

Planning ahead with dementia



Health and
Social Care



Dementia is a progressive condition. This means that the symptoms will gradually get worse over time. There is no definite way of knowing how quickly a dementia will progress, as it can depend on many other factors such as the type of dementia and your overall health.

Planning ahead for your future care and treatment is important. That can be a difficult and emotional experience particularly when you are trying to come to terms with your diagnosis and what this means for you and your family. No one can say when the right time is for each person to start planning their future, but it is always worth thinking about as soon as possible in the dementia journey. This gives you more time to discuss your options and make sure that people around you know what your wishes are and will respect your choices.

This booklet is designed to give people living with a dementia (and those who care for them) information and advice about how to plan for the future.

It is never too early to begin talking

Being able to communicate your wishes and to understand fully your options can become more difficult as a dementia progresses, so it is important to discuss these while you are still able to. Planning ahead can include financial and legal planning, care and treatment and plans for end of life.

It is always good to have a loved one or trusted friend to talk to about your plans. You can also contact your local healthcare professional for more detailed and individual advice on how best to plan for your future. You can speak to your GP, district nurse, specialist nurse, allied health professional or social worker. If you are thinking about making a will, you should contact a solicitor.

There are many helpful sources of information and support available and you should never feel that you have to take on the responsibility of planning the future on your own.

There are some useful links and suggested reading at the end of this booklet which may be helpful to you. The Your life and your choices: plan ahead booklet is also available from <http://pha.site/life-choices-plan-ahead>



End of life planning and palliative care

Planning for your end of life care can be emotionally very difficult for both you and your loved ones.

But, it is good to do so as early as possible so that those who will care for you, family and professional staff, will do so with the knowledge and understanding of your wishes and preferences.

Having a plan for your end of life care can also provide comfort and support to your family and carers in the last months and years of your life by relieving them from having to make certain difficult decisions on your behalf. The exception to this is where medical decisions are required and these will always be made by a senior healthcare professional.

End of life care includes palliative care, which is specialist care that is provided to help you feel as comfortable as possible by managing your pain and other distressing symptoms. Palliative care is provided by a range of professionals including doctors, nurses, social workers and other specialists like physiotherapists, occupational therapists or complimentary therapists. Counsellors, clergy and social care staff will also be available to you.

These professionals and the services they provide can be available to you in your own home, hospital, care home or hospice in order to meet your physical, psychological, social and spiritual needs and those of your family.

Your family and friends may also be closely involved in caring for you.

Palliative care services may be provided by your local trust, a community or voluntary organisation or an independent provider. Speak to your GP or other healthcare professional in your specialist memory team for more information on who can offer this support in your area.

Advance care planning

It is important to plan ahead for your health and social care needs and treatment. It is good to begin making these plans early in your dementia journey.

Planning ahead in this way is sometimes called 'advance care planning', and involves thinking and talking about your wishes for how you are cared for in the final months of your life. Your designated health and social care professional can provide you with the documentation to write an advance care plan and offer information and support in its completion.

Anyone can plan for their future care, whether they are approaching the end of life or not. Advance care planning can let people know your wishes and feelings while you are still able to communicate most effectively.



An advance care plan is a written statement that sets down your preferences, wishes, beliefs and values regarding your future care. The aim is to provide a guide to anyone who might have to make decisions in your best interest if you have lost the capacity to make decisions or to communicate them. This responsibility will rest with a senior healthcare professional.

An advance care plan can cover any aspect of your future health or social care. This could include:

- your personal care needs and preferences, for example if you prefer a shower instead of a bath or like to sleep with the light on;
- your religious or spiritual needs and how these should be reflected in your care;
- concerns about practical issues like who will look after your dog if you become ill;
- where you would like to be cared for, such as at home, care home, hospital or hospice.

Always keep your written advance care plan in a safe place so it can be easily found by those involved in your care. Remember to regularly review your choices and keep them up to date.

For information on choosing a care home please see the guide at www.pha.site/dementiadocs

Advance decision to refuse treatment

You have the right to refuse a particular treatment or intervention. It is important that you make these wishes known to others.

This is known as an 'advance decision' or 'living will' and it can let your family, carers and health professionals know whether you want to refuse specific treatments in the future.

An advance decision can:

- give you more control over your circumstances and future care;
- help you avoid taxing treatments that may not always be helpful anyway;
- clarify that you may want to refuse a treatment in some circumstances but not others;
- ensure that your family and health and social care team will know what you want and can respect your wishes;
- help avoid disagreements about your care and treatment within your family or health and social care team.

Before making an advance decision, you may want to discuss this with your GP or the doctor or nurse specialist who is looking after you who knows about your medical history.

