

## Deciding about place of care at the end of life

This short decision aid is to help you decide about the place of end of life care.

This document is a summary of the online patient decision aid which has much more information to help you. You can access it online at :<http://sdm.rightcare.nhs.uk/pda/end-of-life/>

The options for where to have end of life care are:

- At home
- In a care home, which may be your home already
- In a hospice
- In a hospital

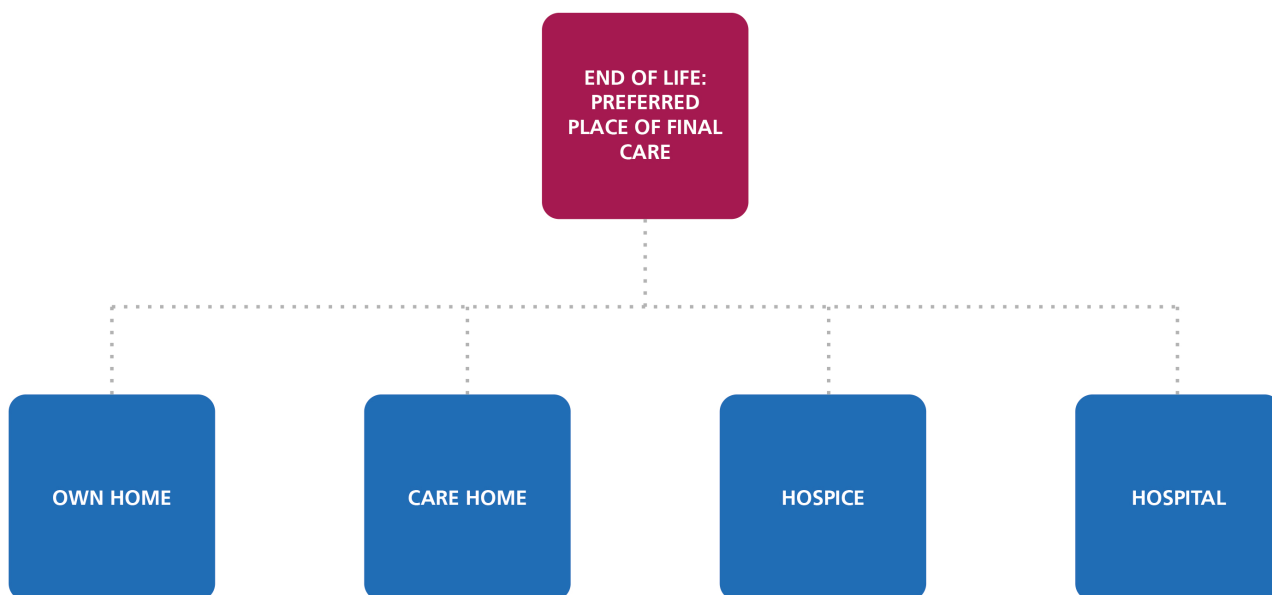
Making a decision about preferred place of care as the end of life approaches can be difficult but doing so in advance will make it more likely that people's wishes are met. The decision depends on people's own living arrangements and finances, their health, the friends, family and carers they have in their lives, their preferences for care at the end of life, and the services available in their local area.

This decision aid will help you think about what is important to you and your family when considering where to have end of life care. It may be helpful to start talking about these options with your family, carers, doctors and other health professionals.

The issues people think about when deciding where they would like to be cared for at the end of life include:

- Is one place better for me than another if I am having treatment for a health problem?
- Is one place better for me than another for access to emergency treatment or life support?
- Is one place better for me than another for treatment to control my symptoms?

The right choice for you may change over time. This decision aid aims to help you make the right choice for you now, but you may wish to change your mind as your life changes.



## What are my options?

	Own home	Care home	Hospice	Hospital
<b>What is the option?</b>	This is when someone is cared for at home towards the end of life. This is possible if a relative or friend is willing and able to be present most of the time. GPs, district nurses, community palliative care nurses and social services provide support.	This is when someone receives end of life care in a care home. It may be their home already. Care home staff provide personal care and sometimes nursing care. GPs, community nurses and palliative care staff may be involved.	This is when someone receives end of life care in a hospice. This is a specialist unit for people with life limiting or terminal illness. Hospice services include medical and nursing care, support for relatives and spiritual and psychological help.	This is when someone receives end of life care in hospital. All hospitals have palliative care teams to help hospital staff care for people nearing the end of life.

