

Caring for someone at the end of their life

Information leaflet



**Palliative and
End of Life Care**
One Gloucestershire

This leaflet is written for people who are caring for someone who may be approaching the end of their life. It may also be useful for the person who is being cared for to read this leaflet if they are well enough to do so. It contains some practical tips and advice about medications to help with symptom management. ¹

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Palliative & End Of Life Clinical Programme
Group Review Date: August 2025

1. Who to call for advice

Your Community Nursing team can assess your relative or friend and arrange equipment and care to support you, including gloves and aprons and help and advice with medication. You can call them 24 hours a day. They may assess over the telephone or come out and see you. Your local hospice can also offer advice and support. 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 Tewkesbury, Newent & Staunton	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): |
|---|
| <ul style="list-style-type: none">▪ You can phone your usual GP Surgery number▪ For an out of hours doctor telephone 111 or use 111.nhs.uk |

Specialist Palliative Care Team
<p>The Specialist Palliative Care Team is made up of a variety of professionals including specialist nurses and doctors who have all received specialist training. They work alongside your GP, district nurses and other providers such as hospice at home and domiciliary care teams in providing support for you and your family with the management of complex problems, particularly when an existing plan does not seem to be working.</p> <p>The Community Specialist Palliative Care Team are available on 0300 422 5370 Monday to Friday, 9:00am to 5:00pm. Even if your relative is not known to the team, telephone advice is available for any healthcare professional and they will be able to contact the team if needed.</p>

¹ Acknowledgement Palliative & End of Life Care | North Bristol NHS Trust (nbt.nhs.uk)
² Practical-Care-For-Dying-Person-Toolkit.pdf (helixcentre.com) (Accessed 4/4/23)

Hospice Care

Hospice care focuses on delivering expert support to individuals with life-limiting illnesses.

In Gloucestershire our Sue Ryder hospice in Leckhampton provides inpatient care, the other providers' work is in the community, supporting people and their families in their own homes.

Hospices are no longer a place where people are admitted for their last days of life; although this option still exists, modern hospices are now more focused on expert symptom management and maximising quality of life, as well as delivering other services such as bereavement support, well-being centres, outpatient clinics and therapy.

There are six hospice providers which support the people of Gloucestershire. The Hospices are partially funded by NHS Gloucestershire, but they also rely on donations to fund their vital work. As the hospices are separate organisations their offers may vary, a brief overview is shared below, please contact them direct to find out more.

Sue Ryder Leckhampton Court, Cheltenham

- Our staff care for people with complex conditions in our hospices, and we also provide care in people's homes, in the community and online.
- Our hospice is Gloucestershire's only inpatient unit for specialist palliative care.
- Our telephone line gives you access to a member of the hospice team who can give you advice on symptoms and nursing care. It is available to all patients who are receiving, have received or are in the process of being referred to any of our care services.
- To contact our Patient Line, please call **0300 303 1395**. This helpline is open 24 hours a day, seven days a week.
- Sue Ryder Leckhampton Court Hospice **01242 230199**

Longfield Community Hospice Care, Minchinhampton, Stroud

- Longfield Hospice at Home team provides free care 365 days a year, for adults in Gloucestershire living with a life-limiting illness and provides support for their loved ones and carers.
- Our Hospice at Home staff might do up to 3 visits per day to each patient and overnight sits.
- Telephone: 01453 886868

Great Oaks Hospice, Forest of Dean

- Our hospice at home nursing care is available to anyone living in the Forest of Dean District. Our nursing care and support is also available for patients suffering an acute episode of life-limiting illness or experiencing a time of illness related crisis.
- Telephone: 01594 811910 or Out of Hours Hospice at Home: 07760 769670

Campden Home Nursing, Chipping Campden

- Campden Home Nursing is an independent local charity based in Chipping Campden, Gloucestershire. We provide free registered nursing care for those living with a life limiting illness who wish to be cared for at home, and holistic support for their families and carers.
- Telephone: 01386 840505 (Office), 07780 660141 (Nurse Co-ordinator)

