



Health and Adult Social Services

MENTAL CAPACITY ACT 2005 TOOLKIT



Hardcopies of this document are considered uncontrolled please refer to intranet for latest version

Disclaimer-Advice given is based upon legislation at the time Toolkit it was produced

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Contact Person (Responsible person) and department:

Either

OR

For public access online (internet) (tick as appropriate)

For staff access only (intranet)? (tick as appropriate)

Yes

No

Yes

No

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INTRODUCTION

This toolkit should be used in conjunction with the Northamptonshire Inter-Agency Mental Capacity Act Policy and Guidance¹. The toolkit is not a substitute for the policy guidance but serves as a collection of working documents that practitioners should find helpful in addressing day to day Mental Capacity Act issues when working with customers and families.

The toolkit includes the following:

- Decision Making Process Flowchart
- Functional Test for Capacity Form
- Best Interests Checklist and Decision Making Tool
- IMCA Service Referral Form
- Advanced Decision to Refuse Treatment Form

The enclosed forms will be held as electronic documents both on the Internet and Care First 6, to facilitate ease of use and should be used with all Customers who lack capacity to make specific decisions about care or treatment they require.

MENTAL CAPACITY ACT OVERVIEW

The Mental Capacity Act (MCA) provides the legal framework for acting and making decisions on behalf of individuals who lack the mental capacity to make particular decisions for themselves. Everyone working with and/or caring for an adult who may lack capacity to make specific decisions must comply with this Act when making decisions or acting for that person, when the person lacks the capacity to make a particular decision for themselves. For that reason it is essential that practitioners utilise this toolkit in order to provide transparent and clear evidence of MCA compatible practice that would lend itself to any scrutiny into work practice.

As a starting point it must be assumed that an adult (or person aged 16yrs and over) has full capacity to make decisions for themselves (autonomy) unless it can be evidenced that they lack capacity to make a decision for themselves at the time the decision needs to be made. The overarching approach of the Act is to ensure that any decision, or action taken on behalf of a person who lacks capacity to make decisions for themselves is done so in their best interests.

¹<http://www.northamptonshire.gov.uk/en/councilservices/asc/services/va/pages/mentalcapacity.asp>
x

DEPRIVATION OF LIBERTY SAFEGUARDS

The Deprivation of Liberty Safeguards (DOLS) were introduced in April 2009 as an addendum to the Mental Capacity Act to provide appropriate safeguards to people who lack capacity to make decisions for themselves and require care or treatment in residential/nursing homes or hospital.

The DOLS legislation provides a legal process for people to have their liberty deprived so long as the care or treatment is in their best interests and there is no less restrictive alternative. The DOLS legislation also ensures that every person who requires an authorisation to cover their care or treatment has the right to request a review of the care/treatment that deprives them of their liberty. This will usually be through the nomination of a 'Relevant Person's Representative' who monitors the care provided, maintains regular contact with the person who lacks capacity and is able to request a review or re-assessment of the person's care if their needs or circumstances change.

In terms of responding to this new legislation, DOLS Services have been established in all Local Authority/PCT regions within England and Wales to carry out the necessary assessment process.

CONTACT INFORMATION

Further information regarding the local DOLS Service can be found on the Intranet² and internet³ or by direct contact with the joint Northamptonshire County Council and Primary care Trust DOLS Team as follows:

Northamptonshire Deprivation of Liberty Safeguards Service

Tithe Barn Council Offices

Tithe Barn Road

Wellingborough

NN8 1BN

Tel: 01933 220724

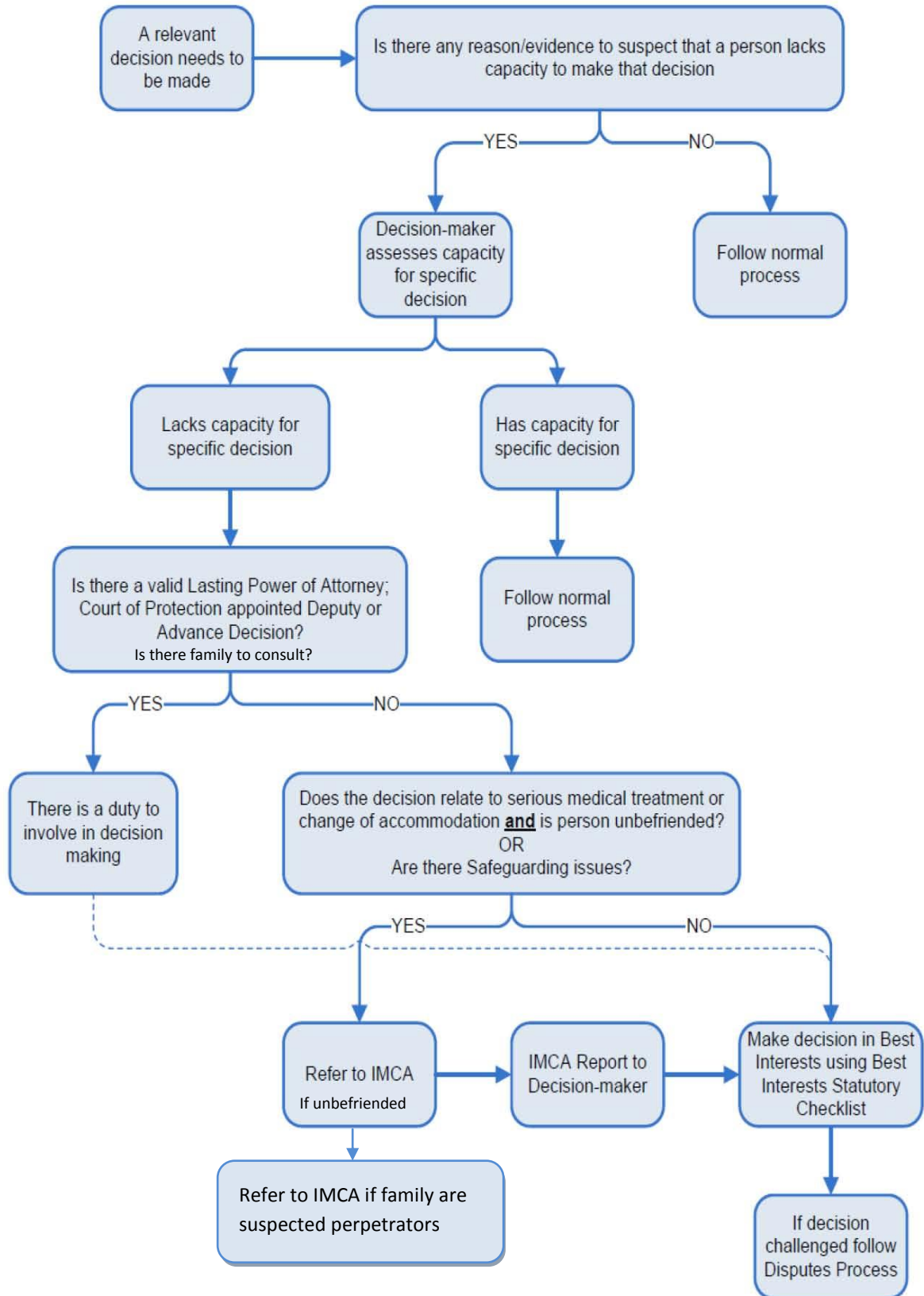
Fax: 01933 201057

Email: dols@northamptonshire.gov.uk

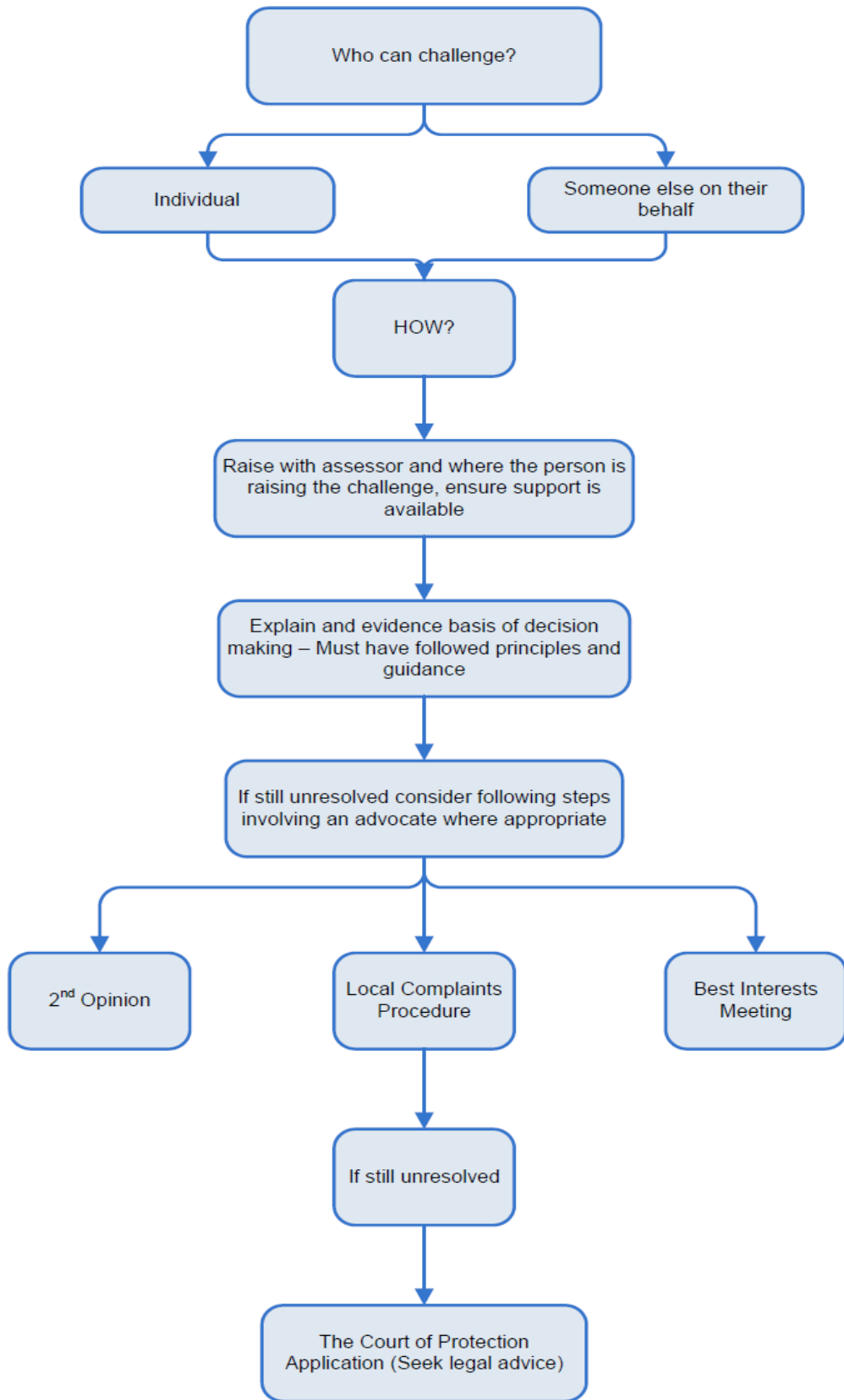
² <http://intranet.northamptonshire.gov.uk/Services/hass/cmsds/Pages/DOLs.aspx>

³ <http://www.northamptonshire.gov.uk/en/councilservices/asc/services/va/pages/dols.aspx>

DECISION MAKING PROCESS FLOWCHART



DISPUTES PROCESS CHART



FUNCTIONAL TEST FOR CAPACITY

FUNCTIONAL TEST FOR CAPACITY

Service User Name:

DOB :

CareFirst No:

STAGE ONE: DIAGNOSTIC THRESHOLD

Does the patient/service user have an impairment of or disturbance in the functioning of their mind or brain?

Yes **No**

(If the answer is **No** then capacity is not an issue. If **Yes** then record nature of the disturbance)

Tick the applicable condition

Neurological Disorder

Learning Disability

Mental Disorder

Delirium, Unconsciousness

Stroke

Head Injury

Dementia

Substance Use

Other (please record)
.....

NATURE OF DECISION

Record in the space below the nature of decision at issue for the person being assessed

.....
.....

STAGE TWO: USING INFORMATION TO FORMULATE A DECISION

See Policy guidance on test criteria (please circle appropriate answer)

1. Does the person understand the information relevant to the decision?

- Yes** | **Supporting Evidence**
 No |

2. Can the person retain the information for long enough for the decision to be made?

- Yes** | **Supporting Evidence**
 No |

3. Can the person use or weigh the information to make a choice?

- Yes** | **Supporting Evidence**
 No |

4. Can the person communicate the decision?

- Yes** | **Supporting Evidence**
 No |

Answering **No** to any part of stage two indicates lack of capacity

Name and role of practitioner/s making assessment:

Name/s:

Role/s/:

Date and Time of assessment:

Date Time:.....

NCC BEST INTEREST CHECKLIST

Best Interests Checklist

For use by staff working with a person lacking capacity in relation to a specific decision

Service User Name:DOB:.....

CareFirst No:

Date of Decision Making/Best Interests Consideration:

.....

DECISION

Record in the space below the decision for which person lacks capacity

Checklist (please tick appropriate answer) and use space for additional information if you wish

1. Has an “advance decision” or “advance refusal” been made about the decision in question (only in relation to healthcare decision) and is it still relevant?

Yes No

If yes then no further assessment is necessary

2. Have you considered whether it is likely that the person may have capacity at some time in the future and whether a delay in decision-making will allow them to make that decision themselves?

Yes No

3. Have you encouraged as far as is practical that person’s involvement in actions undertaken on their behalf or in any decisions affecting them?

Yes No

4. Have you considered as much as is practicable the person’s past and present wishes and preferences about the matter in question?

Yes No

5. Have you considered any relevant written statement the person may have made when they did have capacity?

Yes **No**

6. Have you considered the beliefs and values that would be likely to influence the person's attitude to the decision in question, i.e. religious, and cultural and lifestyle choices?

Yes **No**

7. Have you taken into account other factors that the person would be likely to consider in relation to the matter, i.e. emotional bonds, family obligations in deciding how to spend money or where to reside?

Yes **No**

8. Have you considered alternative actions that produce less restriction on the person's rights and freedoms?

Yes **No**

9. Have you consulted and taken into account the views of other key people as to what would be in a person's best interests and gathered information on their wishes, feelings, values, beliefs:-

a. Anyone named in a statement as someone to be consulted?

Yes **No**

b. Carers, Family, Spouses/Partners?

Yes No NA

c. Others with an interest in their welfare, friends, voluntary workers, other professionals?

Yes No NA

d. Any Lasting Power of Attorney?

Yes No NA

e. Any deputy appointed by the Court of Protection?

Yes No NA

- I. If there are any conflicts in the above consultations there should be an attempt to reach a consensus whatever the final decision. A Best Interests Meeting may be required- to be convened by the Decision Maker in order to try to obtain a consensus.
- II. You should evidence their consultations on (a) in the service user case record/practice notes.
- III. If you answer **No** in question 2 to 9 then you should question whether you are acting in best interests. If no-one is available to consult and/or if there is a serious conflict of opinion and the decision relates to any of the following, you must instruct an IMCA if the decision involves:
 - an NHS body proposing serious treatment
 - an NHS body proposes to provide Accommodation in hospital for a period of more than 28 days, or in a care home for more than 8 weeks
 - where an NHS body proposes to change a persons accommodation to another hospital or care home for a period of more than 28 days in hospital or 8 weeks in a care home.
 - where a local authority proposes to provide or to change residential accommodation for more than 8 weeks.
 - where there is safeguarding adults allegation and proposed strategy meeting.

Name and Role of Worker:

Name.....

Job

Title.....

Contact

Number.....

Date.....

NCC BEST INTEREST MEETING FORM

Best Interest Meeting Form

Name of Customer/Patient:.....

Meeting Convened by:

Date of Relevant Capacity Test:.....

Capacity Test Carried by:

Best Interest Decision Needed:.....