They will be able to tell you what the likely effects of stopping a treatment are and will make sure your advance decision meets the requirements of the law.

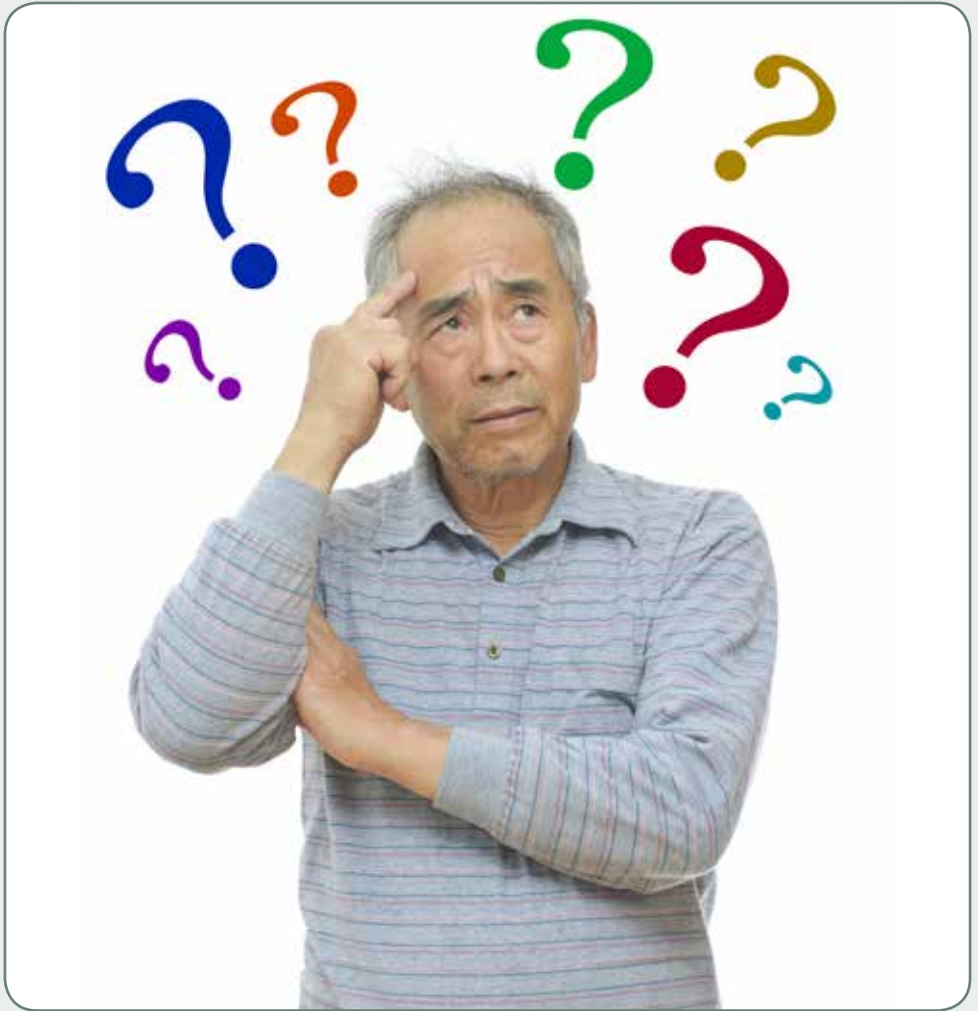
A solicitor can also discuss advance decisions with you and help you write one.

Best interest decisions

If you are no longer able to make a decision for yourself, those who are making decisions for them must do so in your best interests. This ensures that your rights are respected; and the decision is the one which is best for you. Best interest decisions should never be taken just to make things easier for the carer or the professionals involved.

Key things to know about best interest decisions:

- a senior health professional would make the decision based on their experience and understanding of your circumstances;
- decisions cannot simply be based on the your age, dementia or other condition, or their behaviour;
- all the relevant circumstances should be taken into account when making a decision;
- You should be encouraged and enabled to take part in the decision and share your views, where possible;
- It should be considered whether you will regain capacity later, and if the decision can be put off until then;
- your past, present and future wishes and feelings should be taken into account;
- the views of other people, such as carers, friends, family and any attorney or deputy, should be taken into account;



- if the decision involves life-sustaining treatment, there are other special considerations to take into account. For example, checking whether there is an advance decision and considering all the treatment options available. For further information see Your life and your choices: plan ahead booklet available from <http://pha.site/life-choices-plan-ahead>

Future planning for legal affairs

It is important, when you receive a diagnosis of dementia, to begin to think about and plan for your financial and legal future. You may want to make arrangements for your future care needs and ensure that your loved ones are also taken care of. Involving family or friends or getting advice from a professional can help you through this process.

