

Caring for someone at the end of their life

Information leaflet, V5



This is a leaflet written for people who are caring for someone who is very unwell and may be nearing the end of their life. It may also be useful for the very unwell person to read if they are well enough to do so. It contains some practical tips and advice about medications to help with symptom management. This leaflet has been adapted with permission from NBT document, Version 3, Bernstein/Lanfear.

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1. Who to call for advice

Your community nursing team can assess your relative or friend and also arrange equipment and care, you can call them 24 hours a day. They may assess over the telephone or come out and see you.

Your local hospice can offer advice and support including advice about medication. Your GP may offer a consultation face-to-face or by telephone or video. The numbers you need to call us are below:

Community (District) Nurses:

Where you live	Telephone Number
Cheltenham	0300 421 6070
Cotswolds	0300 421 6072
Gloucester	0300 421 6071
Forest of Dean and TNS	0300 421 6074
Stroud and Berkeley Vale	0300 421 6073
Out of Hours (4pm – 8am / evenings, weekends and bank holidays)	0300 421 0555

Community doctor (GP):

- You can phone your usual general practice number
- For an out of hours doctor telephone 111 or use 111.nhs.uk

Sue Ryder Leckhampton Court Hospice telephone advice line:

- Sue Ryder Leckhampton Court Hospice **0300 303 1395**

999:

- In an emergency you can call 999, for example if your relative or friend has a fall and you need help to get them back into bed.

2. General information

We as a team are very grateful that you have been able to care for your relative or your friend at home at the end of their life; it is a loving and generous thing to do.

We hope you have been given information and feel supported with this decision, although acknowledge it may feel overwhelming at times and can create anxiety for you. We also recognise we are in challenging times and the support we usually hope to provide is different and may be less than we would want it to be. It may be helpful to nominate a family member or other support person to provide support for you during this time.

We feel it is important to remember a few things: Look after yourself.

- Take breaks: Having some time to yourself can help you relax and feel more able to cope. This can help the person you are caring for too.
- Your GP will be available for telephone advice. If you yourself are taking any medicines regularly it is important you have a supply of these.
- Try to eat well. If you can, make time to prepare and sit down for a cooked meal. If you don't have time, perhaps you could ask a friend to help you by dropping round some food.
- Getting enough sleep can be difficult too. Many people say that when they are caring for someone who is very ill, they find it difficult to relax at night. You may be thinking and worrying about them and this can keep you awake, or you may need to help them regularly at night. Take naps if you can.
- Do not underestimate the importance of just being with your relative or friend, even if you feel you aren't doing much.
- If possible, creating a sense of calm around your relative or friend can help them to feel settled.
- Talking to your relative or friend can help reassure them, even if they appear to be asleep.
- Listen to the radio or music and watch TV as normal. Perhaps read out loud. You may take this opportunity to create new memories.
- If you feel overwhelmed it may be useful to phone your support person to discuss the care you may wish to give or to check through medications.
- It can also be useful for you to pause, take a breath and consider what you are doing or giving. There is no rush to do anything at this time.
- When someone is dying, medication can be very useful for managing symptoms. These medicines will not hasten death, but it is possible that your relative or friend could happen to die soon after receiving a drug for their symptoms.
- If you, or the person you are caring for, finds strength in or is associated with a particular faith or belief system, it might be helpful to contact a representative of that belief system to support you pastorally or spiritually

3. What you can do practically

What you can do to practically care for someone who is in their last days and hours of life



It is important to be aware of what to expect and how to make the experience as comfortable as possible.

Your health team will advise you on the medications that can help with controlling symptoms experienced at the end of life.

Communication and environment

When approaching the end of life, people often sleep more than they are awake and may drift in and out of consciousness.

Try to imagine what the person you are caring for would want. Provide familiar sounds and sensations, a favourite blanket for example, or piece of music. Keep the environment calm by not having too many people in the room at once and avoid bright lighting. This can reduce anxiety even when someone is unconscious. Even when they cannot respond, it is important to keep talking to them as they can most probably hear right up until they die.