Date of Meeting:.....

Time of Meeting:.....

Venue:.....

Persons Invited

Name	Role

Persons Present

Name	Role

Best Interest Meeting Form

1. Summary Case by Decision Maker including Rationale for Best Interests Meeting

2. Record views of each person related to the decision

a. Name

Views/Recommendations

b. Name

Views/Recommendations

Best Interest Meeting Form

c. Name

Views/Recommendations

d. Name

Views/Recommendations

e. Name

Views/Recommendations

f. Name

Views/Recommendations

g. Name

Views/Recommendations

3. Record of views of person (s) not present or unable to attend

1. Name

Views/Recommendations

2. Name

Views/Recommendations

Best Interest Meeting Form

4. Summary of any conflicting views

5. Are there any additional information/action needed to make the decision?

- Yes
- No

Action Date:

6. Decision Maker's Recommendations

Name of Decision Maker:

Role:

Date:

MENTAL CAPACITY ACT 2005 LEAFLET

Mental Capacity Act 2005

What you need to know



Northamptonshire
County Council

What is the Mental Capacity Act 2005?

The Mental Capacity Act 2005 came fully into force on 1st October 2007 and provides a legal framework for acting and making decisions on behalf of people aged 16 and over who lack capacity and may not be able to make decisions for themselves.

The Act replaces existing common law governing care and treatment of people without capacity. The Act is relevant whenever a person is making a decision on behalf of someone who lacks capacity for that decision - examples may include:

- Personal care
- Activities
- Personal safety
- Where to live
- Medical treatment
- Finances

The Act is supported by the Mental Capacity Act 2005 Code of Practice.

The Act also introduces ways for people to plan ahead for when they may lose capacity.

Who does the Act affect?

It affects all people who may lack capacity to make certain decisions: the people below are those who must follow the Act and have regard to the Code of Practice:

- Doctors
- Nurses
- Social Workers
- Anyone working in a professional or paid role working or caring for people who may lack capacity

It promotes best practice in making decisions on behalf of others and it is important that you know and understand the Act. It also creates a new criminal offence of ill treatment or wilful neglect of a person who lacks capacity. A person found guilty of such an offence may be liable to a fine or imprisonment.



The 5 Core Principles

There are five core principles of the Act that all decisions and actions carried out under the Mental Capacity Act must be tested against. You must know these principles and measure your decisions and actions against them as failure to take them into account could be cited in legal proceedings as evidence of unlawful conduct.

1. A person is assumed to have the capacity to make decisions that affect them. A lack of capacity has to be clearly demonstrated.
2. No one should be treated as unable to make a decision unless all reasonable steps to help them have been exhausted and shown not to work.
3. A person can make an unwise decision. This does not necessarily mean they lack capacity.
4. If it is decided that a person lacks capacity then any decision taken on their behalf must be in their best interests.
5. Any decision taken on behalf of a person who lacks capacity must take into account their rights and freedom of action. Any decision should show that the least restrictive option or intervention is achieved.

How do I assess capacity?

There are two questions to be asked if you are assessing a person's capacity this is called the 2 stage test of capacity: "Is there an impairment of, or disturbance in, the functioning of the person's mind or brain?"

If so...

"Is the impairment or disturbance sufficient that the person lacks the capacity to make that particular decision?"



Any assessment of a person's capacity must consider the following factors:

1. Their ability to understand and retain information related to the decision to be made.
2. Their ability to use or assess the information whilst considering the decision.
3. Their ability to communicate the decision - by any means.

If you have any doubts about a person's capacity and are contemplating making a decision on their behalf you must know and understand this and record both your decision and the reasoning behind your decision in the relevant clinical and practice record.

Best interest's checklist

When you are making a decision for someone who lacks capacity, use this checklist.

- Encourage the person to be involved
- Identify all relevant circumstances – what would the person take into account?
- Find out the person's views, such as:
 - Past and present wishes
 - Beliefs and values
- Don't make assumptions based on age, appearance, culture or behaviour
- Will the person regain capacity? Can the decision wait?

- You mustn't be motivated by desire to bring about death
- Avoid restricting the person's rights – choose the option that is the least restrictive

Remember you must consult with others when making a decision, and record the views expressed.

Decision making

The Act introduces designated decision makers who can make decisions including welfare and treatment choices, on behalf of a person without capacity. The decision maker could be anyone working in a professional or paid role working or caring for people who may lack capacity. It could also be a person with a Lasting Power of Attorney or a Court Appointed Deputy.

It also creates the role of Independent Mental Capacity Advocate (IMCA) who is a trained advocate appointed to support a person who lacks capacity and has no one to speak for them.

There is a statutory duty upon decision makers to refer to an IMCA if the person is "unbefriended", and the decision involves:

- Serious Medical treatment
- An accommodation move and reviews
- Safeguarding Adults
- Complex care reviews- in the community or care homes

The decision maker also has to take into account the report and recommendations from the IMCA involved when they make their decision.

You need to understand the role the IMCA has, including:

- Supporting making decisions
- When and how to involve them
- How much access to confidential information they have

IMCA Services are provided by Total Voice-Northamptonshire 01604 521394





Lasting power of attorney

Adults can plan for the future by making a lasting power of attorney (LPA) giving another person (the attorney) powers to make decisions on their behalf, if later on in life they lack capacity.

There are two kinds of LPA covering decisions about:

- Property and financial **affairs**
- Health and welfare, including healthcare and consent to medical treatment

The following applies to both kinds:

- An LPA must be registered with the Public Guardian
- An attorney must follow the principles in the Mental Capacity Act and Code of Practice
- Any decisions made by the attorney must be in the person's best interests
- A person can choose one attorney or several to make different kinds of decisions

Personal Health and Welfare LPA:

- This can only be used if the person lacks capacity to make that particular decision
- The attorney can make decisions about anything that relates to the donor's personal welfare, subject to any conditions or restrictions in the LPA
- Professionals must ensure that attorneys make these decisions and

should always consult an attorney about any other decisions or action

- An attorney cannot make a decision about life-sustaining treatment, unless the LPA explicitly authorises this

Advance decisions to refuse treatment

An advance decision gives a capable adult the right to refuse specified medical treatment for a time in the future when they may lack the capacity to consent to or refuse that treatment.

- Advance decisions must specify the treatment the person wants to refuse
- They can be cancelled at any time
- They must be valid and applicable to current circumstances
- If the decision refers to life-sustaining treatment it must be in writing, signed and witnessed and it must clearly state the decision applies even if life is at risk
- Advance decisions do not have to use medical terms, but need to clearly describe their wishes
- Advance decisions do not apply to treatment given under the Mental Health Act 1983

The decision would not be valid and applicable if:

- The person had done anything that clearly goes against their advance decision
- The person had withdrawn their decision
- The person had since given the power to make that decision to attorney
- The person would have changed their decision if they had known more about current circumstances

How can I find out more?

- Look at the Mental Capacity Act Code of Practice
- Contact your local training provider
- E-mail for training for Social and Health Care Providers – workforcedevelopment@northamptonshire.gov.uk
- Visit www.publicguardian.gov.uk
- Contact Northamptonshire County Council, Adult & Childrens Commissioning – ACC@northamptonshire.gov.uk
- See the Core Principles poster in your staff room

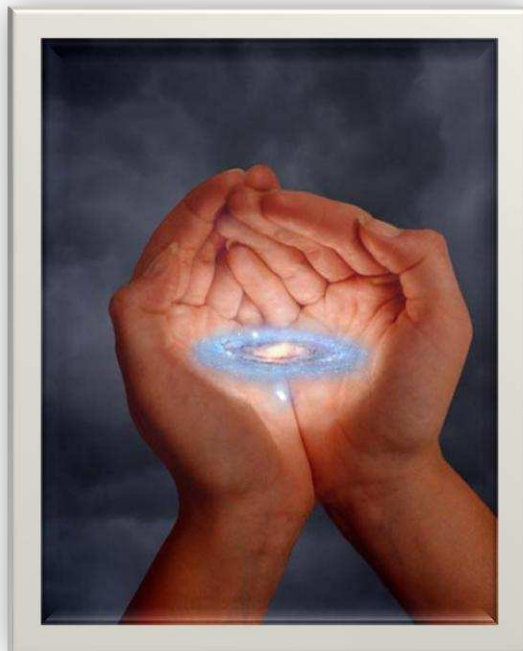
This information is also available in other languages and formats upon request, such as large print, Braille, audio cassette and floppy disk. Please contact 01933 220740.

