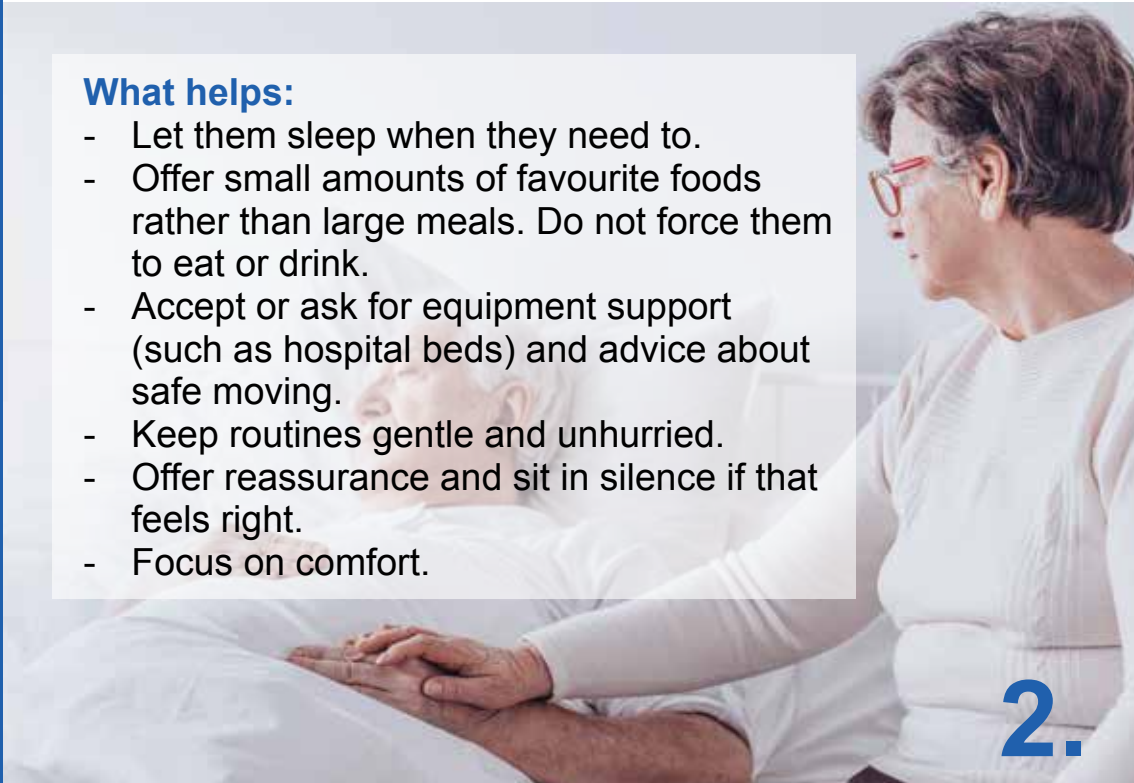
You may notice:

- Increasing tiredness and sleeping more.
- Reduced appetite and drinking less.
- Increasing weakness and reduced mobility.
- Changes in communication and awareness.
- Changes in mood or restlessness.
- Needing more personal care.
- Emotional changes.

These changes happen because the body is conserving energy and naturally slowing down. Activities are using more energy than they used to, muscles become weaker, and the person does not need the same amount of fuel.

What helps:

- Let them sleep when they need to.
- Offer small amounts of favourite foods rather than large meals. Do not force them to eat or drink.
- Accept or ask for equipment support (such as hospital beds) and advice about safe moving.
- Keep routines gentle and unhurried.
- Offer reassurance and sit in silence if that feels right.
- Focus on comfort.



When to seek advice:

- If there is new agitation or confusion.
- Pain or other symptoms are increasing.
- You feel unsure about what you are seeing.

The last weeks of life are often quieter, slower and more inward. Some people may “rally” and become more well for a short period of time. There is no ‘right’ way this time should look and if you have any concerns or worries speak to your healthcare team. Small acts like sitting together, holding a hand and talking matter more than you may realise.