Pain

Some people may be in pain when they are dying. If they are less conscious they may grimace or groan to show this. There are medicines that can be given to ease pain.

Always check their positioning in bed to see if this can also help. They may be too weak to move and this can cause discomfort. Consider if they have any areas that are known to hurt, for example a bad back, and remember this when positioning them.

Feeling sick

Sometimes people can feel nauseated or sick when they are dying.

If vomiting, and unable to sit up, turn the person on their side to protect their airway. There are medicines that can be given to help relieve this.

Going to the toilet

Towards the end of life, a person may lose control of their bladder and bowel. Even though we expect someone to go to the toilet less as they eat and drink less, contact the health care team that is looking after them if they have not passed any urine for 12 hours or more as it can be uncomfortable.

Keep the person comfortable by regularly washing them and changing pads if they are wet or soiled.

Moving

Regular movement and turning the person every 2-4 hours is really important to protect their skin from developing pressure ulcers (sometimes known as bed sores).

Washing the patient daily provides movement and an opportunity to check the persons skin.

Alternate their position from lying on their back to each side. You can use pillows or rolled up towels to support them and also to support under their arms and between and under their legs. When you are washing the person, look for signs of redness, or changes in the colour or appearance of their skin. Check the back of the head and ears, the shoulder blades and elbows and the base of the spine, hips and buttocks, ankles, heels and between the knees.

Mouth care

While people rarely complain of thirst at the end of life, a dry mouth can be a problem due to breathing mostly through their mouth.

It's important to keep lips moist with a small amount of un-perfumed lip balm to prevent cracking. Regularly wet inside their mouth and around their teeth with a moistened toothbrush whether he or she is awake or has lost consciousness. Check for sore areas and white patches on the tongue, gums and inside the cheek which can be sore. If this happens tell the person's healthcare professionals as it can be treated easily.



Breathlessness and cough

Breathlessness and cough can be another cause of agitation and distress and it can make it difficult to communicate. Don't expect the person to talk and give them time and space to respond. Reassure them that the unpleasant feeling will pass.

You can offer reassurance by talking calmly and opening a window to allow fresh air in. If possible, sit the person up with pillows rather than lying flat as this can help the sensation of not being able to breathe.

Before someone dies their breathing often becomes noisy. Some people call this the 'death rattle'. Try not to be alarmed by this, it is normal. It is due to an accumulation of secretions and the muscles at the back of the throat relaxing. There are medicines that can be given to help dry up secretions if it is a problem.



Agitation or restlessness

Some people can become agitated and appear distressed when they are dying. It can be frightening to look after someone who is restless. It's important to check if the cause is reversible like having a full bladder or bowel which can be reversed by using a catheter to drain the urine or medicines to open the bowels. Your health team can assess if this is necessary.

Check if their pad is wet to see if they are passing urine or if they are opening their bowels. If it's not either of these things, there are things you can do and give to help. Try to reassure the person by talking to them calmly and sitting with them. Touch can be effective in doing this too. There are also medicines that can be given to help settle and relax someone.



Looking after yourself

Caring for a dying person can be exhausting both physically and emotionally. Take time out to eat and rest. Try to share the care with other people when possible and remember it is OK to leave the person's side to have a break.



Washing

Sometimes it may be too disruptive for the person to have a full wash. Just washing their hands and face and bottom can feel refreshing.

To give a bed bath, use two separate flannels, one for the face and top half of the body and one for the bottom half. Start at the top of the body, washing their face, arms, back, chest, and tummy. Next, wash their feet and legs. Finally, wash the area between their legs and their bottom. Rinse off soap completely to stop their skin feeling itchy. Dry their skin gently but thoroughly. Only expose the parts of the person's body that are being washed at the time – you can cover the rest of their body with a towel. This helps to keep them warm and maintains their dignity.



