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giftaid it

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Things to think about...



Information and advice to help you plan for the future and help make life easier for those you love.



Contents

- 1 **Statement of Wishes**
- 2 **Making a Will**
- 3 **Lasting power of attorney:**
 - a **Health and Welfare**
 - i **Choices for End-of-Life**
 - ii **Advanced Decisions**
 - b **Property and Financial Affairs**
- 4 **Having been diagnosed with a life-limiting illness**
- 5 **Future care**
 - a **Care at Home**
 - b **Care homes**
 - c **Hospice Care**
- 6 **Information for carers**
- 7 **Planning your funeral**
- 8 **Thinking about your loved ones**
- 9 **Useful organisations**

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Information has been taken from the following sources: Age UK; Carers UK; Carers Trust; Dying Matters; GOV.UK; The Money Advice Service; NHS UK

1 Advance Statement of Wishes

There may come a time when you need help with personal care. In order for all those involved in your care to understand how you would like to be looked after, you may want to write an Advance Statement of Wishes.

An Advance Statement can explain your likes and dislikes and include anything that is important for you to be comfortable. It will be used if you ever lose the ability to make or communicate your own decisions.

You might like to include information on:

- Where ideally you would like to be cared for, for example your home, a care home or hospice
- How would you like to be addressed
- Any dietary requirements
- Foods you do and don't like
- Whether you prefer to take a bath or shower
- What kind of clothes you like to wear
- What music you like and what you like to watch on TV
- Whether you like to sleep with a light on
- Typical bedtime and whether you're an early riser or prefer a lie in
- Your religious or other beliefs and values
- Who you want to be consulted about your care
- Who you would like to visit you.

You have the final say in who sees your Advance Statement. Keep it somewhere safe, and tell people where it is, in case they need to find it in the future. You can keep a copy in your medical notes.

It's a good idea to give a copy to all those involved in your care, especially your care staff, GP and medical team so that they know your wishes.

You don't have to sign an Advance Statement, but your signature makes it clear that it is your wishes that have been written down.

Arthur Rank Hospice has a form that can be used by patients wanting to make an Advance Statement of Wishes.

2 Making a Will

Having a Will is something everyone should have, no matter what your age or what your possessions are - without one it is the law who will decide who gets what and how much and it will take much longer to deal with your estate. By having an up-to-date Will in place, you will be sure that people and organisations that matter to you receive the money, property or possessions you want them to have.

Remember, you will need to think about who you want to be the beneficiary of anything you have to leave, such as:

- Insurance policies
- Pension funds that include a lump sum payment on death
- National Savings (e.g. premium bonds)
- Vehicles
- Personal belongings such as jewellery, pictures and antiques
- Home contents
- On-line accounts, such as PayPal

If you've already made a Will, make sure you update it when your circumstances change, this may be it when:

- Grandchildren are born
- You move house
- There's a marriage or divorce

You can make a Will on your own, but it's generally best to use a solicitor except in very straightforward cases. The Law Society can provide you with a list of local solicitors, see section 9: Useful Organisations.

3 Lasting Power of Attorney

A lasting power of attorney (or LPA) is a legal document that lets you appoint one or more people you trust (known as 'an attorney'), giving them the legal authority to help you make decisions or to make decisions on your behalf.

An LPA gives you more control over what happens to you should you lose the ability to make or communicate your own decisions or chose not to make decisions for yourself.

You must be 18 or over and have mental capacity (the ability to make your own decisions) when you make your LPA. You don't need to live in the UK or be a British citizen.

There are two types of LPA:

- 1 Health and Welfare
- 2 Property and financial affairs

You can choose to make one type or both.

3a Health and Welfare

This allows your attorney(s) to make decisions about things like:

- Your daily routine, for example washing, dressing, eating

- Medical care
- Living arrangements (e.g. moving into a care home, care at home) - see section 6: Future Care
- Life-sustaining treatment
- Choices regarding end of life

It can only be used when you're unable to make your own decisions.