What to expect in the last days

It is not always possible to predict exactly when someone is in the last days of life. However, there are some common signs that a person may be close to dying. These changes are part of the body gradually shutting down. Not everyone will experience all of them and they may not happen in the order below.

You may notice:

- The person is sleeping most or all of the time.
- The person is eating and drinking very little or not at all.
- Changes to breathing pattern, they may breathe rapidly and then have long pauses or sound noisy like ‘rattling’ or ‘gurgling’.
- Changes in skin and temperature.
- Reduced urine output.
- Restlessness or agitation.

These changes are part of the natural dying process. The body has very little energy left and is shutting down, they will not feel hungry or thirsty and may be too weak to cough or swallow. Noisy breathing may occur due to saliva, although this can sound distressing it is not usually distressing or painful for the person.

What helps:

- Let the person sleep, there is no need to wake them.
- Give regular mouthcare, you can ask to be shown how by your healthcare team.
- Use light blankets for warmth.
- Sit with them and give gentle reassurance in a calm voice.
- Gently reposition for comfort.

When to seek help:

- The person appears to be in pain.
- Breathing looks distressed.
- There is severe agitation.
- You feel frightened or unsure.
- Something doesn't feel 'right', you know your loved one the best. Trust your instincts.

The last days of life are often very quiet. What matters most now is comfort, dignity and presence.

Sitting beside someone, speaking softly or holding someone's hand are profound acts of care, you are doing enough.

Managing Common Symptoms

Many symptoms can be anticipated and managed. Your healthcare team will aim to prevent distress wherever possible and respond quickly if symptoms change. Some people may have no symptoms or develop some. Below are some common symptoms:

- Pain
- Breathlessness
- Noisy breathing (secretions)
- Agitation
- Nausea or vomiting
- Anxiety or emotional distress

What helps:

- Giving medications regularly or as needed for pain/nausea.
- Repositioning for comfort, such as upright or on a side to help with secretions.
- A handheld fan may help with breathlessness.
- Giving mouthcare.
- Speaking calmly and reassuringly.
- Distraction, such as watching TV, painting or reading.

When to seek help:

- If symptoms do not seem controlled or are persistent.
- The person is distressed or agitated.
- You feel the person needs something 'stronger' such as an injection.
- You are unsure what to do.
- Something doesn't feel right.

Giving medications safely

You may be supporting with medications in the last weeks or days of life. This can feel like a big responsibility. It is normal to feel unsure at times. If you are giving tablets or liquid medicines below are some tips to make it safe:

- Check the dose.
- Check it is the right medicine for the person you are giving it to.
- Check the time it was last given; you may find it easier to write the times down.
- Make sure the person is awake enough to swallow safely.
- Do not force medicine if someone is too drowsy or refusing it.
- Store medicines in a safe place in their original packaging.

You may have been given anticipatory (just in case) medications to keep at home. These medications are given by healthcare professionals as an injection under the skin. They are given to relieve discomfort and not to hasten death. If you think these medications are needed, contact your community nurses.

When to seek help:

- Symptoms are not controlled with the medications you have given.
- The person can no longer swallow their usual medications.
- You think you may have given them too much medication.
- You feel unsure about what to do.
- You no longer feel you can manage their medication safely.



Personal care (washing, mouthcare, repositioning)

As someone becomes weaker, they may need help with activities of daily living such as washing, dressing, toileting, mouthcare and repositioning. Providing personal care can feel unfamiliar and emotional at first. Especially if the roles have changed within your relationship. Personal care at the end of life is about comfort and dignity.

What may help:

- A gentle wash in bed instead of a shower or bath.
- Changing the persons position every few hours, you can use pillows to support legs and arms for elevation.
- Use a soft toothbrush and lip balm to keep the mouth moist.
- Accept or ask for equipment such as commodes, mobility aids or profiling beds.
- Discuss with your healthcare team about continence products.

When to seek help:

- If you notice red, broken or blistered skin.
- You are unable to reposition them safely.
- The person's mouth is very sore, bleeding or coated.
- The person is unable to pass urine or distressed.
- You feel overwhelmed or unsure of what to do.
- You feel you cannot cope and need help.