Eating

As the body shuts down it no longer needs food and fluid to keep it going. When a person is dying they often lose their desire to eat or drink and finally their ability to swallow. They can lose weight rapidly.

This is often difficult to accept because we often equate food with health and feeding people as an act of love. However, hunger and thirst are rarely a problem at the end of life.

Continue to offer a variety of soft foods and sips of water with a teaspoon or straw for as long as the person is conscious (but allow them to refuse it). It's important **not to force food or drink onto someone who no longer wants it. Remember to sit them up when offering food and fluids to avoid choking.**

When a person is no longer able to swallow some people want them to have fluids via other routes like a drip, but at the end of life this offers little, if any, benefit. The body cannot process the fluid like a healthy body can and it can be harmful to artificially feed and hydrate. Risks include infection at the insertion site or in the blood, and fluid overload resulting in swelling or even breathing problems.

4. Symptoms and medicines

Your relative or friend **may** have been provided with **some** of these medicines. Please follow the guidance below. They may have also been provided with some medication which can be administered by injection by health care professionals if this is required.

Consider calling for advice if you have given 2 doses of medication for one symptom in four hours and it is still uncontrolled. Also call if your relative or friend has needed more than 3 doses of medication for one symptom in a 24 hour period.

(i) Pain:

- People may experience pain due to existing illnesses and may also develop pain as a result of excessive coughing or immobility. At the end of life they may grimace or groan to show this.
- Not being able to pass urine can cause pain

Step 1

- You have been supplied with a bottle of morphine liquid. The instructions on the bottle suggest a range with a lower dose and a higher dose:
 - Squirt the lower dose of oral morphine into the cheek and allow to absorb, without swallowing, up to once every hour when required.
 - If you have tried the lower dose several times and it hasn't been that effective then you can try the higher dose.
 - If the morphine is accidentally swallowed that is OK.

See guide below on giving medicine to be absorbed into the cheek

Step 2

- If pain is persistent and distressing or more than 2 doses are needed in 4 hours please telephone for advice.
-

(ii) Agitation/ Distress:

- Some people may become agitated and confused towards the end of life. They may seem confused at times and then seem their normal selves at other times.
 - People who become delirious may start behaving in ways that are unusual for them- they may become more agitated than normal or feel more sleepy and withdrawn.
 - Pain may worsen agitation (see pain management table)
 - Not being able to pass urine may also worsen agitation
-

Step 1

- If you have been supplied with pre-filled syringes of midazolam
 - Squirt the lower dose of oral midazolam into the cheek and allow to absorb, without swallowing, up to once every hour when required.
 - If the midazolam is accidentally swallowed that is OK.
-

Step 2

- Check medication label to confirm **lorazepam** dose
 - Place HALF or ONE **lorazepam** tablet under their tongue or placed on gum under top lip and allow to dissolve, up to every 6 hours, when required, for anxiety or agitation. They should try not to swallow for 2 minutes after this.
-

Step 3

- Please telephone for advice if
 - you are concerned your relative or friend is unable to pass urine
 - agitation is persistent and distressing
-

(iii) Nausea and Vomiting:

- Sometimes people may feel nauseated or sick when they are dying
-

Step 1

- If nausea persists after an hour, place under the tongue or suck or chew HALF or ONE **hyoscine hydrobromide Kwells®** tablet (every 8 hours if need be).
 - Check medication label for dose.
-

Step 2

- If nausea is persistent and distressing despite trying steps 1 + 2 please telephone for advice.
-

(iv) Rattly breathing:

- Before someone dies their breathing often becomes noisy. Some people call this the 'death rattle'. Try not to be alarmed by this, as it is normal. It is due to an accumulation of secretions and the muscles at the back of the throat relaxing.
 - Medicines intended to dry up secretions may not work, so try to be reassured that if your friend or relative is asleep or unconscious they are unlikely to be distressed.
-

Step 1

- Place ONE **hyoscine hydrobromide Kwells®** tablet under the tongue and allow to dissolve (up to every 8 hours).
-

