One Gloucestershire
Transforming Care, Transforming Communities

NHS

Caring for someone who is dying

Information leaflet

Palliative and End of Life Care

Introduction

This booklet has been written to support you when you are caring for someone who is dying at home.

It is likely to be a difficult time when someone close to you is dying. You may have questions about what to expect in the last days of life, and how someone important to you will be cared for. The approach the care team will use will be individual to you or your loved one.

Healthcare provided by the NHS is free, but not everyone is eligible to free care outside of the hospital and hospice setting.

Most medical and nursing care at the end of life is free on the NHS. Hospices are partly NHS funded but rely mainly on donations.

Help with daily personal care at home may not be free. This is usually means tested by the local authority unless the person is eligible for **NHS Continuing Healthcare (Fast Track)**, which provides full NHS funded care for those who are rapidly deteriorating.

The place where the person is cared for and the support they need will vary. It is important to identify what is important to the person. It may be helpful to discuss what is important to them and discuss how this can be achieved. A person can change their minds at any time so be prepared for this.

Home: the person who is dying is surrounded by their loved ones and be in a familiar place. Care may be available to support this

Hospice: hospices can provide care that is free of charge. They can provide specialist care and emotional and practical support.

Care home / Nursing home: care is provided 24/7 by either carers or registered nurses.

Hospital: the person may need to go to hospital for treatment or tests, particularly if there is a sudden change in their condition and there is an emergency.

Who to contact for advice

General Practitioner (GP)

You can phone your usual GP Surgery number.

Out of hours you can call **111** or use **www.111.nhs.uk**

Community (District) Nursing

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/video. The numbers you need to call for district nursing are below:

Cheltenham locality	**0300 421 6070**
Cotswolds locality	**0300 421 6072**
Gloucester locality	**0300 421 6071**
Forest TNS locality	**0300 421 6074**
Stroud locality	**0300 421 6073**
Out of hours (4pm – 8am / evenings, weekends and bank holidays)	**0300 421 0555**

Who could support you

Continuing Healthcare (CHC) Fast Track

People whose heath is rapidly deteriorating and who may be entering the terminal phase should be considered for the NHS CHC Fast Track funding, so that an appropriate care and support package can be put in place as soon as possible. An appropriate clinician will complete the fast-track tool to establish eligibility for NHS Continuing Healthcare.

Hospice Care

Hospices focus on helping people feel as comfortable as possible, managing symptoms, and improving daily life. Many also offer things like bereavement support, wellbeing activities, outpatient care and therapies.

There are six hospice providers in Gloucestershire. Hospices are sometimes partially funded by the NHS, but most are charitably funded and rely on donations to fund their vital work. As the hospices are separate organisations their offers may vary.

Campden Home Nursing

Campden Home Nursing is an independent local charity based in Chipping Campden. They 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)

Friends of Fairford and Lechlade

A Home Nursing service available to patients of Fairford and Lechlade GP Surgeries to support end-of- life patients that wish to remain at home.

Telephone: 01285 707300

Great Oaks Hospice

The Hospice at Home nursing care is here for anyone living in the Forest of Dean District. Attentive support is offered for people living with a life limiting illness. The aim is to bring comfort, reassurance, and skilled care. Staff work alongside the Community Nursing and Palliative care teams to ensure the best patient centred care possible.

Telephone: 01594 811910

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

Longfield Community Hospice

Longfield Hospice at Home team provides care 365 days a year for adults in Gloucestershire living with a life-limiting illness and provides support for their loved ones and carers.

Hospice at Home staff might make up to 3 visits per day to each patient and overnight sits.

Telephone: 01453 886868

Sue Ryder Leckhampton Court, Cheltenham

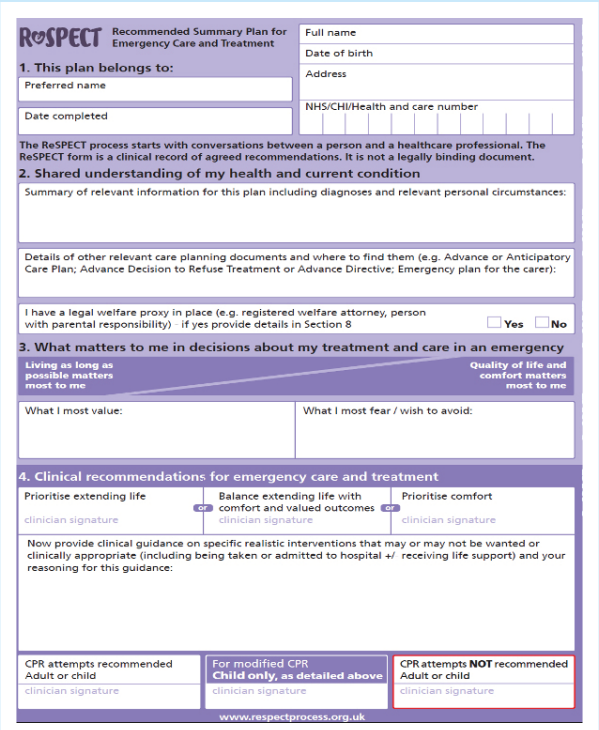
Staff at Sue Ryder care for people with complex conditions in our hospices, and they also provide care in people's homes, in the community and online.