Choices for End-of-Life

Planning for your end of life is something many of us avoid. However, we often start thinking about it when someone we know becomes ill or we lose a friend or family member. When we do start thinking about it, we soon realise that we have an opinion on our future treatment and care.

Being able to make your own decisions regarding your end-of-life care is something we believe is vital in achieving a good quality of both life and death. However, many of us aren't aware of our rights, and so don't know how to make sure our wishes are respected.

You can plan ahead in a way that is legally binding by:

- Making an Advance Decision to Refuse Treatment (ADRT)
- Making a Lasting Power of Attorney (LPA) for Health and Welfare

Your wishes can also be expressed in:

- an Advance Statement
- an Advance Care Plan
- a Do Not Attempt Resuscitation (DNAR) form

These are not legally binding in the same way as an ADRT or an LPA.

Advanced Decisions

An Advance Decision allows you to make a legally binding refusal of treatment if you lose capacity - capacity is the ability to make a decision. This means that, so long as your Advance Decision is valid and applicable, if you lose capacity, a doctor cannot lawfully give you treatment that you have refused in your Advance Decision.

You may want to make an Advance Decision with the support of a clinician.

If you decide to refuse life-sustaining treatment in the future, your advance decision needs to be:

- Written down
- Signed by you
- Signed by a witness

If you wish to refuse life-sustaining treatments in circumstances where you might die as a result, you need to state this clearly in your Advance Decision. Life-sustaining treatment is sometimes called life-saving treatment.

You may find it helpful to talk to a doctor or nurse about the kinds of treatments you might be offered in the future, and what it might mean if you choose not to have them.

An Advance Decision may only be considered valid if:

- You are aged 18 or over and had the capacity to make, understand and communicate your decision when you made it
- You specify clearly which treatments you wish to refuse
You explain the circumstances in which you wish to refuse them
- It is signed by you and by a witness if you want to refuse life-sustaining treatment
- You have made the Advance Decision of your own accord, without any harassment by anyone else
- You haven't said or done anything that would contradict the Advance Decision since you made it (for example, saying that you have changed your mind)

You have the final say on who sees your Advanced Decision, but you should make sure that your family, carers, or health and social care professionals know about it, and know where to find it. You can keep a copy in your medical records.

Arthur Rank Hospice has a template for patients, however it must be signed and agreed with a doctor.

More information can be found on: [nhs.uk/Planners/end-of-life-care](https://www.nhs.uk/Planners/end-of-life-care)

3b Property and Financial Affairs

You should use this LPA to give your attorney(s) the power to make decisions about money and property for you, for example:

- Managing a bank or building society account
- Paying bills (including your mortgage)
- Collecting benefits or a pension
- Making repairs to your home
- Selling your home

If you lose the ability to make or communicate decisions and you don't have a Lasting Power of Attorney, your family, friends or carer will have to apply to the Court of Protection who can either make decisions on your behalf or appoint

someone else (a deputy) to do so. This is expensive and time-consuming so it's best to get a Lasting Power of Attorney in place while you can.

4 Having been diagnosed with a life-limiting illness

Who can I talk to?

If you've been diagnosed with a life-limiting illness, talk to your GP and medical team about any questions, worries or fears you and your family or friends might have. Your doctor should explain your condition and treatment options in a way that you understand and answer any questions about your condition or life expectancy.

If phrases are used that you're not familiar with, make sure you ask them to explain. You can decide how much or how little information you want at any one time. You can take your time over asking questions - never be afraid to go back and ask additional questions or for further information once you've digested what's been said. You can discuss your situation at your own pace.