Step 2

- See guidance for managing agitation/distress above
-

Step 3

- Repositioning your relative or friend in the bed by using pillows to support them at a different angle can help reduce rattly breathing
-

Step 4

- If your relative or friend seems distressed by their noisy breathing despite waiting an hour after the measures above please telephone for advice.
-

(v) Breathlessness:

Step 1

- You may wish to try some relaxation techniques
 - Opening a window or door can reduce air hunger and keep the room cool
 - Cooling the face by using a cool flannel or cloth can help
 - Portable fans are not recommended for use during outbreaks of infection.
-

Step 2

- You only need to give medicine if your relative or friend is distressed by their breathing. If they are breathing fast but seem comfortable and settled you do not have to treat it. If you are not sure call your local hospice for advice.
- You have been supplied with a bottle of morphine liquid. The instructions on the bottle suggest a range with a lower dose and a higher dose:
 - Squirt the lower dose of oral morphine into the cheek and allow to absorb, without swallowing, up to once every hour when required.
 - If you have tried the lower dose several times and it hasn't been that effective then you can try the higher dose.
 - If the morphine is accidentally swallowed that is OK.

See guide below on giving medicine to be absorbed into the cheek

After 2 doses of oral morphine if still in distress

Step 3

- Check medication label to confirm **lorazepam** dose
 - Place HALF to ONE **lorazepam** tablet under the tongue and allow to dissolve, up to every 6 hours, when required, for anxiety or agitation. Your relative or friend should try not to swallow for 2 minutes after this.
-

Step 4

- If breathlessness is persistent and distressing or more than 2 doses are needed in 4 hours please telephone for advice using the numbers above.
-

(vi) Cough:

Step 1

- If your relative or friend is awake enough to swallow, simple non-drug measures may help, e.g. a teaspoon of honey.
 - Elevate their head with pillows if able.
-

Step 2

- You only need to give medicine if your relative or friend is distressed by their cough. If you are not sure call your local hospice for advice.
- You have been supplied with a bottle of morphine liquid. The instructions on the bottle suggest a range with a lower dose and a higher dose:
 - Squirt the lower dose of oral morphine into the cheek and allow to absorb, without swallowing, up to once every hour when required.
 - If you have tried the lower dose several times and it hasn't been that effective then you can try the higher dose.
 - If the morphine is accidentally swallowed that is OK.

See guide below on giving medicine to be absorbed into the cheek

Wait half an hour

Step 3

- If cough is persistent, unrelenting and causing distress or more than 2 doses are needed in 4 hours please telephone for advice using the numbers above.
-

(vii) Fever:

Fever is not harmful but can be treated if the symptoms cause distress

Signs and symptoms of a fever

- shivering
 - shaking
 - chills
 - aching muscles + joints
 - other body aches
 - may feel cold despite body temperature rising
-

Step 1

- If your relative or friend is unable to swallow insert **TWO paracetamol** suppositories rectally up to every 4 hours (can also help with pain relief).
- Suppositories should not be given by mouth.

Do not use more than 8 suppositories (4g) per day

See guide below on how to give a suppository

Please ensure care in administering this and protect your face.

Step 2

- Try a cool flannel applied across the face
 - Reduce room temperature - open a window or door
 - Wear loose clothing
 - Oral fluids if able to drink
-

When to give buccal lorazepam

Consider using buccal lorazepam if someone is having symptoms of distress, restlessness, or other behaviour that is out of the ordinary. If in doubt, do phone a health care professional for advice.

How to administer lorazepam buccally:

- This medication can provide relief from anxiety, agitation and other symptoms.
- The medication can be given inside the mouth, between the cheek and gum where it can be absorbed easily.

Below is a step-by-step visual guide to support you in this process.