Produced Sept 2010

ADVANCE DECISION TO REFUSE TREATMENT AND ADVANCE STATEMENT OF WISHES

Advance Decision to Refuse Treatment and Advance Statement of Wishes

My Healthcare in My Hands (Physical and Mental)



This Advance Decision to Refuse Treatment (ADRT) is devised to comply with the requirements of the Mental Capacity Act 2005.

This Advance Statement of Wishes (ASW) is a second edition. It includes space for those people who wish to make known general and specific wishes regarding their health in the event of not being able to make decisions for themselves.

The ADRT and ASW are different in status and are included as two distinct documents.

The documents give you the chance to plan your future care in a proactive way.

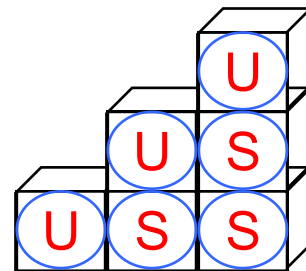
Acknowledgements go to Monica Endersby and the Service User Reference Group who developed the first edition of the Advance Statement in March 2004 and to The Mid Trent Cancer Network.

This booklet was compiled by:

Users Support Service (USS) and the Service User Reference Group (SURG).

If you would like further information about this ADRT and ASW and/or copies, please contact:

Administrator
Users Support Service
104 St. James Road
Northampton
NN5 5LF
Telephone: 01604 756845



Users Support Service
Building Change Together

E-mail: adminuss@btconnect.com
Website: www.userssupportservice.co.uk
Endorsed by Northamptonshire Healthcare NHS Trust
JULY 2008

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A Advance Decision to Refuse Treatment

What is an Advance Decision to Refuse Treatment?

There may be some time in the future when you are unable to think and make decisions about your health care, which may include life sustaining treatments. This is known as lacking in capacity. You may not be able to tell people your wishes, especially about treatment you do not want.

To overcome this eventuality the Mental Capacity Act 2005 provides a legal right for anyone over the age of 18, while they still have capacity, to advise others, either in written or spoken form, of treatments they do not wish to receive. This is an Advance Decision to Refuse Treatment (**ADRT**).

If, for no good reason, doctors and other healthcare workers do not respect the decisions made, they will find themselves liable to prosecution.

Making an ADRT

One key part of the decision making is ensuring the **ADRT** is valid. This means that the maker fully understands the implications of the **ADRT** when made. Another key part is that it is applicable to proposed treatments.

You may use the form provided in this booklet but if you decide to write your own **ADRT** it should:

- Be in writing (It is valid if made orally and recorded in notes, but a written statement is clearer). You do not **HAVE** to use the form included in this document.
- Give details of the maker including full name, date of birth, home address and any distinguishing features - in case of identification need whilst unconscious.
- Include name and address of GP and preferably whether they hold a copy.
- Include a statement that the **ADRT** should be used if the person lacks capacity to make treatment decisions.
- Specify the particular treatment that is to be refused and the circumstances in which the **ADRT** will apply.

Indicate the date written (and dates of any review). It is in your interests to review the **ADRT** regularly.

- Include the maker's signature (or the signature of someone the maker has asked to sign on their behalf and in their presence).
- Include Witness's signature, name and contact details, signed in the presence of the maker at the same time as their signature.

As this is a legal document you may wish to consult a solicitor as to its presentation.

An **ADRT** can be verbally given and under such circumstances care must be taken to ensure that the information is written in patient notes.

Refusal of Life Sustaining Treatment

Certain treatments maintain or keep life going. The best known of these are:



Cardio-pulmonary Resuscitation: this is used to restart the heart and breathing and involves regular downward pressure on the chest accompanied by breathing into the mouth or administering oxygen.

The heart can also be 'shocked' into restarting using a machine called a defibrillator.



Assisted Ventilation: this is to provide help with breathing and could involve administering oxygen or attaching to a machine (a ventilator) which takes over the breathing function.



Artificial Nutrition and Hydration: this is giving food or drink by routes other than the mouth. This can include a tube passing directly into the stomach via the nose or by attaching to a drip.

It is important that you discuss the implications surrounding refusal of life sustaining treatment with a healthcare professional as decisions may alter with circumstances.

If the **ADRT** incorporates the **Refusal of Life Sustaining Treatment** it must:-

- be in writing (if the person is unable to write, someone else must write it for them).
- be signed by the maker. (If unable to sign, the maker can direct someone to sign on their behalf.)
- be signed in the presence of the Witness. The Witness must then sign in the presence of the maker. If the maker cannot sign, they can direct someone to sign on their behalf in front of the maker.
- include a clear written statement that the **ADRT** is to apply to a specific treatment '**even if life is at risk**'. If this part of the **ADRT** is made at a separate time it must be signed and witnessed as previously stated.

Please note a verbal **ADRT cannot** include a Refusal of Life Sustaining Treatment.

ADRT and Mental Health

For people being treated on a voluntary basis for a mental health issue an **ADRT** has to be respected in the same way as any other decision. However, where a person is detained under the Mental Health Act 1983 the decision regarding treatment for the mental illness problem can be overridden by the compulsory treatment provisions of Part 4 of that Act. Where a detained patient is also having treatment for a physical disorder the **ADRT** can still be applied for that disorder.

Status of Witnesses

The witnessing of the **ADRT** or signature does not imply that the Witness has assessed the capacity of the maker.

Choosing and Telling People an Advance Decision Has Been Made

Think who you would wish to convey your wishes for you e.g. family members, friends, advocates or other persons if you are unable to speak for yourself. It is important to choose your representatives with care, and that you ensure they understand your views and know your wishes and would act in accordance with them. You need to have complete trust and faith in the people that you choose to speak for you if you are unable to speak or communicate for yourself.

Inform the person/s who you have chosen, so that they are aware of your views and decisions should you lose capacity.

You must also realise the great responsibility that you are entrusting to, and asking of, the people that you wish to speak for you. This is not a decision to take lightly and will involve discussing in depth with the person(s) you choose.

Giving a Person the Authority to Act on Your Behalf

This will allow that person to refuse treatment on your behalf. This is called a **Lasting Power of Attorney (LPA)**.

A **Personal Welfare LPA** will act in respect of personal healthcare and wellbeing. Once the **Personal Welfare LPA** has been properly registered an **ADRT is invalidated and wishes can be overridden**.

You will need the help of a solicitor to arrange these appointments as this is a legal process.

Reviewing, Amending or Withdrawing an ADRT

This can be done at any time by the maker, if they have capacity. It can be done in any form, including verbally, unless an **ADRT** refusing life-sustaining treatment is being added. It is good practice to do this in writing and let people who are involved in your care planning know.

If the **ADRT** is to be withdrawn **all copies** of the original document must be marked as '**No longer active**'. The date of cancellation and who cancelled the **ADRT** should also be indicated.

Questions and Answers about ADRT

So, what goes in an Advance Decision to Refuse Treatment?

Any treatment that you **DO NOT** wish to have in the future. There is no set format unless your decision includes refusing treatment that sustains life when it must be written. Making an **ADRT** is entirely voluntary.

Advance Decisions to Refuse Treatment..... What are they?

There may be times in the future when you may need to receive medical treatment. At these times, the health and social care professionals that treat you will always try to give you the best treatment possible.

But, in some cases, you may have strong feelings about treatment you decide not to have in particular circumstances in the future. An Advance Decision to Refuse Treatment is how you record such decisions.

Are Advance Decisions to Refuse Treatment legally binding?

Yes. This is a precise way of expressing a decision **NOT** to have a specific treatment in specific circumstances in the future and is binding providing the **ADRT** is valid and applicable. These decisions **MUST** also be your **OWN** decisions.

