

Planning for your future care (Advance Care Planning)



- Preparing for the future
- Assisting with practical arrangements
- Enabling the right care to be given at the right time

This document may contain a completed Advance Decision to refuse life sustaining treatment.

You may wish to carry this document with you.

Endorsed by the wide range of health and social care organisations shown on the back cover.

Advance Care Planning

Advance Care Planning is very important.

By recording your preferences in this booklet it will help to ensure that your wishes are taken into account.

It will let health and social care professionals know what your wishes are and what is particularly important to you should you become too unwell to be able to tell anyone. We stress that any instructions in this booklet only come into force when you cannot make decisions at the time you are asked.

There is no set format for an *Advance Care Plan*, but it may help you to read the document *Planning for your Future Care – A Guide*.

Ask your doctor/GP for a copy, alternatively it can be found on the following web site.
<http://www.endoflifecareforadults.nhs.uk/publications/planningforyourfuturecare>

However, you need to follow some formalities if you intend to refuse a treatment in advance.

The Mental Capacity Act 2005 has clarified the law on a number of matters and you will see this referred to throughout the document. The following link will make your rights clear.

<http://www.dh.gov.uk/en/SocialCare/Deliveringsocialcare/MentalCapacity/MentalCapacityAct2005/index.hm>

Or ask for the booklet: *Making Decisions...about your health, welfare or finance. Who decides when you can't?*

We have used the terms 'unwell' and 'illness' to cover a wide range of situations when you might not be able to speak up for yourself.

Please note that this booklet is not designed to be completed all at once. It can be filled in over a period of time, as and when you feel comfortable to do so.

This document is in three parts as shown on the next page.

The three parts

Part 1: About me

Page 5

This is where you give important information about yourself and what has happened in the past.

Part 2: Things that I want people to know

Page 7

This part will help people to know about important things that you may need help with.

For example, it could be about having your pet looked after, or instructions about financial issues.

Part 3: About my treatment preferences

Page 9

This part is to help people understand the way that you would prefer to be treated, should you need increased health care.

There is a special section where you can record your wish to refuse certain treatments (e.g. some people refuse blood transfusions on religious grounds). It may be a treatment that you want to refuse in all circumstances.

It is very helpful to record your full wishes on these issues.

There is a section for people who also want to refuse a treatment, even where that refusal could put their life at risk. This is your legal right if you want to do so.

Who to give your advance care plan to:

When you have completed your Advance Care Plan, decide who you would like to know about it. These people might include: relatives, friends, an advocate, your medical consultant, your general practitioner, your solicitor (if you have one) or anyone else you want to know about it.

Your GP and your consultant should be given a copy of the Advance Decision to refuse treatment if completed.

Advance Care Planning – how it can help plan your future care

Please note that this booklet is not designed to be completed all at once.

It can be filled in over a period of time, as and when you feel comfortable to do so.

Advance Care Planning (ACP) can help you prepare for the future.

It gives you an opportunity to think about, talk about and write down your preferences and priorities for your future care, including how you want to receive your care towards the end of your life. Anything can be included. If it is important to you, record it, no matter how insignificant it may appear.

Advance Care Planning can help you and your carers (family, friends and professionals who are involved in your care) to understand what is important to you. The plan provides an ideal opportunity to discuss and record in writing your views with those who are close to you. It will help you to be clear about the decisions you make and it will allow you to record your wishes in writing so that they can be carried out at the appropriate time.

Remember that your feelings and priorities may change over time. You can change what you have written whenever you wish to, and it would be advisable to review your plan regularly to make sure that it still reflects what you want.

The choice is yours as to whom you share the information with.

This booklet has been designed in consultation with patients and carers to assist you with the planning and recording of your preferences and wishes.

Statement of my wishes and care preferences

Print name _____ Date _____

I have written this following statement to help professional health and social care workers understand my wishes should I be unable to explain.

I would like this statement to be put in my medical and social care records (if it is not put on your records, it will be more difficult for medical staff to know that this statement exists). **YES / NO**

Signature: _____ Date of birth: ____ / ____ / ____

My address: _____

Part 1 - About me

I have these distinguishing features:
(It may be wise to include any distinguishing features in case you are ever found unconscious and cannot identify yourself).

