

The last few days or weeks of life at home

**A guide for people caring for someone at
home at the end of their life**

Introduction

This booklet is designed to help you care for someone at home during the final few days or weeks of their life. Even when you know that your friend or relative is approaching the end of their life, you may not feel prepared.

As a carer, understanding what to expect can help to reduce some of the fear and confusion. A carer is someone who is providing care and/or support for an individual. You may be a partner, other family member or friend.

The information contained in this booklet will support the discussions you have had with the palliative care team. We will plan what equipment and practical help you will need before your friend or relative comes home. This booklet will also guide you through the first steps to take after the person you have been caring for has died.

When you are preparing to care for someone at home

The time between making the decision to come home and your relative or friend actually arriving home may not be very long, perhaps only a few days. There are a number of things you need to think about and start preparing.

Preparing a room

Firstly, you will need to prepare a suitable room. This will depend on what works best for you and other people involved in providing care. The ward team or the palliative care team will talk to you about any equipment that you may need. Please see the checklist on page 10 as a guide.

You may need to move furniture around to make space for a hospital bed, which should be placed near an electrical socket. The professional carers will need space to walk around the bed, rather than it being pushed against a wall. If you need a hospital bed, this will be delivered and assembled for you in the home.

Preparing yourself

It can be very fulfilling to support your friend or relative dying at home, although there may be challenges. It can be helpful to have someone supporting you during this time. If you are able to share the care with others, you may find this helpful. You need to look after yourself if you are to continue looking after someone else.

You may want to think about doing some things differently for a while. For example, it may be helpful to reconsider shopping arrangements and work commitments if possible.

The hospital teams will liaise with your family member or friend's GP to update them on discharge from hospital. The GP may contact you to speak to you over the telephone or may arrange a home visit.

If your relative or friend has any religious or spiritual needs you may want to arrange for visits from a religious or spiritual practitioner to be made, particularly if any special practices need to be carried out.

Help with caring

If carers have been arranged by the hospital, they will come to the home to assist with the personal care of your relative or friend. This may include tasks such as washing the person and changing nightclothes. Carers (who are usually healthcare assistants rather

than registered nurses) can visit up to four times a day, depending on what level of help is needed. They are not able to help with any household tasks.

A night sitting service may be available up to two or three times a week, but this service may not be available on a regular basis. We would advise liaising with the hospital team or, once at home, with the community palliative care or district nursing team regarding this. The nurse or carer would stay in the same room as your relative in a comfortable chair and would be able to help with tasks that arise during the night. This would enable you to have some much needed rest.

Visitors

You may receive telephone support or home visits from the following people:

- The GP, who has overall responsibility for care at home. Out of surgery hours, there will be an on-call doctor available via NHS 111.
- A district nurse. They can provide a range of care including changing dressings, giving medication and advising on personal care. In some areas, the district nurses offer a 'twilight' or evening service and they may be available overnight. This will be confirmed by your local district nursing team who will give you all the relevant contact numbers.
- Carers to assist with personal care.
- The community palliative care team. They are usually based at the local hospice. The team can provide specialist advice on pain and symptom control and emotional support. They can also consider referral for an inpatient bed at the hospice if appropriate.

What should I do if...?

Not knowing what to expect or what to do if something unexpected happens can be overwhelming. These are some of the questions that people commonly ask.

What should I do if the carers don't arrive?

In the first instance, you should contact the care agency. If the matter remains unresolved, contact the district nurses or community palliative care team.

What should I do if my relative or friend has uncontrolled symptoms?

If you have concerns regarding symptoms such as pain, breathlessness, chest secretions or agitation, telephone the district nurses for advice in the first instance.

They may be able to visit to carry out an assessment and can administer medications by injection if appropriate. Alternatively, you can contact the community palliative care team for advice.

What should I do if I need support with my relative or friend's personal care and the carers are not present?

Telephone the care agency in the first instance – they may be able to visit depending on the time of their next scheduled visit. Alternatively, the care agency may advise you to contact the district nurses for assistance.

What should I do if I'm worried that I am not coping well?

Many people feel overwhelmed and worry about not coping. Circumstances can change and you may feel that caring for your relative at home is no longer the best place for them. Speak to your community palliative care team for advice early and seek support from your GP if the situation is difficult.

What should I do if my relative or friend falls out of bed?

Contact the district nursing team for advice in the first instance. Depending on the situation, they may advise you to contact the ambulance service via 999 to help assist your relative or friend back into bed. It is important that you do not put yourself or your relative or friend at risk by trying to do this without assistance.

Physical changes

As the dying process progresses, you may notice that your relative or friend experiences a range of physical changes. Although most changes are gradual, occasionally, a change in condition can occur more quickly. If you are concerned, contact your district nursing team or community palliative care team for support.

Mobility

You are likely to notice that your relative or friend will become progressively more tired and will spend more time in bed. An air mattress can help prevent discomfort and pressure ulcers and this can be provided via your district nursing team. The carers or district nurses will show you how you can move your relative or friend safely.

Eating and drinking

As the dying process progresses, it is very common for people to lose interest in eating and drinking.