	Own home	Care home	Hospice	Hospital
<b>What about pain control?</b>	In a survey, 17 in 100 relatives of people who had end of life care at home said pain relief was provided all the time if needed. [1]	In a survey, 45 in 100 relatives of people who had end of life care in a care home said pain relief was provided all the time if needed. [2]	In a survey, 62 in 100 relatives of people who had end of life care in a hospice said pain relief was provided all the time if needed. [3]	In a survey, 36 in 100 relatives of people who had end of life care in hospital said pain relief was provided all the time if needed. [4]

	Own home	Care home	Hospice	Hospital
<b>What about dignity, respect and privacy?</b>	In a survey, 79 in 100 relatives of people at home said the patient had been shown dignity and respect at all times by nurses. 92 in 100 felt their relative had enough privacy. [5]	In a survey, 61 in 100 relatives of people cared for in care homes said they had been shown dignity and respect at all times. 95 in 100 said the patient had enough privacy. [6]	In a survey, 80 in 100 relatives of people cared for in a hospice said they had been shown dignity and respect at all times by nurses. 95 in 100 felt the patient had enough privacy. [7]	In a survey, 57 in 100 relatives of people cared for in hospital said they had been shown dignity and respect at all times. 72 in 100 said they had enough privacy. [8]

	Own home	Care home	Hospice	Hospital
<b>What support is there for family/carers?</b>	In a survey, 66 in 100 relatives of people who had end of life care at home said they had enough support from health and social services. [9]	In a survey, 46 in 100 relatives of people who had end of life care in a care home said they had enough support from staff. [10]	In a survey, 56 in 100 relatives of people who had end of life care in a hospice said they had enough support from staff. [11]	In a survey, 41 in 100 relatives of people who had end of life care in hospital said they had enough support from staff. [12]

	Own home	Care home	Hospice	Hospital
<b>Is there access to emergency care/life support?</b>	Most people having end of life care at home will need to be admitted to hospital for emergency care.	People having end of life care in a care home will need to be admitted to hospital for emergency care but could return to the care home after treatment.	Someone needing emergency care may need to be transferred from a hospice to hospital.	Someone having end of life care in hospital should have access to emergency care at all times, where appropriate.

	Own home	Care home	Hospice	Hospital
<b>Is there access to professional care at all times?</b>	Someone at home should have access to GP cover at all times. In some areas hospice staff are on call 24 hours a day.	Someone in a care home may not have immediate access to professional care. It depends how well care is co-ordinated in the area between the NHS and the care home.	Someone in a hospice will have immediate access to nursing care at all times.	Someone in hospital should have immediate access to medical and professional care at all times.

	Own home	Care home	Hospice	Hospital
<b>How close will I be to family/friends?</b>	Someone having end of life care at home will be near family and friends.	Policies on visitors depends on each care home. Some may have overnight facilities for relatives. Factors such as distance and transport links are important.	Hospices encourage contact between patients and families and provide facilities for families. Factors such as distance and transport links are important.	Visiting hours will depend on the hospital. Some hospitals allow family to stay overnight during end of life care. Factors such as distance and transport links are important.

	Own home	Care home	Hospice	Hospital
<b>Does this take into account my preferred place of death?</b>	Someone having end of life care at home will be able to stay at home to die if they wish, provided they have enough support from family members and community services. In a survey, 88 in 100 relatives of people at home said they had enough choice about where to die. [13] Sometimes if symptoms get worse, they may prefer to be admitted to a hospice or hospital.	In some care homes, people at the end of life may have to be transferred into hospital. It depends on the individual care home and how well prepared it is for palliative care. In a survey, 53 in 100 relatives of patients in care homes said they had enough choice about where to die. [14]	Hospices aim to care for someone until the end of life, if that is their wish. In a survey, 70 in 100 relatives of people in hospices felt they had enough choice about where to die. [15]	Someone having end of life care in hospital may die there if that is their wish, or it should be possible for them to return home to die, if this is what they prefer. In a survey, 29 in 100 relatives of people having end of life care in hospital felt the patient had enough choice about where to die. [16]

## What are the pros and cons of each option?

People deciding about end of life care have different experiences and views. Choosing the option that is best for the patient means considering how each option will affect their life.

Here are some questions people may want to consider about place of end of life care:

- How important is it for me to be in a familiar environment, close to family/friends?
- Am I worried about becoming a burden/dependent on my family?
- How important is it that pain and other symptoms are well controlled?
- How important is it that I have access to emergency care/life support?
- How important to me is immediate access to medical/professional care 24 hours a day?
- If I have important spiritual/emotional needs where would these be met?
- How important to me are privacy and being treated respectfully?