My diagnosis/es:

A brief history of my illness:

The main professional carer involved with caring for me is:

Print name: _____

He / she
is based at: _____

Tel number: _____

Please contact:

- Below are the names of people who know me well, like family members, friends, and advocates.
- They have given their permission to be contacted should I become unwell and I would like them to try to assist me if possible.
- I am happy for health and social care staff to discuss my condition and/or treatment with them.

| Name | Relationship | Phone No(s) and/or other contact details |
|------|--------------|--|
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Please do not contact:

Should I become unwell and unable to make the decision for myself, I would **not** like the following people to be told.

| Name | Relationship | Details |
|------|--------------|---------|
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Part 2: Things that I want people to know

List here anything else with which you may need help should you become unwell.

For example, you may wish to include information about the care of your children and/or other dependants, information about your pets, about important work issues or financial affairs such as mortgages, bills, rent etc.

You may also wish to include other matters about keeping things going at home e.g. milk, papers, security etc. It will be helpful to name particular people who may be able to help with any of these.

The following additional things are important to me:

Things I want people to know

Other things that people need to know to help with my care:
(List things that are important to you, as part of your care).

Help with communication: (for example if you have hearing loss):

Diet: (like needing halal or vegetarian food):

Medication or treatments for a medical or physical condition:
(like diabetes or sight loss):

Allergies:

I have an Implantable Cardioverter Device (ICD).

Delete as appropriate

Yes / No

I have made a decision regarding this device for the future.

Yes / No

I wish to have this device deactivated when I approach the end of my life.

Yes / No

I have informed my main professional carer.

Yes / No

Religious or spiritual beliefs that may affect my care:

Name of religious leader:

Contact details:

Cultural requirements for yourself or your family when confronting serious illness:

Other:

Part 3: About my care and treatment preferences

You may wish to say where you would like to be cared for if it is not suitable for you to stay at home, you may have already completed a Preferred Priorities of Care (PPC) document, in which case we suggest you keep a copy of the PPC with this document.

There may be other preferences that you wish to document below, as your preferences of care must be taken into account by health care professionals making decisions about you should you be unable to tell them at the time.

With regard to treatments and care, you are reminded that you can only express a preference, you cannot demand them.

Any specific refusals of treatment can be recorded in the next sections.

If I become unwell, my preferences regarding care and treatment are as follows:

Appointing Someone to Make Decisions for You

There are some situations when you might anticipate that you will deteriorate mentally (e.g. dementia). If this is the case you may well decide to ask a specific person to undertake the responsibility for making decisions for you if and when you are unable to do so yourself. That person is given Lasting Power of Attorney (LPA).

The person chosen can be a friend, relative or a professional. More than one person can act as attorney on your behalf.

Lasting Power of Attorneys are exclusive to you and the amount of power and limits of that power are decided by you.

There are two types of Lasting Power of Attorney:

Property & Affairs Lasting Power of Attorney

- This LPA gives another person (your attorney) the power to make financial decisions for you e.g. managing bank accounts or selling your house. Your attorney has the power to take over the management of your financial affairs as soon as the LPA is registered with the Office of the Public Guardian, unless the LPA states that this can only happen after you lose the capacity to manage your own financial affairs.

Since 1 October 2007 the Enduring Power of Attorney (EPA) has been replaced by the Property and Affairs LPA. However, valid EPAs that were already arranged before 1 October 2007 will still stand.

Personal Welfare Lasting Power of Attorney

- This LPA allows your attorney to make decisions regarding your health and personal welfare e.g. where you should live, day to day care or about your medical treatment. It only comes into force if/when you lose the ability to make these decisions for yourself and is only valid once it has been registered with the Office of the Public Guardian.

LPAs must be registered and there is a cost implication for registration. The forms can be completed and registered without the input of a solicitor, but this can be a complex procedure without guidance. If legal help is sought, then there may be a cost attached.

Advance Decision Making

An Advance Decision (AD) is different from your preferred priorities for care as it is a formal, legally binding document which allows an individual to refuse certain treatments.

It does not allow for a request to have life ended and cannot be used to request medical treatments.

An Advance Decision is very specific and is used in situations when particular treatments would not be acceptable to someone. An example would be if a person had a severe stroke which resulted in swallowing problems. If the thought of being fed by alternative methods such as tube feeding was not tolerable then this could be documented formally as an Advance Decision.

