



Papworth Hospital
NHS Foundation Trust

Managing the last days of life

Information about care
and support at home



Through our lives, experiences of death and dying may have determined our views about how we would want to die. Some people wish to die in their own homes, in familiar surroundings. You will 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 Papworth can explore with you what will be needed for this to be possible. This may involve referral to a social worker and/or other health professionals. If you have any information which you have written down regarding your wishes, such as Lasting Power of Attorney, organ/tissue donation, or a Preferred Priorities of Care 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 co-ordination 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 health care professional whom you are seeing.

Community Palliative Care Teams

Your local Palliative Care Team (Hospice teams, Macmillan nurses, etc.) may advise/liaise with your GP or the district nurse who is working with you.

Other considerations may include:

Finances

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

Legal

Health care professionals cannot advise you about legal issues, but if you think there is anything which should be discussed with them please feel free to do so. If

you wish to address legal issues a legally trained person will need 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, these may include:

- Medications 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, nausea/vomiting. These would be in addition to any regular medications you may have.
- If already started in the hospital, you may be discharged with a syringe pump containing medications to maintain your comfort. The GP and district nursing team will be responsible for this once you are home.
- A list of who to contact in an emergency which we recommend you keep by your phone
- Documentation for your GP and district nurse to keep them informed of your current condition and wishes.
- Important information/

guidance about your care which 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 Resuscitation' form.

- Some items for which you will be assessed will have to be delivered to your home prior to 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 can be delivered once you are at home. Once 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 discuss this with us. Please raise any concerns with us; health care 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 'Managing the Last Days of Life: Information for Families and Carers' that we can also give to you.

Other sources of information you may find helpful include:

- **NHS Choices**

End of Life care

www.nhs.uk/Planners/end-of-life-care/Pages/End-of-life-care.aspx

Useful guide with information for patients and carers, this includes a link to 'Planning for your future care: a guide'.

Age UK

Charity working with and for older people. Age UK Advice number: 0800 169 6565.

www.ageuk.org.uk

Dying Matters website

Helpful information on dying, death and bereavement.

www.dyingmatters.org

Winston's Wish

A charity that supports young people who have experienced bereavement.

www.winstonswish.org.uk

Please use the space below to list the people involved in your care and their contact details:

Profession	Name	Contact Number
GP		
District Nurse		
Macmillan/Specialist Nurse		
'Out of Hours' District Nurse		
'Out of Hours' Doctor		
Other:		

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