It may be helpful to write down any questions you have and to ask them over several appointments so that you limit how much information you have to digest at once. Everyone appreciates that the conversations may not be easy so don't worry if you get upset. It can be hard for GPs and medical teams to know how best to start a conversation about end-of-life care but don't be afraid or embarrassed to ask them any questions. It might be useful to discuss the following:

- What to expect as your illness progresses
- The advantages and disadvantages of your treatment options
- Any treatment you don't want to receive
- Your life expectancy
- Where you would like to die
- The different methods of pain relief available
- The practical and emotional support available
- The physical and emotional changes you could experience

If you would like to take notes or record your conversation, speak with your doctor beforehand. You may also like to take someone along to appointments with you to help you remember the information and offer emotional support.

Your doctor and healthcare team should be able to tell you about support groups in your local area where you can discuss your thoughts and feelings freely.

Depending on your condition you may be referred to the Arthur Rank Hospice, who provide a number of services to help you manage and come to terms with your illness, there may also be support groups and professionally staffed helplines who can offer you practical advice and emotional support. Please see section 9 for further information.

5 Planning your funeral

Many of us have thought about whether we want to be buried or cremated, however that's usually as far as we get in our thinking.

A funeral allows friends and family to say goodbye and celebrate your life. Talking about what you would like and putting some plans in place will provide friends and family with great comfort from knowing that your funeral is exactly how you want it to be.

Some of the things you might like to discuss and plan include:

- Where you would like your funeral to be held
- Whether you want a burial or cremation
- Whether you want a religious service
- Who you would like invited
- What songs or readings you would like
- Whether you want flowers or donations to a cause you care about

You might have a special request, such as a woodland burial or a coffin made from materials like wicker or cardboard.

If you want to take care of the costs and arrangements of a funeral in advance, you may want to consider setting up a funeral pre-payment plan. You can find out more information about these from your funeral director or the National Association of Funeral Directors - see section 9: Useful Organisations.

We work with a local company who offer funeral plans provided by Safe Hands Funeral Plans. You can either contact them directly or via local agents: Inheritance Legal Services.

6 Future care

It may be that as your condition changes, you will have different care needs. It can therefore be helpful to think about where / how you would like to be cared for further down the line. It may not always be possible to fulfil your choices, but stating your wishes means doctors and loved ones can do their best to make it happen. Your GP and medical team will be able to tell you what you can expect as your illness progresses, what options

are available in your local area and the support you can get. We recommend you discuss your preferences with your family or carer so they can share their thought and you can make a decision together.

Wherever you are cared for, the most important thing is that you receive the support you need to spend your final days in the most peaceful and dignified way for you. In collaboration with you, your medical team should develop a care plan that is tailored to your needs and preferences and regularly review and update it as necessary.

Every GP surgery holds regular meetings to discuss patients thought to be in the last six to twelve months of life, which is attended by a representative from Arthur Rank Hospice's Community Team, which will help ensure that everyone involved in your care is aware of your preferences and wishes.

Care at home

You may wish to be cared for at home where you are in familiar surroundings. Some people find this helps them feel more comfortable, in control and makes it easier to say goodbye. If you would like this, talk it over with your GP and the people you live with to see how they feel about it.

Arthur Rank Hospice provides specialist palliative care throughout most of Cambridgeshire. We are involved in supporting people who wish to remain at home through a mix of specialist services such as hands-on care, practical advice and support, advice on controlling pain and symptoms, emergency advice lines and information. We work closely with GPs and community nurses to co-ordinate your care.

Arthur Rank Hospice Community Team has two main functions:

- **Clinical Nurse Specialist (CNS) Function:** This is a 9am - 5pm service, 7 days a week, ensuring integrated care within the patient's home by working closely with the hospice services and multi-disciplinary team, GPs, District Nurses and wider community services.

Their role varies according to patients' needs and wishes, and they see individuals who are living with a life limiting illness. This often involves symptom control through medicines management and also non-pharmacological methods.

The CNS Team talks to patients and their loved ones about support and services available and provides psychological support, face-to-face and over the phone.

A large part of the team's work is future care planning, facilitating discussions with patients about their wishes and preferences, particularly around end-of-life care. The staff member then documents this so other services can be aware and the various teams can work together to fulfil them.