What does an Advance Decision to Refuse Treatment form look like?

It can be a simple form, which you fill in yourself. An example can be provided although you are free to write your own (following a certain format if you are refusing life sustaining treatment).

Where can I get hold of the Advance Decision to Refuse Treatment form?

By asking a health or social care professional or contacting USS. Often it is best to ask your GP or Hospital team who may already be involved in your care.

Special Circumstances

There may be a number of circumstances that might make such an **ADRT** more complicated to write and for professionals to follow. This might include women who may become or are pregnant. You should seek help if you have any doubts before making an **ADRT**.

Communicating your Advance Decision to Refuse Treatment

If you have made an Advance Decision to Refuse Treatment you must ensure that key people / organisations know this. Guidance and support can be given to help you do this.

This will help you avoid difficult situations especially when an emergency happens.

Can I name someone to make my decisions about treatments I don't want if I become unable to?

Yes. A lasting power of Attorney can be appointed by you to make healthcare decisions should you become unable to make your own decisions. Appointing a Lasting Power of Attorney can be done through your solicitor.

Does my Advance Decision to Refuse Treatment need to be witnessed?

Any **ADRT** must be witnessed. If you are writing an **ADRT** the witness must sign in your presence. If you cannot sign ask someone to sign for you, in front of you and the witness. If possible consider asking someone to witness who is independent and has nothing to gain as a consequence of the **ADRT**.

Who should I discuss the types of treatment I don't want with?

We advise you to talk your advance decisions through with your close family, the doctor, nurse or GP who is involved in your care – though you are not obliged to do so. If you have a family solicitor, it may be useful to talk your wishes through with them.

Who writes my Advance Decision to Refuse Treatment form?

You do. Once you have discussed and decided on what treatment you want to refuse, you can complete the Advance Decision to Refuse Treatment.

Does a Doctor or Nurse have to sign my Advance Decision to Refuse Treatment?

No. We advise you to discuss what you have put in (or want to put in) your **ADRT** with your Doctor. This can be your GP or another doctor involved in your care. If at any point you do speak to a doctor about your decisions, please ask if their details can be included in your **ADRT** form as a point of contact in the future.

Who should know about my wishes?

Once you have made your **ADRT** and written, signed and witnessed it, we advise you to give a copy of it to your close family members, your GP, any other Doctor, nurse and social worker involved in your care and potentially your family solicitor but this is not essential.

Don't forget to keep a copy of your document in an easy to access, visible place within your home and record how many copies exist, in case you change your mind.

What should I do if I want to use my Advance Decision to Refuse Treatment?

Tell the Health Professional involved in your care that you have an Advance Decision. Tell them **where to find it**, and who can support your decisions.

Remember a time may come when you cannot tell a health professional about your **ADRT**. This is why you should let people know about it as soon as possible.

Can I Change My Mind?

Yes - at any time. If you change your mind then simply inform all your health and social care professionals straightaway. It is important that you inform all those individuals who have a copy of the previous Advance Decision as this is now invalid.

Where can I go for further advice and support?

The staff responsible for your care, including your doctors and nurses, will be able to discuss this with you. A copy of this form is available at your request. Additionally the Patient Advice and Liaison Services (Northamptonshire Healthcare NHS Trust, 01536 494130; Northampton General Hospital, 01604 545784; Kettering General Hospital, 01536 493305), can be of particular help.

Your solicitor can also give advice and guidance on how to produce an **ADRT**.

Useful websites include:

Users Support Service www.userssupportservice.co.uk

Ministry of Justice www.justice.gov.uk

Department of Health www.dh.gov.uk

Help the Aged www.helptheaged.org.uk

My Advance Decision to Refuse Treatment

Name	Any distinguishing features (in the event of unconsciousness)							
Address	Date of Birth							
	Telephone Number							
<p>These are my advance decisions about my health care, in the event that I cannot consent to treatment and they replace any previous decisions I have made.</p> <p><i>In these specific circumstances:</i></p> <p><i>I wish to refuse the following treatments:(Include treatments for physical and mental illness)</i></p> <p><i>I would also wish to refuse life sustaining treatment, "even if my life is at risk" such as</i></p> <p><i>Restarting my heart or breathing (Cardio-pulmonary Resuscitation)</i> <input style="float: right;" type="checkbox"/></p> <p><i>Help with breathing (Assisted Ventilation, including by use of a machine)</i> <input style="float: right;" type="checkbox"/></p> <p><i>Being given food or water by any other route than by mouth, (Artificial Nutrition and Hydration)</i> <input style="float: right;" type="checkbox"/></p> <p><i>I have marked the boxes to show that these are specific treatments I do not want. I am aware that I will be provided basic care, support and comfort.</i></p>								
Maker`s Signature		Date of Signature						
<p>Witness of Signature</p> <table style="width: 100%; border: none;"> <tr> <td style="width: 50%; border: none;">Print Name</td> <td style="width: 50%; border: none;">Signature</td> </tr> <tr> <td style="border: none;">Address</td> <td style="border: none;">Telephone No.</td> </tr> <tr> <td style="border: none;"></td> <td style="border: none;">Date.</td> </tr> </table>			Print Name	Signature	Address	Telephone No.		Date.
Print Name	Signature							
Address	Telephone No.							
	Date.							

Person to be contacted to discuss my wishes:

Name

Relationship

Address

Telephone no

I have discussed this with (*e.g. name of Healthcare Professional*)

Profession / Job Title
Contact Details

Date

I give permission for this document to be discussed with my relatives / carers

YES

NO

(*please circle one*)

My General Practitioner is : (*name*)

Address
Telephone Number

Review 1: Date/Time of review

Valid Until

Maker`s Signature

Witness Signature

Review 2: Date/Time of review

Valid Until

Maker`s Signature

Witness Signature

The following list identifies which people have a copy and have been told about this Advance Decision to Refuse Treatment

Name	Relationship	Telephone Number

I have/ have not appointed a Lasting Power of Attorney (LPA) for Welfare

If Yes:- Name of LPA _____

Contact Details _____

_____ Tel. no. _____

I understand that a LPA appointed after I have made this ADRT can override my wishes.

B Advance Statement of Wishes

What is an Advance Statement of Wishes?

An Advance Statement of Wishes (**ASW**) is usually a written document that you can choose to complete to make sure your personal informed wishes are known in the event that your health may affect your ability to make or communicate decisions. This could be in relation to your mental and/or physical health, any support and treatment you receive, any practical matters relating to your home and family and anything else you want to ensure people know about. You can also make your wishes known verbally.

Unlike an Advance Decision to Refuse Treatment (ADRT) an Advance Statement of Wishes (**ASW**) is not legally binding.

Why Have an Advance Statement of Wishes (ASW)?

Sometimes a person's health means their ability to make decisions is affected. People may also feel that they are not always listened to. An **ASW** ensures that other people know what your wishes are and that these can be clearly communicated to those who may be called upon to make decisions on your behalf.

Making an Advance Statement of Wishes

As with an **ADRT** you need to have 'capacity to make a decision'. This means:

- Having a general understanding of what decision needs to be made and why it needs to be made
- Understanding the 'likely' consequences of making, or not making , this decision
- Having the ability to understand, retain, use and weigh up the information relevant to the decision
- Communicating the decision (by talking, sign language or any other means)

You must think carefully about all the circumstances that may arise. As an example, perhaps a drug has given unwanted side effects and you do not wish to take it again. However, the drug might improve its performance or a newer drug become available. So be clear as you can be about particular drugs or treatment/s that you have an opinion about.

You do not have to make an **ASW**. It is your choice.

The following pages can be used, partially or fully, in the making of your **ASW**. Use the sections that are useful to you and you will have a document that will help to ensure that your wishes are respected.

Choosing and Telling People an Advance Statement of Wishes Has Been Made

As with an **ADRT** this is very important. People will only be able to respond to your wishes if you make them known to those who may be involved in making decisions.

You are strongly advised to keep a copy with your GP and/or other healthcare staff, otherwise it may not be possible to trace your **ASW** when you become ill.