Kate's Home Nursing, Bourton on the Water

- Kate's Home Nursing is a local charity, employing the services of registered nurses to care for people in their own homes through the last stage of illness, offering support and care for the patient, their family, and carers.
- Telephone: 07841 025909, Nursing Coordinator: 07800 830302

Friends of Fairford & Lechlade Communities

- We are a Home Nursing service available to patients of Fairford and Lechlade GP Surgeries. Our team of registered nurses and healthcare assistants support end-of-life patients that wish to remain at home.
- Telephone: 07938 244335

2. ReSPECT Plan

- ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment.
- It is a nationally recognised and agreed plan that is used in Gloucestershire to record 'what matters' to individuals, their values and fears to enable healthcare professionals to indicate what clinical treatment your relative or friend may want in an emergency situation or approaching the end of their life, where they are not able to make decisions or express their wishes.
- The ReSPECT plan also records a person's resuscitation wishes and whether they are for an attempt at cardiopulmonary resuscitation (CPR) or not.
- If your relative or friend has documented on their ReSPECT plan that they do not want an attempt at CPR, then when approaching the end of their life, this information will help to inform healthcare professionals caring for your loved one allowing them to die a natural death.
- For more information on the ReSPECT process please contact your health care professional or discuss with their GP.

ReSPECT Recommended Summary Plan for Emergency Care and Treatment

Full name
Date of birth
Address
NHS/CHI/Health and care number

1. This plan belongs to:
Preferred name
Date completed

The ReSPECT process starts with conversations between a person and a healthcare professional. The ReSPECT form is a clinical record of agreed recommendations. It is not a legally binding document.

2. Shared understanding of my health and current condition
Summary of relevant information for this plan including diagnoses and relevant personal circumstances:
Details of other relevant care planning documents and where to find them (e.g. Advance or Anticipatory Care Plan; Advance Decision to Refuse Treatment or Advance Directive; Emergency plan for the carer):

I have a legal welfare proxy in place (e.g. registered welfare attorney, person with parental responsibility) - If yes provide details in Section 8 ☐ Yes ☐ No

3. What matters to me in decisions about my treatment and care in an emergency
Living as long as possible matters most to me
Quality of life and comfort matters most to me
What I most value:
What I most fear / wish to avoid:

4. Clinical recommendations for emergency care and treatment
Prioritise extending life
Balance extending life with comfort and valued outcomes
Prioritise comfort
Now provide clinical guidance on specific realistic interventions that may or may not be wanted or clinically appropriate (including being taken or admitted to hospital +/- receiving life support) and your reasoning for this guidance:

CPR attempts recommended Adult or child
For modified CPR Child only, as detailed above
CPR attempts NOT recommended Adult or child

www.respectprocess.org.uk

3. General information

Caring for someone at the end of their life can be rewarding and bring you closer together; it is a loving and generous thing to do. But it is also physically and emotionally demanding and may affect your relationship. There is no right or wrong way to feel, but it can help to talk and to look after your own wellbeing.

Registering with the carers hub may also offer you some support. Contact:

www.gloucestershirecarershush.co.uk or **0300 111 9000** Mon, Wed and Fri 9am-5pm, Tues and Thurs 8am-8pm

The information given in this leaflet is to help you feel supported with this decision, although it is acknowledged it can feel overwhelming at times and may cause anxiety for you. It might be helpful to nominate a family member or a friend to provide support for you during this time.

It is important to look after yourself. Here are some things to consider:

- 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. Creating a sense of calm around your relative or friend can help them to feel settled.
- 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. 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. Remember, it is OK to talk and sometimes even laugh around people who are dying at home. Try to keep the home environment as you usually would.
- 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 such as pain, nausea and vomiting. These medicines will not hasten death. With the right professional support, people should be able to have their symptoms managed and be kept comfortable during this time.
- 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.