The hospice is Gloucestershire's only inpatient unit for specialist palliative care.

Telephone: 01242 230199

ReSPECT Plan

- **ReSPECT** stands for Recommended Summary Plan for Emergency Care and Treatment.
- It is a national plan used in Gloucestershire to record what matters to a person — their wishes, values and worries.
- It helps healthcare professionals understand what care or treatment they would want in an emergency or near the end of life if they cannot speak for themselves.
- The **ReSPECT** plan should be stored in place that is easily accessible in the event of an emergency and should be taken to all appointments and if you are admitted to hospital.
- 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

1. This plan belongs to:

Preferred name

Date completed

Full name

Date of birth

Address

NHS/CHI/Health and care number

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 clinician signature

or

Balance extending life with comfort and valued outcomes clinician signature

or

Prioritise comfort clinician signature

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 clinician signature

For modified CPR **Child only, as detailed above** clinician signature

CPR attempts **NOT** recommended Adult or child clinician signature

www.respectprocess.org.uk

Help for you / things to consider

Caring for someone can be hugely rewarding but can also be tiring and sad and can feel very challenging. There is no right or wrong way to feel, but it can help to talk and to look after your own wellbeing.

The GP will support any concerns you have and works closely with the Community Nurses. Specialist Palliative Care may also be involved and will work collaboratively with other healthcare professionals to support you.

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. The HCP's involved will monitor and advise if medication is needed and support with uncontrolled 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.

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

Practical care for someone who is in their last days and hours of life

If you have concerns about any symptoms, you can contact your care teams involved for more specific advice.

Moving and Handling

A hospital bed and pressure relieving mattress can be provided. Community nursing teams will assess and monitor skin condition and can support and advise you about moving and positioning if needed.

Washing

Sometimes it may be too disruptive for the person to have a full wash. Washing their hands, face and bottom can feel refreshing. Please speak to the care teams involved for specific advice.

Going to the toilet

Towards the end of life, a person may lose control of their bladder and bowel. This can be managed well with pads and hygiene.

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 probably hear right up until they die.

Mouthcare

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 the inside of their mouth and around their teeth with a moistened toothbrush whether they are awake or have lost consciousness.)

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. These symptoms can be difficult to manage and your healthcare team will work with you to keep them comfortable.

In some scenarios reassurance can help such as talking to them calmly, sitting with them, listening to music or television. Touch can be effective in doing this too.

Eating

People lose their appetite when they are nearing the end of their life. The body follows the natural process of slowing down, such as a loss of energy, the need for more sleep and rest, and reducing appetite. The gut works more slowly, it absorbs less nutrients, and less calories are needed for energy.

An additional leaflet provides more information about eating and drinking.

Feeling sick

Sometimes people can feel sick when they are dying. Avoiding strong cooking smells and perfumes can help as can some fresh air. 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. Please discuss symptoms with your health team.

Pain

Some people may have pain when they are dying. If they are less conscious, they many grimace or groan to show this.

Your health team will advise you on the medications that can help. While waiting for an assessment or for medication to work, giving your reassurance and comfort can help. Other things that may help include heat pads or a change of position.

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 the 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 the secretions if it is a problem.

Medicines

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.

Inform your community nurses if your relative or friend has been prescribed JIC medications 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 available in the home.

The JIC medications 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.

The medications may include some or all of the following:

- **Morphine Sulphate (or equivalent)**
  A strong pain relief which can also help with shortness of breath.
- **Midazolam**
  Can help with anxiety, agitation & distress, shortness of breath and restlessness.
- **Levomepromazine**
  Can help with nausea and sickness.
- **Glycopyrronium**
  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**
  Used when one or more injectable medicines are given through a syringe pump to relieve more than one symptom together.

Syringe Pump

Some people approaching the end of their life will need a syringe pump/sometimes called a syringe driver (see picture below).

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:

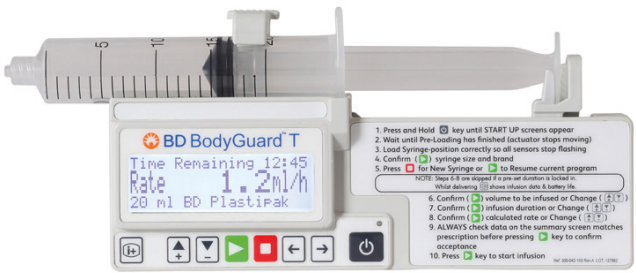
- They have difficulty swallowing tablets or syrups.
- They are feeling nauseous or vomiting.
- Multiple injections throughout the day aren't the most effective way to manage symptoms.
- The medication recommended isn't available orally.