In order to make an Advance Decision advice should be sought from someone who understands the complexity of the process such as a member of your health care professional team, your GP/Doctor, or a solicitor.

An Advance Decision can be written or verbal, but if it includes the refusal for life-sustaining treatment, it must be in writing, signed and witnessed and include the statement '*even if life is at risk*'.

An Advance Decision will only be used if, at sometime in the future, you lose the ability to make your own decisions about your medical treatment. To be valid, an Advance Decision must be made before you lose your ability to make such decisions. You can change your mind about your Advance Decision, or amend it at anytime, provided you are still able to do so.

Further Information

Government information on the Mental Capacity Act

www.direct.gov.uk

http://www.direct.gov.uk/en/Governmentcitizensandrights/Death/Preparation/DG_10029429
accessed April 2012

End of Life Care

www.endoflifecareforadults.nhs.uk

<http://www.endoflifecareforadults.nhs.uk/publications/pubadrtguide>
accessed April 2012

Age UK

www.ageuk.org.uk

http://www.ageuk.org.uk/documents/engb/factsheets/fs72_advance_decisions_advance_statements_and_living_wills_fcs.pdf?dtrk=true
accessed April 2012

Essex County Council

www.essex.gov.uk

<http://www.essex.gov.uk/health-social-care/Mental-Capacity-Act>
accessed April 2012

Advance Decision Making (part 1 of 5)

Your name:

Your date of birth:

You will need 4 copies of this completed form:

- One for you to keep.
- One for your GP to keep with your records.
- One to be kept with someone who you wish to be consulted about your treatment should this ever be necessary (eg next of kin, solicitor).
- One to be kept with Palliative Care Team, Community Palliative Care Nurse/Hospice Team/District Nurse/ Mental Health Team and Care Home as appropriate.

All forms should be signed by at least one person who is not a close relative or expecting to benefit from your will.

I also have an Advance Statement of wishes and preferences for my care.

Yes / No

See page 5

Advance Decision Making (part 2 of 5)

If I become unwell I would like the following contacts to be involved if it ever becomes too difficult for me to make decisions for myself.

Contact 1. Name: _____

Relationship to you: _____

Telephone: _____

Address: _____

Do they have Lasting Power of Attorney? **Yes / No**
(If yes please state which type?)

Contact 2. Name: _____

Relationship to you: _____

Telephone: _____

Address: _____

Do they have Lasting Power of Attorney? **Yes / No**
(If yes please state which type?)

To my family, my doctor and all other persons concerned this Advance Decision is made by me:

Full Name: _____

Of (address): _____

I am writing this at a time when I am able to think things through clearly and I have carefully considered my situation. I am aware that I have been diagnosed as suffering from:

Advance Decision Making (part 3 of 5)

I declare that if I become unable to participate effectively in decisions about my medical care, then and in those circumstances, my directions are as follows (only sign the sections you feel are applicable).

1. Any distressing symptoms are to be controlled by appropriate treatments aimed at keeping me comfortable.

Signature: _____

2. I am not to be subjected to any medical interventions or treatment listed below.
I understand that such treatment may be aimed at prolonging my life and I wish to refuse them **even if my life is at risk**.

Signature: _____

Examples:

- I do not wish for an attempt for my heart and lungs to be restarted if they stopped functioning. (Cardiopulmonary Resuscitation)
- I do not wish to be artificially fed or hydrated.
 - I do not wish to receive antibiotics for a particular infection (please state).
 - I do not wish to receive Non-invasive Ventilation (NIV) if my breathing becomes more difficult.
- (Please state your wishes in the box below / on a separate sheet if necessary)

| <p>Treatment to be refused (e.g, stoma formation, surgery) If you wish to refuse resuscitation please also ask your doctor about a specific DNACPR form - see page 19.</p> | <p>Reasons and circumstances (see examples above)</p> |
|---|--|
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Advance Decision Making (part 4 of 5)

This is my Advance Decision to refuse treatments. It may include life-sustaining treatments as indicated on the preceding page, even if my life is at risk.

I understand the decisions that I am making here are in consideration of future circumstances and ask that these be included in my medical records. I understand that this binding Advance Decision remains effective unless I make it clear that my wishes have changed, and that it only comes into effect when I am unable to communicate my wishes by any manner.