1	Wash your hands and put on gloves.	
2	Remove the tablet of lorazepam from its wrapper and place it in the palm of your hand.	
3	Add a few drops of water to the tablet in your hand. You will see the tablet start to dissolve.	
4	Support the head. Gently place the dissolving tablet into the patient's mouth between the cheek and lower or upper gum.	

5

If their mouth is particularly dry consider adding a couple more drops of water to the tablet inside the mouth.



Storage

- Keep your 'Just In Case' medication at room temperature, away from bright light, direct sunlight and heat.
- Do not store this medication in a fridge

How to give medicine to be absorbed into the cheek:

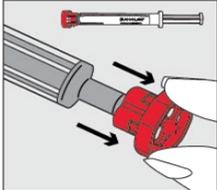
Instructions on when to give buccal medication

'Is the person needing the medication able to indicate whether they are in agreement with you administering this or not?' Always consider discussion with a healthcare professional especially if they are unable to give their consent.

How to administer midazolam buccally:

Morphine can be administered using the same method from step 2

- Your Doctor or Nurse may advise you to administer buccal midazolam to the person you are caring for. This medication may not have been supplied.
- Midazolam can be used to treat agitation, seizure and other symptoms.
- Midazolam can be given inside the mouth, between the cheek and gum where it can be absorbed easily.
- We will guide you through the process over the phone but below is a step-by-step visual guide to support you in this process.

1	Remove the syringe from it's container. Remove the cap from the end	
2	Support the head. Gently insert the syringe into the patient's mouth between the cheek and lower gums.	
3	Slowly administer half the liquid in the syringe by pushing the plunger downwards. Then repeat on the other side.	

Storage

- Keep your buccal Midazolam at room temperature, away from bright light, direct sunlight and heat.
- Do not store this medication in a fridge

How to administer medication rectally:

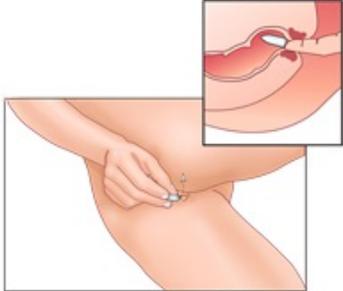
Instructions on when to give rectal medication

'Is the person needing the medication able to indicate whether they are in agreement with you administering this or not?' Always consider discussion with a healthcare professional especially if they are unable to give their consent.

- The Doctor or Nurse may advise you as a carer to administer the individual's tablets rectally (into their bottom).
- This might be necessary when they are no longer able to swallow their medication.
- The medication may be necessary to provide relief from pain, agitation and other symptoms.
- The medication is absorbed from the rectum in much the same way as it is absorbed in the stomach.
- We will tell you when to do this and guide you through the process over the phone but below is a step-by-step visual guide to support you in this.

How to give medication rectally

1	Wash your hands and put on gloves.	
2	Have the medication ready. Remove the tablets you are going to give from the sleeve or the bottle and have the lubricant at hand.	

3	Position the individual on their side (ideally their left). You may require help from a friend or relative to do this safely.	
4	Remove or pull their underwear down and out of the way.	
5	Gently pull the uppermost knee towards their chest as far as is comfortable.	
6	Lift the upper buttock to expose the rectal area.	
7	Apply a small amount of lubricant to the tablets and to the tip of the gloved finger you will use to insert it with.	
8	Insert the tablets (one at a time if multiple to be given) through the anus. Gently push them inside to approx. 1 inch.	
9	Keep the individual on their side for 5 minutes if comfortable to prevent medication from being expelled. After this gently reposition them back to a comfortable position.	
10	Remove your gloves and wash your hands.	