Personal care can be physically and emotionally tiring. You may feel unsure you are doing it correctly or determined that you provide the care alone. Accepting help is not a sign of failure but part of providing good care, you don't have to do it all alone.

Eating, drinking and swallowing changes

As someone becomes more unwell during the last weeks and days of life changes in swallowing are very common. This can happen with many illnesses, and it is usually a sign of the body becoming weaker. Swallowing changes can be part of the natural process of decline.

What you may notice:

- It takes longer to swallow food or drinks .
- The person may hold the food in their mouth.
- Coughing when eating or drinking.
- Difficulty swallowing tablets .
- Being too tired to eat or drink or sleeping through mealtimes.

This can be distressing to watch, you may feel you are not caring for them well enough. It is important to know that reduced appetite and swallow changes are normal and not your fault, the most likely cause is the illness.

What may help:

- Offer small amounts of food if they are awake and wanting it.
- Try softer foods such as yoghurt, custard or mashed foods.
- Use a teaspoon instead of a larger spoon to help with smaller mouthfuls.
- Sit the person in their optimum upright position when having food or fluids.
- Allow the person plenty of time and if they get tired stop.
- If they are not awake enough do not try to give food or fluids .
- Give mouthcare as this often becomes more important for comfort.
- Check mouth is clean and clear after eating. Provide mouthcare if needed.

When to seek help:

- The person is unable to swallow their medications
- There is repeated choking and distress from the person.
- The person's swallow has suddenly become much worse.
- You are unsure what to do.

It can be incredibly hard watching someone eat and drink less. You may be told your loved one can eat and drink 'at risk'. This means there may be a risk of aspiration where food or drink goes into the airway instead of the oesophagus. It is important to remember these changes are natural and it is natural for your role to shift from providing nourishment to providing comfort.

Looking after yourself

Caring for someone in the last weeks and days of life is one of the most demanding things a person can do. It can take more out of you than you expect. Your wellbeing matters, if you become exhausted or unwell it becomes harder to keep going. Looking after yourself is not selfish.

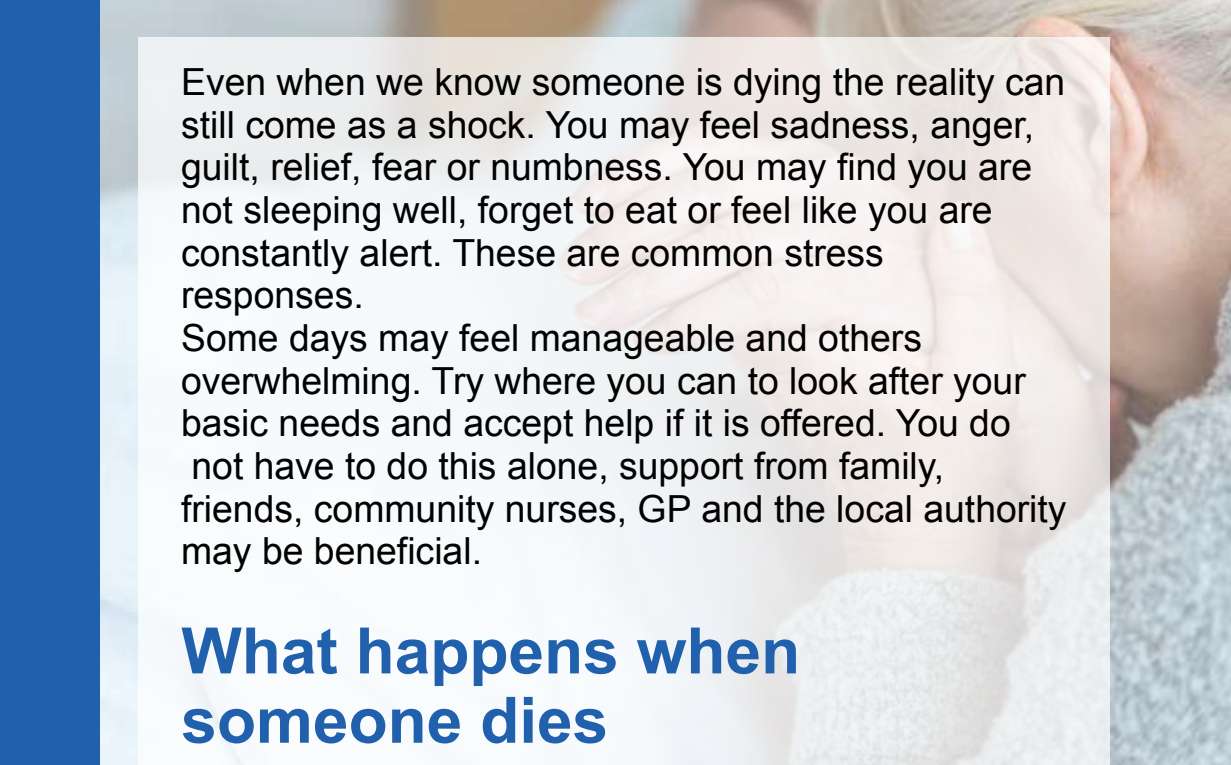
Quotes from carers who have looked after a loved one before their death:

Remember to look after yourself - if you fall, they fall.

Appreciate the moments in the difficult times and hold on to the laughs when you can.

Prepare for an emotional roller coaster.

It will be emotionally difficult and even if you are prepared it affects your sleep, appetite and motivation.



Even when we know someone is dying the reality can still come as a shock. You may feel sadness, anger, guilt, relief, fear or numbness. You may find you are not sleeping well, forget to eat or feel like you are constantly alert. These are common stress responses.

Some days may feel manageable and others overwhelming. Try where you can to look after your basic needs and accept help if it is offered. You do not have to do this alone, support from family, friends, community nurses, GP and the local authority may be beneficial.

What happens when someone dies

When someone dies at home it can be overwhelming, knowing what to expect can help reduce anxiety. When a person dies their breathing will stop, their chest will no longer rise and fall and there will be no pulse. Their body will gradually become still and may become stiff; they will gradually become colder. You may notice their mouth or eyes remain open. The person's skin may change colour to very pale or have a blue purple colour. These are natural changes.

If the death was expected you do not need to call an ambulance. Call your community nurses or out of hours service such as 111. A healthcare professional will then come to verify (confirm) the death. Waiting can feel long but support is on its way. Once the death has been verified a funeral director can then collect your loved one when you are ready. You can sit with them for as long as you wish. You may want to call family members to be with you to say goodbye, take the time you need.

If equipment has been provided you can contact the company for this to be collected later, there is no immediate urgency. There is no need to rush. There is no correct way to feel in the moment or days after someone dies. Bereavement support is available if you need it, you can speak to your GP if you are struggling.

Support available for you

Caring for someone at home at the end of life can be exhausting and emotional. There are services and organisations that can help both you and the person you are caring for. Below are some services available.



Saint Catherine's

Caring for you at Hospice and Home

Saint Catherines Hospice – They can offer specialist palliative care in the community. They can support with symptom control, family support, emotional and spiritual support, social work and advice.



Humber Teaching

NHS Foundation Trust

Community nurses – They can offer support and advice regarding mouthcare, repositioning and personal care. They are also able to provide hands on care such as injections and dressings as well as equipment provision. You can contact them for advice and discuss any concerns.



Marie Curie Support – They can provide free limited overnight care at home for people in the last weeks of life. Availability of this is dependent on their capacity and referrals can be made by a healthcare professional. They can also offer support and advice via telephone.



Fast Track Continuing healthcare funding – They can provide care packages for people in the last weeks of life. Your healthcare team can complete the fast track referral, check eligibility and amendments made if care needs change.

Financial support – You may be entitled to attendance allowance, carers allowance or adaptations to your house. Your GP, local authority or hospice social worker can advise you.

Local authority – You can request a carers assessment from your local authority to discuss how caring for a loved one affects your life and what support you might need. You may be offered different options such as a care package or breaks from caring.

This booklet was co-produced with the staff and patients with lived experience from the **Humber Teaching NHS Foundation Trust** and in partnership with the **Cheshire and Wirral Partnership NHS Foundation Trust**.

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