4. 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.

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.

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 person daily provides movement and an opportunity to check their skin. Your health team can help with providing this care.

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.

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.

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.

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.

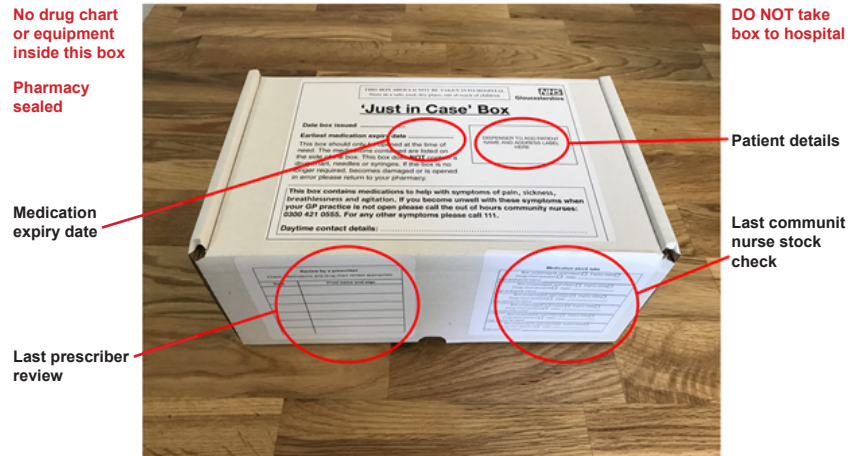
When a person is no longer able to swallow some people want them to have fluids via other routes like a drip, but at the end of life this offers little, if any, benefit. The body cannot process the fluid like a healthy body can and it can be harmful to artificially feed and hydrate. Risks include infection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

5. Symptoms and medicines

Your relative or friend may have been provided with some of these medicines that could help to ease the symptoms as described in section 4.

5.1 Just in Case Medication

Just in Case (JIC) medications are for people who are deteriorating or in the last few months of their lives and are unable to swallow their medication orally. They usually come in a sealed box, see picture below. Inform your community nurses if your relative or friend has been prescribed a JIC box so that they are able to keep a check of the medications and ensure there is a signed drug chart and equipment such as syringes and needles are available in the home.



These are medications that would be given by a healthcare professional and if needed you can contact the community nurses in or out of hours. If you have been given additional numbers such as for a palliative care / hospice team you can contact them.

JIC boxes contain their personalised anticipatory symptom control medications as prescribed by their GP.

These may include some or all of the following:

- **Morphine Sulphate 10mg in 1ml** - a strong painkiller which can also help with shortness of breath.
- **Midazolam 10mg in 2ml** - which can help with anxiety, agitation & distress, shortness of breath and restlessness.

- **Levomopromazine 25mg/1ml** - which can help with nausea and sickness.
- **Glycopyrronium 200 micrograms/1ml** – this is a medication for secretions that can pool in the back of the throat leading to noisy breathing (sometimes called death rattle)
- **Water for injection 10ml** – used when one or more injectable medicines are given through a syringe pump to relieve more than one symptom together.

5.2 Syringe pump

Some people approaching the end of their life will need a syringe pump. A syringe pump is a small battery operated pump which is designed to give a constant supply of prescribed medication when the person is unable to take it by mouth. This could be because:

- They have difficulty swallowing tablets or syrups.
- They are feeling nauseous or vomiting.
- Multiple injections throughout the day aren't the most effective way to manage symptoms.
- The medication recommended isn't available orally.

Some of the commonly used medications in syringe pumps help to manage:

- Nausea or vomiting
- Pain
- Chesty secretions
- Restlessness and agitation

The Syringe pump (see picture below) will be managed daily by the Community Nursing team and overseen by your GP and / or Specialist Palliative Care team.