Giving a Person the Authority to Act on Your Behalf

As with an **ADRT** you can also appoint a Lasting Power of Attorney (LPA) for Welfare. It could, however, also be beneficial to appoint a LPA for Property and Affairs who will make decisions in respect of your property and financial affairs.

My Advance Statement of Wishes

This is my Advance Statement of Wishes which I have written in case it is decided that I am unable to make decisions or speak or communicate on my own behalf.

My name (please print).....

Address.....

.....Tel.No.....

Date of Birth.....

Name of Mental/Physical Health Worker e.g. Community Mental Health Team or Support Worker with whom this was discussed (this is optional)

.....
Contact address.....

Contact tel.no.....

General Practitioner.....

Names of family members/friends/advocates that know about and understand my Advance Statement of Wishes. (Please contact one of the people on the list and they will speak on my behalf).

Nearest Relative.....

Tel.no.....

Address.....

.....
Contact name 1.....

Tel.no.....

Address.....

.....
Contact name 2.....

Tel.no.....

Address.....

Whilst I appreciate that certain sections of the Mental Health Act legislate that my Nearest Relative be contacted either way if I am an informal or detained patient, I wish the following people NOT to be involved in my support and treatment:

.....
.....
.....

My choice of solicitor is:



In the event that the choices expressed in this Advance Statement of Wishes are not followed, I expect this to be recorded fully in writing, so that I will be provided with a full explanation when/if I regain capacity.

Where I keep copies of my Advance Statement

(You could keep copies with a family member, carer or friend, a support worker, doctor or with your care plan or all of these. It is important to remember to change all copies if you change one.)

.....

Copies of my Advance Statement are held by: (Please print)
(If you have a copy at home, please specify where it is.)

1.....

.....

2.....

.....

3.....

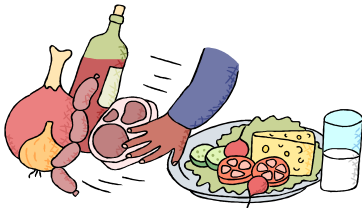
.....

Support and Treatment with Regard to My Health (Mental and Physical)

Mindful that I may have no option for certain treatments if detained under the Mental Health Act 1983, I declare that my wishes are as follows:
My wishes regarding medication and treatment are as follows (it is helpful to give reasons why)



Needs that are special to me, which I would like those caring for me to know about e.g. diet, faith, physical health, personal anxieties, possible phobias, preferences with regard to privacy etc.



My wishes regarding who delivers my support and treatment e.g. Consultant, Care Co-ordinator (this could be a named worker or a preferred worker e.g. Nurse, Doctor, male or female),



My wishes are that the following people are **not** involved in my support and treatment.



The following worked well for me when I was receiving support and treatment (It may be helpful to give reasons).



The following did **not** work well for me when I was receiving support and treatment in the past (It may be helpful to give reasons).



My Wishes Regarding My Home Life While I am Unwell

I declare that my wishes are as follows:

1. I would like the following people to be told immediately that I have become unwell and/or admitted to hospital and for them to be kept updated.



2. I do **not** want the following people to be told that I have become unwell or have been admitted to hospital.

3. Other people to contact and tell that I am **not** at home e.g. home care worker, regular visitors, milkman etc.



4. CHILDREN OR DEPENDANTS

Complete this section if you have children or dependants and would like them to be cared for in a particular way:

My children's/dependant's names are (dates of birth for children)
School contact details (if applicable):



a). I would like the following people (who are aware of this) to care for my children or dependants: (Names and relationship to children/dependants)



b). When someone explains where I am to my children, I would like them to be told the following: (You may want to state here what their current understanding is.)

5. CONSULTATION

I would like to be consulted before people are told how I am etc.

Yes No (please tick)

6. FINANCES

a). I would like the following arrangements to be made for my finances.



b). I would like the following arrangements to be made if it is decided that I need an appointee to authorise my state benefits.

7. SECURITY AND MY HOME.



a). I would like the following person(s) to make sure that my home and car etc. are secure:



b). I would like them to hold a set of my keys

Yes No

Signed.....

c) Other instructions about home (e.g. Prepayment meters, collection of post, checking my home etc.)

8. PETS

Complete this section if you have pets to be cared for.

a). I have the following pets:



b). I would like the following people to look after my pets:



c). People may need to know the following about my pets:



9. OTHER INFORMATION

(Anything else you would like to make known)

Signature.....Date

Print Name

Witness Signature.....Date

Print Name

**C My Wishes Regarding Correspondence Written About Me
When I am Unwell**

I would like to receive copies of my admission and discharge letters.

(Please tick) Yes No

I would like to receive copies of all correspondence written about me
when I am unwell.

(Please tick) Yes No

I would like the copies to be sent to the following address (leave blank if
home address):

.....
.....
.....

I would like my medical correspondence to be available to the following
people only:

.....
.....
.....

I would like to receive these copies, (please tick)

Whilst I am still in hospital
After I have been discharged

D Organ Donation

In the event of your death you may wish to donate organs for the benefit of others.

The carrying of a donor card is not sufficient. It is recommended that you become a registered donor. You can do this by:

- contacting the NHS Organ Donor Line on 0845 60 60 400
- visiting www.uktransplant.org.uk

Please tick

I do not have a donor card

I have a donor card

I am not a registered donor

I am a registered donor and my registration details are

.....

I request after my death

a) Any part of my body be used for the treatment of others

or my

b) kidneys corneas heart lungs liver pancreas
be used for transplant.

Signed..... Date

Witness signature Date

E Reminder to Review my Advance Statement to Refuse Treatment and/or my Advance Statement of Wishes

You should remember to review your **ADRT** and/or **ASW** regularly to ensure that it still meets your needs and to change statements if necessary.

The dates that these reviews/changes are made must be recorded in order to avoid confusion as to whether it is your most current decision.

You must inform all the people that hold copies of any changes you make, otherwise they may not be able to follow your wishes.

DIGNITY IN DYING ADVANCE DECISION

Dignity in dying

your life, your choice



Advance decisions toolkit

Guidance for Health Professionals

About Dignity in Dying

We support:

- Patient choice at the end-of-life
- Improvements in palliative care in all settings
- A dignified death for all

Dignity in Dying is also the UK's leading provider of advance decisions, (otherwise known as living wills). Advance decisions allow people to specify any medical treatment decision they would like to be made on their behalf should they lose capacity. However, this toolkit will concentrate only on decisions to refuse life-sustaining treatment. In this document therefore the term advance decision will mean specifically an advance decision to refuse life-sustaining treatment.

Dignity in Dying distributes thousands of our '*pro-choice* Advance Decisions' every year to members of the public who are keen to maintain as much control as possible over their future healthcare decisions. General practitioners, hospitals, care homes and lawyers regularly ask us to provide them with large numbers of these documents, and advise them on best practice. We have over 70 years' experience of dealing with end-of-life care issues including expertise on drawing up and implementation of advance decisions.

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Executive Summary

What are advance decisions?

Advance decisions are statements made by adults with capacity, in which they can make decisions about all treatment they may receive. For example, they may be used to note down their wish to refuse (but not request) life-sustaining medical treatment at a point in the future, in case the individual loses the capacity to make such decisions. For example, a patient may use an advance decision to refuse mechanical ventilation in the event that he or she becomes permanently unconscious and unable to breathe. An advance decision to refuse treatment must be made in writing, signed and witnessed.

The Mental Capacity Act 2005 (MCA) which came into effect in 2007¹, puts advance decision making on a statutory footing. It applies solely to England and Wales. It sets out the criteria that advance decisions must meet in order to be 'valid and applicable'. Provided that an advance decision meets these criteria, it is legally binding and must be complied with. The Mental Capacity Act 2005, refers to advance decisions. In some parts of the world such decisions may be known by another term 'advance directives' or 'advance statements'. Living will is also a common, informal term, and one that the public is likely to be familiar with. But we use the term: advance decision/s throughout this document.

The purpose and scope of the toolkit

While the MCA puts all advance decisions to refuse treatment on a legal footing, advance decisions that refuse life-sustaining treatment must meet additional requirements within the MCA, and raise particular issues for health professionals.