Name: _____ Date of birth: ____/____/____

Address: _____

Signature: _____ Date: _____

Distinguishing marks: _____

Signature of a witness to the Advance Decision, who was there when you signed it.

Name of witness: _____

I have witnessed that: _____ has signed this **Advance Decision** in my presence.

(Signature of witness) _____

Relationship of witness: _____ Date: _____

Contact details: _____

Signature of the health care professional with whom I have discussed this Advance Decisions to refuse treatments.

Name of Professional: _____ Job Title: _____

Address: _____

It is my view that (name) _____ has capacity to make this decision at this time.

How long have you known this person? _____

Signature of professional: _____ Date: _____

Advance Decision Making (part 5 of 5)

Remember to review this document at regular intervals especially if your circumstances change to ensure it still represents your wishes. Signing and dating at the bottom when you do this will indicate how recently you have thought about it. If you change your mind about anything you have written, tell your GP, hospice nurse, next of kin or appointed representative and amend the document accordingly.

Reviews:

These decisions were reviewed and confirmed by me on:

Signed: _____ Date: ____ / ____ / ____

Signed: _____ Date: ____ / ____ / ____

Signed: _____ Date: ____ / ____ / ____

Signed: _____ Date: ____ / ____ / ____

Putting your affairs in order

Ensuring that your paper work and documents are up to date and easy to find will save time and reduce anxiety for your family/next of kin if you become unable to attend to your affairs or if you are taken ill or suddenly die.

Tick below to show that you have thought about and recorded in a safe place the details listed. Have you nominated someone you can trust who will be able to access those details if the need ever arises?

- _____ Bank Name/Account Details (including credit card)
- _____ Insurance Policies
- _____ Pension Details
- _____ Passport
- _____ Birth/Marriage Certificate
- _____ Mortgage Details
- _____ Hire Purchase Agreements
- _____ Will (see page 18 for further guidance)
- _____ Other Important Documents/Contacts e.g. Solicitor
- _____ Details of any Funeral Arrangements or Preferences
- _____ Addresses and Contact Number of Family, Friends and Colleagues
- _____ Organ Donation / Donor Card
- _____ Tax Office Address and Contact Details
- _____ Other _____

Making a Will

Many problems occur when a person dies without making a Will as there are clear regulations which dictate how your possessions would be allocated.

If there is no Will the time taken to sort things out can be lengthy and expensive and will cause added stress to your family/next of kin.

In addition, the outcome of this process may not be as you would wish, so it is advisable to make a Will to ensure that your personal effects are left to the people you want to inherit them.

You can make a Will without a solicitor, and forms can be purchased from stationers or via the internet. This is only advisable if the Will is straightforward; the Law Society suggests that specialist advice is sought from a solicitor.

Think about the following aspects prior to visiting a solicitor as this will save you time and money.

- ✓ A list of all beneficiaries (people who you would like to benefit from your Will) - and what you would like them to receive
- ✓ A list of your possessions -savings, pensions, insurance policies, property etc
- ✓ Any arrangements you want for your dependants or pets
- ✓ Decide who will be your executor(s) - the person/s who will deal with distributing your money and possessions after your death. You may have up to four, but it is a good idea to have at least two in case one dies before you do. They can also be beneficiaries and care should be taken when choosing executors to ensure that they are suitable and also willing.

Related documents

1. Preferred Priorities for Care.

This Advance Care Plan document is to complement the Preferred Priorities for Care (PPC) that your health care professional may have completed with you.

If so, then it would be useful to keep these two documents together.

2. Do Not Attempt Cardiopulmonary Resuscitation

If your Advance Care Plan includes a determination to refuse resuscitation, you may wish to discuss completing a Do Not Attempt Cardiopulmonary Resuscitation form (DNACPR) with your doctor.

This document could then be kept with your Advance Care Plan.



St Helena Hospice
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Local Services, Local Solutions



Colchester Hospital University 
NHS Foundation Trust

Mid Essex Hospital Services 
NHS Trust

North Essex Partnership 
NHS Foundation Trust

The Princess Alexandra Hospital 
NHS Trust

South Essex Partnership University 
NHS Foundation Trust


Central Essex Community Services


Ipswich and East Suffolk
Clinical Commissioning Group


Mid Essex Clinical Commissioning Group


North East Essex
Clinical Commissioning Group


West Suffolk
Clinical Commissioning Group