6. After someone has died

Verification of death

Verifying a death is the process of formally confirming a person has died³. This must be carried out by a healthcare professional trained to do this. In the community, this ideally will be done within four hours of the person's death.

Verification of death might be called different things. You might come across the terms 'confirmation of death', 'verification of life extinct' or 'recognition of life extinct'.

Who to call if you think your relative or friend has died:

- **During the day in the week:** If the Community Nursing team is involved with your relative or friend's care, then call the District Nurse locality hub phone number or your GP surgery promptly to inform them of the death so they can verify the death (see page 3).
- **During the night / evenings / bank holidays and weekends:** If known to the Community Nursing day team, then call the District Nursing hub phone number **0300 421 0555**
- You do not need to call the police or ambulance; this was an expected death. The time the death is verified, will be the official time of death.
- If your relative or friend is not currently receiving care from the community nurses, then please contact their GP surgery during the week or via 111 out of hours. Please state: 'this is an expected death'. You may be asked if your relative or friend has a ReSPECT plan if they do and it states not for an attempt at CPR, (see section 2), then please inform 111.
- Call other family members and / or a friend if you feel you need to.
- If appropriate to your faith/belief system, this may be a time to contact a representative of that faith/belief if you haven't already done so.
- 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 by turning off the radiator and opening a window.
- Do not allow pets in the room unattended.
- When you are ready, you will need to contact your chosen funeral director (undertaker) who will arrange for your relative or friend's body to be taken from their home to the mortuary.
- The funeral director will usually advise you of the next steps in planning and arranging the funeral.

7. Register a death

You **must aim to register your relative or friend's death within five days of the date of death**, in the registration district in which it took place. This includes weekends and Bank Holidays. By registering you will be able to obtain death certificates, a green form for cremation or burial and use the 'Tell Us Once' service in the link below.

If the death has been reported to the coroner you will not be able to register until the coroner has completed their investigation.

Please make sure you book an appointment. For more information please visit: <https://www.gloucestershire.gov.uk/births-marriages-deaths-and-civil-partnerships/register-a-death/>

8. Grief

Grief is a completely natural way to respond to the death of someone important to you. There's no right or wrong way to grieve and it feels different for everyone. Each time that we grieve during our lifetime will feel different too.

Many feelings can occur at this time, for example numbness, disbelief, exhaustion, relief, sadness and anger.

You do not have to go through the grieving process alone. There are lots of ways to get support, whether you prefer to talk to someone in person or to join an online community.

Even if you feel like you are managing OK and can cope with day-to-day life, you may still look for bereavement support as a way of helping you to process your feelings of grief.

These organisations may be useful:

Cruse Bereavement Care

0808 808 1677

www.cruse.org.uk

Longfield Hospice provides Counselling and Bereavement services

01453 886868

Marie Curie

Marie Curie Support Line | Helpline

0800 090 2309

Winston's Wish

Support for bereaved children and young people 08088 020 021

www.winstonswish.org

The Good Grief Trust

www.thegoodgrieftrust.org

Your Circle

Home | YourCircle

³ <https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/final-days/care-after-death#when> (Accessed 11.4.23)



One
Gloucestershire

Transforming Care, Transforming Communities

For further advice please contact:

Patient Advice and Liaison Service (PALS)

NHS Gloucestershire Integrated Care Board (ICB)

FREEPOST RTEY-EBEG-EZAT

Shire Hall, Westgate Street, Gloucester,
Gloucestershire, GL1 2TG

Tel: **0800 0151 548** / Email: glicb.pals@nhs.net

To discuss receiving this information in large print or
Braille please ring: **0800 0151 548**

To discuss receiving this information in other formats
please contact:

এই তথ্য অন্য ফর্ম্যাটে 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

আ মাহীতী বীজা ভ্রমের সমস্যা মনোবানী চর্চা করবামতে কৃপাকরী সংপর্ক করে

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 0151 548