The commonly used medications in syringe pumps help to manage:

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

If you are at home the Syringe pump will be managed daily by the Community Nursing team and overseen by your GP and / or Specialist Palliative Care team. In the rare occasion of the pump alarming, please contact your community nursing team for support.

If you are in a Nursing Home or hospital the Nursing staff will manage the syringe pump.



After someone has died

Verification of death

Verifying a death is the process of formally confirming a person has died. 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.

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.

Continued...

- 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 you 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.

Register a death

Medical Examiner Service

- The role of Medical Examiner (ME) was created to oversee and authorise paperwork needed to register a death.
- An ME is a senior doctor who was not involved in providing care to the deceased but understands the circumstances leading to their death.
- Prior to release of the certificate of cause of death the ME will need to review medical records and liaise with the clinical teams who provided care. This is because the ME is responsible for countersigning the certificate completed by the doctor who treated the patient.
- As part of their role the service must speak to the nominated family member or friend to enable them to raise concerns and provide feedback on the care received.

You must aim to register your relative or friend's death within five days of the date you are advised by the Medical Examiner service that the certificate of cause of death is complete.

You are encouraged to register the death in the county in which it took place.

The registration process will allow you 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 there will be a different process to follow. The coroner service will be able to advise you personally about obtaining death certificates once they have completed their investigation.

Please make sure you book an appointment to register the death.

For more information please visit:
www.gloucestershire.gov.uk/births-marriages-deaths-and-civil-partnerships/register-a- death/

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.

On the next page there are some organisations that can provide support...

2 Wish - www.2wish.org.uk
Supporting those affected by the sudden and unexpected death of a child or young adult aged 25 or under

Age UK - www.ageuk.org.uk

Alzheimer's Society - www.alzheimers.org.uk

Ataloss - www.ataloss.org

Campden Home Nursing - www.campdenhomenursing.org

Charlies - www.charlies.org.uk
Supporting those affected by cancer

Cruse Bereavement Support - www.cruse.org.uk

Friends of Fairford - www.friendsoffairford.org.uk

Gloucestershire Muslim bereavement council - https://masjidenoor.org.uk/gmbc/

The Good Grief Trust - www.thegoodgrieftrust.org

Your Circle - www.yourcircle.org.uk

Great Oaks Hospice - www.great-oaks.org.uk

Grief Kind - www.sueryder.org/our-campaigns/grief-kind/

Kate's Home Nursing - www.kateshomenursing.org

Longfield Community Hospice - www.longfield.org.uk

Maggies - www.maggies.org
Support for people with cancer and their friends and family

Marie Curie Support Line - Helpline 0800 090 2309

Rethink Mental Illness - www.rethink.org

Winstons Wish - www.winstonswish.org / 08088 020 021
Support for bereaved children and young people

Scan the QR code to access more information on the webpages ‘A Personalised approach to Palliative, End of Life and Bereavement Care’.

To discuss receiving this information in other languages, large print or Braille please contact:

Aby omówić możliwość otrzymywania tych informacji w innych językach, w formacie dużą czcionką lub alfabetem Braille’a, prosimy o kontakt:

Pro projednání možnosti obdržení těchto informací v jiných jazycích, velkým písmem nebo v Braillově písmu, prosím kontaktujte

Pentru a discuta despre primirea acestor informații în alte limbi, cu caractere mari sau în alfabet Braille, vă rugăm să contactați:

এই তথ্য অন্য ভাষায়, বড় অক্ষরে বা ব্রেইল লিপিতে পাওয়ার বিষয়ে আলোচনা করতে, দয়া করে যোগাযোগ করুন:

如果您想讨论以其他语言、大字版或盲文获取此信息，请联系：

لمناقشة إمكانية الحصول على هذه المعلومات بلغات أخرى، بخط كبير أو بطريقة برايل، يرجى التواصل مع

برای بحث در مورد دریافت این معلومات به زبان‌های دیگر، با خط بزرگ یا به خط بریل، لطفاً تماس بگیرید:

اس معلومات کو دیگر زبانوں، بڑے حروف یا بریل میں حاصل کرنے پر بات کرنے کے لیے، براہ کرم رابطہ کریں:

Email: glicb.pals@nhs.net / Tel: 0800 015 1548

FREEPOST RRYY-KSGT-AGBR
PALS, NHS Gloucestershire ICB,
Shire Hall, Westgate Street,
Gloucester, GL1 2TG