This toolkit is solely concerned with advance decisions relating to life-sustaining treatment; that is, where a patient with capacity has made a decision to refuse life-sustaining treatment at a point in future, and at a time when he or she may have lost capacity. The toolkit is not concerned with patients refusing any other type of treatment, whether contemporaneously or in advance. Nor does it refer to the withholding or withdrawing of treatment from patients whose wishes have not been set out in an advance decision.

The primary purpose of the toolkit is to improve the effectiveness of advance decision making and implementation. It identifies the potential difficulties health professionals may face when acting on advance decisions to refuse life-sustaining treatment, and also gives practical guidance on avoiding these difficulties. It gives a clear explanation of health professionals' obligations pursuant to the Mental Capacity Act. This toolkit should be read in conjunction with the Mental Capacity Act 2005 and its Code of Practice.

Who should use the toolkit?

The toolkit is designed for those who might be involved in implementing a patient's advance decision - typically doctors and nurses in the acute hospital setting. It may also be relevant to health professionals working in the community setting, and to general practitioners who may be approached by patients seeking advice on drafting an advance decision.

Part 1: The Principles and the law

1. Introduction

Background

1.1 Modern medical treatments such as mechanical ventilation and artificial nutrition and hydration offer considerable benefits to vast numbers of seriously ill patients. However, many patients are concerned that these treatments should not be used to prolong the dying process if their disease or condition cannot be reversed, or their quality of life improved.

1.2 Adults with capacity to understand the decision they are making have the legal right to refuse treatment. They may weigh up the benefits, burdens, risks and overall acceptability of any treatment,² but the right to refuse is enshrined in law, even if it results in his or her own death.³

My wife has been ill for many years and so we both made advance decisions. Following an operation she ended up on life support. Her advance decision was of considerable assistance when I was faced with discussing what my wife would want, with her doctors.

Raymond (Husband).



1.3 Adults with capacity also have the legal right to refuse medical treatments in advance, via an advance decision, so that their wishes will be known if they lose the capacity to express them in the future. **This right is now enshrined in the Mental Capacity Act 2005, which came fully into force in October 2007.**

The benefits of advance decisions

1.4 Patients who make advance decisions to refuse treatment are often predominantly concerned with avoiding a lingering death. Some may have witnessed the slow deterioration of a relative, perhaps due to stroke or Alzheimer's disease, and wish to maintain as much autonomy and control as possible at the end of their own lives.

1.5 Health professionals' views on what their patients want do not always match the wishes of their patients. Research has found that active treatment is often provided during the final months of life even when the patient or family would have preferred comfort care only.⁴ Some health professionals admit to providing more treatment to patients than they would want themselves.⁵

1.6 Advance decisions to refuse treatment are legally binding under the Mental Capacity Act and must be followed even if others may not believe this to be the best course of action. While different views and feelings may be held by those close to the patient, clarity about the patient's wishes as set out in advance decisions is paramount.⁶

1.7 There is evidence that the vast majority of seriously ill patients are willing to discuss their care, but health professionals are sometimes reluctant to initiate these conversations.⁷ The existence of an advance decision can form a useful starting point for these difficult discussions.

1.8 Advance decisions have also been found to alleviate some of the anxiety family members experience when consulted by healthcare professionals on treatment decisions at the end of a loved one's life. This can lead to a more positive bereavement process.⁸ Consultation with family members is given statutory force under the Mental Capacity Act. Additionally, if a Lasting Power of Attorney (LPA) has been drawn up under the provisions of the Mental Capacity Act by an individual, this will mean that for the first time, family members who are nominated under the LPA may make decisions, rather than the doctor.

Potential difficulties from past experience in implementing advance decisions

1.9 Unfortunately, advance decisions to refuse treatment in the past have not always operated as well as they could in practice, often due to one or more of the situations in Box 1 arising:



2. Advance decisions and the law

The Mental Capacity Act 2005

2.1 Prior to the Mental Capacity Act, advance decisions were regulated under the common law.¹⁰ The Act codifies the common law rules and puts advance decisions on a statutory footing, with some additional safeguards. Advance decisions made prior to the Act coming into force may be valid if they do not refuse life-sustaining treatment. Advance decisions made prior to the Act coming into force, which do refuse life-sustaining treatment, are likely to require some amendment in line with the new safeguards, paying particular attention to point g in Box 2. Box 2 gives a number of general requirements that advance decisions to refuse life-sustaining treatment must meet in order to be legally binding:

Box 2: The Mental Capacity Act's general requirements for advance decisions to refuse life-sustaining treatment:

Advance decisions to refuse life-sustaining treatment must:

- a) Specify the treatment(s) that is to be refused, although this may be expressed in layman's terms;
- b) Be made only by persons who are 18 years or older;
- c) Be made only by persons who have capacity, as defined in the Act;
- d) Be in writing;
- e) Be signed by the patient (or, if the patient is unable to sign it, by another person in the patient's presence) in the presence of a witness;
- f) Be signed by the witness, in the presence of the patient;
- g) Be verified with a statement to the effect that the advance decision should apply even if life is at risk. This can be included in the document itself or can be a separate statement - in which case it must also be signed by the patient and a witness.

Note: Advance decisions to refuse treatment may set out the circumstances when the refusal should apply - it is helpful to include as much detail as possible.

2.2 In order to be legally effective, an advance decision to refuse treatment will need to be both valid and applicable. The Act sets out circumstances that will make an advance decision to refuse treatment invalid and/or inapplicable:

Box 1: Potential difficulties from past experience in implementing advance decisions

- **Health professionals may be unaware that an advance decision to refuse treatment has been written.** Patients may not be well enough to inform the health team that they have an advance decision to refuse treatment. At present there is no national registration system to help health professionals quickly establish whether an advance decision to refuse treatment has been made.
- **The advance decision may not follow the patient to other wards, departments or institutions.** Patients' care can be transferred many times during the last months, weeks and days of life - for example, between a geriatric ward, an emergency department and an intensive care unit. If communication between the various staff is not carefully co-ordinated, the existence of the advance decision may not emerge.
- **Relatives might object to the content of the advance decision to refuse treatment.** Faced with the imminent death of a loved one, relatives may urge health professionals to ignore an advance decision to refuse treatment and sustain the patient's life as long as possible. However, under the Mental Capacity Act, as indicated above, the advance decision to refuse treatment is legally binding.
- **There may be confusion about the legal status of advance decisions to refuse treatment.** Historically, research suggests that there has been confusion as to the legally binding nature of an advance decision to refuse treatment. Advance decisions to refuse treatment under the Mental Capacity Act are legally binding and the Act gives much greater legal clarity to the issue. Health professionals have a legal obligation under the Mental Capacity Act to comply with valid and applicable advance decisions.⁹
- **An advance decision may be worded too ambiguously.** A patient may have little knowledge of end-of-life conditions and treatments, and write an advance decision that does not provide clinically useful instructions. For example, a patient might refuse all medical interventions in the event that his/her life becomes "intolerable". The health professional is then left to ponder whether the patient would consider the present situation intolerable or not. Under the MCA, ambiguous advance decisions may not be valid. It is therefore important that the individual specifies the treatment refused.
- **The advance decision may be worded too specifically.** Conversely, if an advance decision describes a condition or situation different to that which has arisen, it may be unclear whether the decision should still apply. For example, a patient may refuse artificial nutrition in the event that he/she becomes unable to swallow, but give no preference in the event that he/she becomes permanently unconscious. Family members may insist the patient would want the advance decision to apply, but the health professional will have no evidence to support this view.

Chapters 4 - 6 present solutions to the above challenges.



Box 3: Validity and applicability

An advance decision is invalid if:

- a) The patient has withdrawn the advance decision at a time when he/she had capacity to do so (a patient with capacity can withdraw an advance decision at any time either in writing or verbally; no formal procedures are required); or
- b) The patient has created a Lasting Power of Attorney after creating the advance decision, which gives the attorney the power to give or refuse consent to the life-sustaining treatment in question (see paragraphs 2.5 - 2.8 below); or
- c) Since making the advance decision, the patient has acted in a way that is clearly inconsistent with the advance decision remaining his/her fixed decision. (See case study 1 below).