Your relative or friend's need for fluids and food will lessen in the last days to weeks of life. This can be concerning as we often view eating and drinking as important elements of sustaining life. However, these changes are a natural part of the dying process. In the last hours to days of life, your friend or relative may be too drowsy to eat and drink. It is important only to offer

sips of fluid if they are awake and sitting upright, to avoid the risk of coughing or choking.

You can moisturise your relative or friend's lips with Vaseline and gently clean their mouth to keep it moist with mouth sponges supplied by the district nurses. You can use their favourite tastes (e.g. juice or Coca Cola) as an alternative to water with the mouth sponges to promote pleasure and comfort.

Communication

Fatigue can make it difficult to concentrate and join in conversations. It can become more difficult to stay interested in things that were previously important. It is often a good idea to say anything you want to tell your relative or friend before they become too fatigued and to make sure that they have time to rest.

Consciousness and cognition

As your relative spends more time sleeping, you may find it more and more difficult to wake them up. Gradually, they are likely to become unconscious, although they may have brief moments when they are awake. While you may not be able to hold a conversation with them, it can still be comforting to talk to them. They may be able to hear what is said to them even if they don't respond.

Some people may become restless or disorientated as part of the dying process. If you are at all concerned, contact the district nurses or community palliative care team.

Breathing and secretions

You may notice that your friend or relative's breathing pattern changes. Their breathing may become irregular and breaths may become fast and shallow. You may

notice episodes when breathing pauses for what seems like a long period of time. In the last moments, breathing may become slow and shallow. You may hear noisy respiratory secretions (this is sometimes referred to as 'death rattle'). This is a common part of the dying process and there are medicines which may help with this. If you have any concerns, contact the district nurses or community palliative care team.

The last few moments

It is difficult to know exactly when someone will die but there are some signs to suggest that someone is in the last hours to days of life.

Your friend or relative's breathing may become irregular and shallow. They may appear to stop breathing for a time, then take another breath. This does not usually cause distress to the person who is dying but can make it difficult to tell if it is the last breath.

When you touch your relative or friend, their skin may feel cold and moist. These changes are normal and are part of the dying process. As their body relaxes some people may lose control of their bladder and bowels.

When someone dies at home

After your relative or friend has died, contact the GP, district nurses or the community palliative care team and they will advise you regarding the next steps.

A healthcare professional will need to visit to see your friend or relative's body after they have died to carry out the verification of death checks. Once this has occurred, you will be advised when you can contact a funeral director to collect your friend or relative's body.

After death

After the death of someone who is close to you, there are many practical tasks that need to be carried out. Please ensure that you take time to look after yourself during this very difficult time. Although you may have prepared for this moment, it can still be a shock when death occurs. You can contact the community palliative care team or your GP to access bereavement support.

When you are ready, contact the district nurses if you are unsure how to arrange for equipment or medication to be collected or disposed of.

Where do I register the death?

A doctor will need to complete a medical certificate to confirm the cause of your friend or relative's death (often called the 'death certificate') – this will usually be done by the GP.

There have been a number of changes to this process recently in light of the COVID-19 pandemic. The current process is that the Medical Certificate of Cause of Death ('death certificate') will be sent electronically to the local register office. The register office will then contact the death registrant (usually the next of kin) to ask some questions in order to prepare the death certificate.

This appointment usually takes place over the telephone. The registrar will inform you of the exact arrangements when they contact you. This process may be subject to further change in future and you will be informed if this is the case.

Checklist

You may find this checklist helpful when you are preparing for your relative or friend to come home.

Checklist	✓
<p>Preparing the layout of the room</p> <ul style="list-style-type: none"> • Moving furniture, if necessary • Deciding where to put the bed (near to an electric socket) • Where to put other pieces of equipment you may need • Providing bed linen 	
<p>A suitable container to store medication (out of the way of children and pets)</p>	
<p>Washing facilities (perhaps a bowl to use by the bed)</p>	
<p>Toilet facilities (may need a commode or bedpan, if the toilet is not nearby)</p>	
<p>A baby monitor/hand bell for your relative to attract attention</p>	
<p>A list of key contacts numbers (such as GP, district nurse and community palliative care team) near the telephone</p>	
<p>Think about the practical help you may need, for example, with shopping, cooking, cleaning etc.</p>	
<p>Think about the support you need from other people to help you provide care</p>	

Contact details

These are the names and contact details of the key people involved in helping you provide care at home.

GP (family doctor)

_____ Tel: _____

Out-of-hours doctor

_____ Tel: _____

Community Palliative Care Team

_____ Tel: _____

District Nursing Service

_____ Tel: _____

Hospital Palliative Care Team

_____ Tel: _____

Care Agency

_____ Tel: _____

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.stgeorges.nhs.uk

Additional services

Patient Advice and Liaison Service (PALS)

PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9.30am and 4.30pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough wings (near the lift foyer).

Tel: 020 8725 2453 **Email:** pals@stgeorges.nhs.uk

NHS Choices

NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.

Web: www.nhs.uk

NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.

Tel: 111

AccessAble

You can download accessibility guides for all of our services by searching 'St George's Hospital' on the AccessAble website (www.accessable.co.uk).

The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.

