

Managing the last days of life

A patient's guide

Throughout our lives, experiences of death and dying may have formed our views about how we would wish to die.

Some people prefer to die in their own homes, in familiar surroundings. You need to inform everyone involved in your care (including your GP, consultant, specialist nurse and your family) if this is important to you. The team at Royal Papworth can explore with you and those important to you what is necessary for this to be possible. This may involve referral to a social worker and / or other healthcare professionals.

If you have any information that you have written down detailing your wishes, such as lasting power of attorney (LPA), organ / tissue donation, or a Preferred Priorities of Care (PPC) document, please let us know.

Thinking about looking after someone who wishes to die at home often raises many questions. This leaflet outlines information to support you and your carers, but please ask questions about any aspect that concerns you.

Your GP

When you are discharged, we will let your GP know and will pass on the discussions we have had with you and those who will care for you. Once you are home, your GP will be responsible for your overall care.

It is important that your GP reviews your care at the earliest possible opportunity. Your GP will be able to review your symptoms and general aspects of your care. This will ensure that you are comfortable and will provide support for those who are caring for you. Your GP may liaise with other services, including staff from your local hospice (if appropriate).

District nurses

District nurses are part of a team that will work with your GP and other community services. They will also give advice on your general care - such as pressure area care, issues with toileting and coordination with those who may help look after you. They will telephone you to arrange a visit.

Personal carers (via agencies)

If you have personal care needs, such as help with washing, personal carers may be arranged.

This might have been arranged before your discharge from hospital or may be arranged as your needs develop at home.

Discuss this with any healthcare professional that you are seeing.

Community palliative care teams

Your local palliative care team (hospice teams, Macmillan nurses, etc.) may see you at home and / or liaise with your GP or district nurse.

Other considerations may include:

Finances

The financial benefits available to each individual vary and need to be assessed. Your healthcare professional will explore this with you, and may recommend additional advice, for example from a social worker.

Legal

Healthcare professionals cannot advise you about legal issues, but if you think there is anything that should be discussed with them please feel free to do so. If there are any legal issues a legally trained person will have to be consulted.

As part of your preparation to go home, you may be discharged with some items to ensure that you receive good quality care, such as:

- Medication to anticipate any symptoms you may experience. These may include injectable medications that a registered nurse could administer should you experience symptoms such as pain, restlessness or nausea / vomiting. These would be in addition to any regular medication.
- If already started in the hospital, you may be discharged with a syringe pump containing medication to maintain your comfort. The GP and district nursing team will be responsible for this once you are home.
- A list of whom to contact in an emergency which we recommend you keep by your phone.
- Important information and guidance about your care that we recommend you keep somewhere easily accessible to others. If it has been discussed with you in hospital, this may include your Do not attempt cardiopulmonary resuscitation (DNACPR) or ReSPECT form.
- There are some items that would usually be delivered to your home before your discharge from hospital, such as oxygen, a hospital bed, commode, etc. Please let us know if this will be a problem. There may be some equipment that could be delivered once you are at home.

At home the need for any changes or additional equipment can be reviewed by the district nurse.

As things progress and change, your wishes may also change.

Please raise any concerns with us; healthcare professionals are here to support you.

You or your loved ones may have questions about what happens when someone dies. We have written a leaflet called Last days of life - information for families and carers (PI 137) that we can also give to you.

Other sources of information you may find helpful include:

NHS Choices: end of life care
Useful guide with information for patients and carers. This includes a link to a guide to planning for your future care.
[nhs.uk/conditions/end-of-life-care/](https://www.nhs.uk/conditions/end-of-life-care/)

Age UK

Charity working with and for older people. Age UK Advice number: 0800 169 6565.
[ageuk.org.uk](https://www.ageuk.org.uk)

Dying Matters

Helpful information on dying, death and bereavement.
[dyingmatters.org](https://www.dyingmatters.org)

Out of hours help and advice

Each area has different arrangements for out of hours telephone contact. 'Out of hours' usually means 17:00 - 09:00 on weekdays, Friday 17:00 - Monday 09:00 and bank holidays.

The most likely reasons to ring out of hours services are for help with managing symptoms (for instance pain or nausea) or because there has been an unexpected change in your condition.

Some community palliative care teams have contact details for out of hours use and they will be able to give you these. However some areas may not have this facility so you will need to use other community services such as the out of hours GP or district nurse.

Out of hours GP

This will not be your usual GP. It will be the GP on duty for your area. They can assist and advise if you or the person you are caring for is having problems with symptoms. They are able to review what medication you are on, if extra medication could be helpful and prescribe this for you.

If you are caring for a loved one who has died out of hours the on duty GP will be able to visit to confirm this and advise what you should do next.

Out of hours district nurses

If the GP has prescribed medication to be given by injection, the district nurse will be able to come and administer this if necessary. Sometimes they will help administer medication via a device called a syringe pump, which will ensure that the correct amount of medication is consistently administered over a 24 hour period, to help stabilise symptoms more effectively. They will be able to assess the situation at home and advise on what to do next.

The district nurse can often decide if extra help is needed for care overnight such as a Marie Curie nurse (night sits) and can put in a request for this.

NHS 111

This is a National Health Service helpline. If you or the person you are caring for is having problems with symptoms and you are not sure who to contact, they can advise and guide you on what to do next.

They offer 24/7 medical advice from fully trained advisors and are supported by experienced nurses and paramedics.

Please use the space below to list the people involved in your care and their contact details. This will ensure that should you need advice, you will have the numbers ready to use:

Profession	Name	Contact number
GP		
District nurse		
Macmillan / specialist nurse		
Out of Hours district nurse		
Out of Hours doctor		
Other:		

Royal Papworth Hospital NHS Foundation Trust

A member of Cambridge University Health Partners



Papworth Road
Cambridge Biomedical Campus
CB2 0AY



royalpapworth.nhs.uk



01223 638000

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View a digital version of this leaflet by scanning the QR code.



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