This should be done when it feels right for you but it is advisable that you begin this process as early as possible in your dementia journey so that you are able to communicate your wishes clearly and have peace of mind about your care, treatment and other arrangements.

There are many professionals and organisations who can offer assistance through this process. Some of these are listed at the back of this booklet, but you can also talk to your healthcare professional.



Making a will

Making a will as early as possible in the dementia journey is a good idea. A will can help provide clarity about who benefits from your property and belongings and how these are to be distributed after your death.

Making a will is something that many of us don't like to talk about but it is an important document to leave you and your loved ones feeling more secure. You may have a family solicitor who can take you through the process but if not, there are many other sources of information and support available. Details of organisations which can help are available on page 14–15 of this booklet.



Although it is possible to write a will yourself, it is advisable to use a solicitor as there are various legal formalities that you need to follow to make sure that your will is valid. You may also need legal advice for more complicated matters.

If you need help to find a local solicitor you can contact the Law Society of Northern Ireland (www.lawsoc-ni.org).

There are also some voluntary organisations that can offer free information and support on the process for making a will.

Making decisions about money or property

You may need to give permission to another person to make decisions or take actions on your behalf in relation to your property and financial or legal affairs. An Enduring Power of Attorney is a legal document that allows someone to act on your behalf. It means that the person whom you have chosen will take decisions on your behalf when you are no longer able to do so.

It is an effective way to ensure that the people who know your wishes can act in your best interests when your ability to do so decreases. Your mental capacity to make decisions will be assessed by trained healthcare professionals.

You can seek advice from your healthcare professional. Also remember you can limit the power to certain parts of your affairs, for example, you may wish them to handle your money but you might want to leave out the power to sell your house.

For further information and support on the above, please contact the Office of Care and Protection.



Planning your funeral

Although it can be difficult, more and more people are planning ahead for their funeral, which can include your spiritual wishes and how the service takes place. You can speak to your spiritual adviser for more help with this.

You should also let family and friends know your wishes. This will help reduce any anxieties that they might have about this.

Key messages

- **Plan early**
- **Ask for help**
- **Information and support is available**
- **Talk to family, friends and professionals**

Planning for your future can leave you feeling more secure knowing you have taken steps to be in control of your journey and that as much as possible your needs and wishes will be met in the way you want.

For further information and practical resources to assist with planning for your future, this booklet should be used along with *Your life and your choices: plan ahead*, available from <http://pha.site/life-choices-plan-ahead>

Useful contacts

Advice NI

1 Rushfield Avenue,
Belfast BT7 3FP
028 9064 5919
info@adviceni.net
www.adviceni.net

Age NI

3 Lower Crescent,
Belfast BT7 1NR
0808 808 7575
www.ageuk.org.uk/northern-ireland

Alzheimer's Society

Unit 4
Balmoral Business Park
Boucher Crescent
Belfast
BT12 6HU
028 9038 7770
www.alzheimers.org.uk

Carers Northern Ireland

58 Howard Street,
Belfast BT1 6JP
Tel 028 9043 9843
www.carersuk.org/northernireland

Citizens Advice

46 Donegall Pass,
Belfast BT7 1BS
www.citizensadvice.co.uk

Dementia NI

54 Elmwood Avenue
Belfast BT9 6AZ
028 9068 6768
info@dementiani.org
www.dementiani.org

The Law Society of Northern Ireland

96 Victoria Street,
Belfast BT1 3GN
028 9023 1614
www.lawsoc-ni.org

nidirect

www.nidirect.gov.uk/dementia
Online information regarding
dementia in Northern Ireland

Northern Ireland Health and Social Care Interpreting Service

Business Services Organisation
Franklin Street
Belfast BT2 8DQ
028 9536 3777

Northern Ireland Hospice

www.nihospice.org

Northern Ireland Organ Donation

Services Team
12A Clarendon Road,
Belfast BT1 3BG
028 9051 8917

**The Office of Care and Protection
(OCP)**

Room 2.2A, 2nd Floor,
Royal Courts of Justice,
Chichester Street,
Belfast BT1 3JF
028 9072 4733
www.courtsni.gov.uk

**Belfast Health and Social Care
Trust**

info@belfasttrust.hscni.net
www.belfasttrust.hscni.net

**Northern Health and Social Care
Trust**

www.northerntrust.hscni.net

**Southern Health and Social Care
Trust**

www.southerntrust.hscni.net

**South Eastern Health and Social
Care Trust**

www.setrust.hscni.net

**Western Health and Social Care
Trust**

www.westernttrust.hscni.net



Public Health Agency
12-22 Linenhall Street, Belfast BT2 8BS.
Tel: 0300 555 0114 (local rate).
www.publichealth.hscni.net