5. After someone has died

Please find below a practical checklist for what you need to do now:

- You do **not** need to call the police or ambulance, this was an expected death.
- Call your nominated family member or support person if you feel you need to.
- **During the day in the week:** call the District Nurse locality hub phone number or your GP surgery to inform them of the death (see page 3).
- **During the night / evenings / bank holidays and weekends:** call the District Nursing hub phone number **0300 421 0555**
- You can care for your relative or friend after death as much as you feel able to. If possible, lie them straight in the bed.
- Keep the room cool if possible by turning off the radiator.
- Do not allow pets in the room unattended
- If appropriate to your faith/belief system, this may be a time to contact a representative of that faith/belief

6. Grief

Many feelings can occur at this time, for example numbness, disbelief, exhaustion, relief, sadness and anger. Under these extraordinary circumstances you may feel emotions more acutely. Grieving in isolation can be one of the hardest aspects of the current situation. Do reach out to others however you can - online, via telephone, letters and videos.

If difficult feelings persist or you feel you are not coping then seek help. These organisations may be useful:

Cruse Bereavement Care

0808 808 1677

www.cruse.org.uk

Winston's Wish

Support for bereaved children and young people

08088 020 021

www.winstonswish.org

The Good Grief Trust

www.thegoodgrieftrust.org

7. Cleaning in cases of covid infection

- Cleaning an area with normal household disinfectant will reduce the risk of passing the infection on to other people.
- Wherever possible, wear disposable or washing-up gloves and aprons for cleaning. These should be double-bagged, then stored securely for 72 hours then thrown away in the regular rubbish after cleaning is finished.
- Using a disposable cloth, first clean hard surfaces with warm soapy water. Then disinfect these surfaces with the cleaning products you normally use.
- Pay particular attention to frequently touched areas and surfaces, such as bathrooms, grab-rails in corridors and stairwells and door handles.
- If an area has been heavily contaminated, such as with visible bodily fluids, from a person with coronavirus (COVID-19), consider using protection for the eyes, mouth and nose, as well as wearing gloves and an apron.
- Wash hands regularly with soap and water for 20 seconds, and after removing gloves, aprons and other protection used while cleaning
- For latest government guidance see GOV.UK:
<https://www.gov.uk/government/publications/covid-19-decontamination-in-non-healthcare-settings/covid-19-decontamination-in-non-healthcare-settings>

8. Carer diary for medicines

It is not essential to keep this diary, but you may find it helps and the nurses and doctors may wish to see it

Patient name:							Date of birth:							
Allergies or Adverse Drug Reactions:														
Drug Form and strength	Indication for use	Dose (see medication label for frequency and maximum dose)	Record of administration Record date, time and dose given											
Morphine sulphate 10mg/5mL Oral liquid	Pain, shortness of breath or cough	See medicine label for dose												
Lorazepam tablets 1mg	Panic/ Agitation/ Restlessness	Half to one tablet (500microgram to 1mg)												
Midazolam	Seizures / Agitation / Restlessness	See medicine label for dose												
Hyoscine hydrobromide 300mcg tablets	Rattly breathing/nausea	Half to one tablet (150 to 300micrograms)												
Paracetamol 500mg suppositories	Symptoms of fever	2 suppositories (1g)												



For further advice please contact:
Patient Advice and Liaison Service,
Gloucestershire Clinical Commissioning Group,
FREEPOST RRYY-KSGT-AGBR,
Sanger House, 5220 Valiant Court,
Gloucester Business Park, GL3 4FE
Telephone: **01452 566698**
Email: glccg.pals@nhs.net

To discuss receiving this information in large print
or Braille please ring **0800 015 1548**.
To discuss receiving this information in other
formats please contact:

এই তথ্য অন্য ফর্মাটে পেতে আলোচনার জন্য দয়া করে যোগাযোগ করুন
如需以其他格式接收此信息，请联系

V případě, že potřebujete obdržet tuto informaci v jiném formátu, kontaktujte
prosím

આ માહિતી બીજા ફોર્મેટમાં મળવાની ચર્ચા કરવામાટે કૃપાકરી સંપર્ક કરો
Aby uzyskać te informacje w innych formatach, prosimy o kontakt

По вопросам получения информации в других форматах просим
обращаться

Ak si želáte získať túto informáciu v inom formáte, kontaktujte prosím

0800 015 1548