- **Hospice at Home:** This compassionate and experienced team of nurses and healthcare assistants supports patients, and their family, approaching end-of-life within the final two weeks of life. The main function of the team is to provide hands on care and support between the hours of 10pm and 7am, however Hospice at Home also supports families in crisis to avoid hospital admission. This team works in partnership with the wider health system, particularly District Nurses and GPs, the wider hospice team and other specialists, to support patients and families to be cared for at home if that is their wish.

If you live alone, speak to your healthcare team to see what support would be available around the clock. Your GP has overall responsibility for your care at home. They should put you in touch with organisations that can support you, talk you through what might happen as your condition gets worse, prescribe medication or refer you to other doctors if necessary.

If you begin to find personal care and other tasks difficult, you can ask for a care assessment from social services. Depending on the outcome of your assessment, you might receive support, or specialist equipment or adaptations to help you stay independent and safe. Age UK has produced a free guide: 'Getting help at home', which you may find useful. For more information see section 9: Useful Organisations.

Your GP can arrange for you to be supported by a district nurse who will organise and coordinate your care at home. The district nurse or an occupational therapist can assess how easily your home can accommodate additional equipment that you might need. They can advise you on this and make necessary arrangements.

Care homes

If you live in a care home you may wish to ask whether it can offer you the care and support your doctors say you need in the last few weeks and days of your life. Talk to the manager about their experience of supporting residents at this time. You may want to ascertain what specialist training staff may have had and what GP and community nursing support is available to allow you to die in familiar surroundings and avoid hospital admission as your health deteriorates. We work closely with care homes, providing training and support to staff.

If you currently live in a residential care home you may need to move to a nursing home where nursing staff are on duty 24 hours a day. If you do need to move, ask your medical team if your needs mean the NHS should be responsible for funding your care. If you need to move to a different care home, think about the practical considerations of such a move. Will you still be near your family and friends? Will your doctor and healthcare team stay the same? Discussing all these considerations with your medical team and family, friends and carers should mean that you are all comfortable with your future care. The Care Quality Commission website (see section 9) allows you to search for and read inspection reports on care homes in England. You can also search for care homes that have been recognised as providing high quality end-of-life care by visiting [goldstandardsframework.org.uk/accredited-care-homes](https://www.goldstandardsframework.org.uk/accredited-care-homes).

Hospice Care

Arthur Rank Hospice is an adult hospice that provides specialist palliative care for people living with a life-limiting illness and often become involved from the point of diagnosis. We offer an extensive range of professional, compassionate and practical services, here is an overview:

- Inpatient Unit
- Evelyn Day Therapy Centre
- Hospice at Home
- Specialist Palliative Care Home Team
- Patient and Family Support Team
- Education and Learning

Bradbury Wellness Centre:

- Complementary Therapy
- Lymphoedema Clinic

Serving Wisbech and the Fenlands:

- Alan Hudson Day Treatment Centre

All services are supported by Volunteer Services and Volunteer Management.

More information can be found throughout our website on each of these areas as background to each of the services is very interesting.

We have medical, nursing and other experts to provide pain control, rehabilitation, emotional and bereavement support, as well as other supportive services such as complementary therapies for you and those close to you. The care and support we provide is individualised: meaning its tailored to your specific needs.

You can be referred to the hospice for many reasons. It may be for a short time while your symptoms are being controlled or for social and emotional needs. People are also cared for by us during the final stages of their illness. Visiting is 24/7 and patient's loved-ones can also receive complementary therapies, and emotional and bereavement support.

Referrals are accepted from any healthcare professional and also from patients and families where appropriate.

For further information, you can speak to us directly by calling **01223 675800** or you can speak to your GP or district nurse.

Our care is provided completely free of charge.

7 Information for Carers

A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support. Many people do not see themselves as a carer - it's just something they do.

Although for many carers, caring can have positive and rewarding aspects, there are lots of reasons why caring can also leave you needing support. Caring can have an impact on many aspects of your life, such as:

- Money and benefits
- Health and wellbeing
- Getting out and about
- Working and learning

It can be very easy to overlook your own needs as a carer, as you submerge yourself in making sure your loved-one is looked after. Accessing help and support and making time for yourself is important for your health and wellbeing.

You can ask your local council for a carer's assessment. This is an opportunity to discuss with the local council what support or services you need. The assessment will look at how caring affects your life, including for example, physical, mental and emotional needs, and whether you are able or willing to carry on caring.

If you spend at least 35 hours a week caring, you may also be entitled to financial assistance, such as Carer's Allowance. Make sure you tell your GP that you're a carer and discuss the impact this is having on your own health.

It's important to remember that there are limits to the care you can provide and having a break can give you the energy to carry on caring.

You should never feel alone as a carer. Carers Trust Cambridgeshire is on hand to provide you with any help and advice you may need. You may also find helpful information from Age UK. To find out how to contact either organisation, see section 9.

8 Thinking about Your Loved Ones

Perhaps there are things you would like to share with people before you die, or maybe you want to create something to leave behind. Some people find it helpful to write down their family history for the next generation or put together a memory box or scrapbook of their life. These activities are what people often choose to do with the support of our Day Therapy team. There is also a book titled 'Before I Go'. This book helps anyone to plan how they would like to be remembered, with pages to fill in, ranging from 'Wise Words' to 'Happy Memories' 'Favourite Songs, Poems' and 'Wishes For Your Family' to 'Milestones I'd still like you to Celebrate', there's even a space for a sealed 'My Send Off' envelope for specific final wishes.

We offer support and information to the loved-ones of those we have cared for, however there are a number of other charities and organisations that can offer support and information to your loved-ones after you die. Cruse Bereavement Care in Cambridge provides free, confidential support after the death of someone close.

The most important thing throughout this whole process is to do what feels right for you, when it feels right.



9 Useful organisations

Age UK Cambridgeshire and Peterborough:

Provide a wide range of services and support for older people across the county.
web ageuk.org.uk/cambridgeshireandpeterborough tel **0300 666 9860**

Alzheimers Society:

Provides advice, information and support to people with dementia, their families and carers through its helpline and local branches. tel **0300 222 1122**
web alzheimers.org.uk tel **01954 250322**

Arthur Rank Hospice:

Provide specialist end-of-life care and support to patients and their families.
web arhc.org.uk tel **01223 675777**

Care Quality Commission:

National, independent regulator of all health and social care services in England.
web cqg.org.uk tel **03000 616161**

Carers Trust Cambridgeshire (Crossroads):

Local advice and support for carers
web carerstrustcambridgeshire.org tel **0345 241 0954**

Carers UK:

Provides expert advice, information and support.
web carersuk.org tel **020 7378 4999**

Cinnamon Trust:

For the terminally ill and their pets, providing volunteers to help keep them together.
web cinnamon.org.uk tel **01736 757900**

Cruise Bereavement Care:

Bereavement support for adults and children.
web cruse.org.uk/Cambridge tel **01223 633536**

Dying Matters:

Aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life.
web dyingmatters.org tel **08000 214466**

NHS choices:

Provides a guide to social care, how to live well and explains illnesses and conditions.
web nhs.uk

Safe Hands Funeral Plans:

Funeral plan provider.
web safehandsplans.co.uk tel **0800 917 7099**

Safe Hands local agent:

Inheritance Legal Services:
web inheritancewills.co.uk tel **01223 795050**

The Association of Funeral Directors:

Independent and inclusive, the NAFD is the largest trade association for the funeral sector, offering support and information about funerals in the UK.
web nafd.org.uk tel **0121 71 1343**

The Law Society:

Helps people find a solicitor, advises on what to expect when they visit one and produces guides to common legal problems.
web lawsociety.org.uk tel **020 7242 1222**

Woodland Wishes:

Provides natural burial services which take place in a woodland burial ground located in Cambridgeshire.
web woodlandwishes.co.uk tel **01223 651653**