An advance decision is not applicable if:

- d) At the material time, the patient still has the capacity to give or refuse consent to treatment; or
- e) The treatment in question is not the treatment specified in the advance decision; or
- f) If the circumstances are different from those that may have been set out in the advance decision; or

Note: Whilst an advance decision should set out the treatment being refused, an advance decision refusing all treatment in any situation, (for example, one that explains a person holds a particular religious or personal belief) may be valid and applicable.

- g) There are reasonable grounds for believing that circumstances exist which the patient did not anticipate at the time of making the advance decision, and which would have affected his/her decision. (For example, if the refused treatment has developed significantly since the time the patient created the advance decision).



CASE STUDY 1: Mr Smith creates an advance decision refusing mechanical ventilation in the event that he becomes unable to breathe. A year later, he is involved in a serious road accident and is paralysed from the neck down, but remains conscious and consents to artificial ventilation. Some weeks later, he loses consciousness and it is only then that his advance decision is discovered.

Given that Mr Smith had consented to treatment and remained on the ventilator for some time, the validity of his advance decision could be called into question. In this case it would be appropriate for the health professionals to supplement the information in his advance decision with a broader understanding derived from conversations with relatives or friends.

Limitations

2.3 Patients do not have a legal right to demand that any specific treatment be given, whether contemporaneously or via an advance decision.¹¹ Requests for treatment should be given serious consideration, but health professionals are under no obligation to provide treatments that they consider clinically unnecessary, futile or inappropriate.

2.4 Advance decisions cannot be used to request unlawful procedures such as assistance in dying, or to refuse basic care such as warmth, shelter and hygiene measures.

Lasting Powers of Attorney and their relationship to advance decisions

2.5 Section 9 of the Mental Capacity Act creates a new legal tool called Lasting Powers of Attorney (LPA), to replace the current system of Enduring Powers of Attorney (EPA). It allows a person (described in the Act as a 'donor') to appoint another person (an 'attorney') to make decisions for them if they lose capacity to do so in the future. These can be financial decisions, or decisions about welfare and healthcare. This is a significant change from the EPA system, under which attorneys had no power to make welfare or healthcare decisions.

2.6 Donors may confer on their attorneys the power to give or refuse consent to life-sustaining treatment, provided that an express statement is included in the LPA document to that effect (and subject to conditions set out in the Act).

2.7 An attorney will not have the power to give consent to any treatment that is specifically refused in an advance decision to refuse treatment. However, if the donor has created a LPA *after* creating the advance decision to refuse treatment, and has given the attorney the *specific* power to give or refuse consent to the treatment in question, the LPA will take precedence, and the advance decision to refuse treatment becomes invalid.

2.8 Attorneys must be named individuals who are at least 18 years of age. The Act does not impose any further restrictions on who can be an attorney in relation to health or welfare decisions.¹²

Liability of Health Professionals

2.9 The Mental Capacity Act's Code of Practice states at 9.57, "Healthcare professionals must follow an advance decision if they are satisfied that it exists, is valid and is applicable to their circumstances. Failure to follow an advance decision in this situation could lead to a claim for damages for battery or a criminal charge of assault."

2.10 However, it adds that health professionals with genuine doubts about the existence, validity or applicability of an advance decision can provide treatment without incurring liability. In such situations, health professionals should make clear notes explaining why they have not followed the advance decision.

Conscientious objection

2.11 Health professionals with a conscientious objection to limiting treatment in line with a patient's advance decision do not have to act contrary to their beliefs. However, health professionals must not simply abandon their patients and have a duty to find another doctor who will comply with the wishes of the patient.¹³

2.12 Paragraph 9.62 of the Code of Practice advises that health professionals with a conscientious objection should make their views clear when the matter of the advance decision is initially raised. Patients with capacity should immediately be given the option of having their care transferred to another health professional, where this is feasible. If the patient lacks capacity, the health professional should make arrangements for their care to be transferred.

2.13 If transferral of the patient's care cannot be agreed, the Court of Protection has the power to direct that a different health professional takes responsibility for the patient (see Sections 45 to 56 of the Act and Chapter 6 below for more on the Court of Protection and its role).

3. Definitions and related guidance

3.1 The General Medical Council and the British Medical Association (amongst others) have produced a wealth of guidance to help health professionals make difficult end-of-life treatment decisions.¹⁴ Below is a summary of the guidance most relevant to advance decisions to refuse treatment. This is by no means comprehensive; health professionals should refer to the full guidance to ensure they act within the law and in accordance with best practice.

Life-prolonging or life-sustaining treatments

3.2 The British Medical Association defines life-prolonging treatments as “all treatment which has the potential to postpone the patient's death and includes cardiopulmonary resuscitation, artificial ventilation, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection and artificial nutrition and hydration.”¹⁵ The MCA defines life-sustaining treatment for the purposes of advance decision as that which “in the view of a person providing health care for the person concerned, is necessary to sustain life.” This is the definition that will determine whether or not an advance decision has to meet the requirements that relate to life-sustaining treatment. In the context of advance decisions, life-sustaining treatments usually refers to a distinct group of therapies whose purpose is to maintain or replace a vital bodily function, and without which death would most likely occur as a result of organ or system failure.

Artificial nutrition and hydration (ANH)

3.3 'ANH' refers to a group of medical techniques used to administer nutrition or hydration to patients who are unable to swallow. Options include percutaneous endoscopic



gastrostomy (PEG), subcutaneous hydration, nasogastric tubes or intravenous cannula.

3.4 ANH is distinguished from oral nutrition and hydration (ONH), which is swallowed in the usual process. ANH is classified in common law as medical treatment, because it involves specialised knowledge and input from health professionals.¹⁶ In contrast, ONH is considered part of 'basic care' rather than medical treatment.

3.5 Whilst patients have a legal right to refuse medical treatment in an advance decision, they do not have a right to refuse basic care. Thus ANH can be refused in an advance decision, but ONH cannot.

Identifying capacity

3.6 The Mental Capacity Act stipulates at Section 2 (1) that, for the purposes of the Act, "A person lacks capacity in relation to a matter if at the material times he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain."

3.7 A person must always be assumed to have capacity unless the opposite is established.¹⁷ The Act therefore requires that the inability to make a decision be caused by an impairment or disturbance in the mind or brain. If no impairment or disturbance can be diagnosed, the person cannot be said to lack capacity. Section 2(3) makes clear that a lack of capacity cannot be established merely by reference to a person's age or appearance, or from unjustified assumptions based on the person's condition or behaviour. Nor can a person be said to lack capacity merely because he/she makes an unwise decision (Section 1 (4)).

3.8 Section 3 (1) sets out a functional test for determining the person's ability to make a decision for him/herself:



Box 4: A person is unable to make a decision if he/she is unable to:

- a) understand the information relevant to the decision
- b) retain that information
- c) use or weigh that information as part of the process of making the decision, or
- d) communicate the decision (whether by talking, using sign language or any other means).

3.9 A lack of decision-making capacity in one area of life does not automatically indicate a lack of capacity to make a decision on a different issue - each decision must be considered separately.

Respecting patients' views and beliefs

3.10 Health professionals have a duty to recognise and respect their patients' individual values and beliefs,¹⁸ and must never put pressure on a patient to accept treatment contrary to his/her wishes. Health professionals must acknowledge that competent patients have an absolute legal right to refuse treatment, "notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent."¹⁹

"Advance decisions are a powerful tool to ensure that patient's wishes are respected when they have impaired mental capacity and their wishes are at risk of being overridden."

Professor Raymond Tallis, Emeritus Professor of Geriatric Medicine

Part 2: Good practice

4. Procedural policy on advance decisions

4.1 The following procedures are recommended for inclusion in hospital advance decision policies.

Establishing that an advance decision exists

4.2 One member of staff on each ward/department should be responsible for determining whether an advance decision to refuse treatment has been made, as part of routine practice. It is for the individual PCT or hospital to appoint the appropriate member of staff.

4.3 If the patient cannot speak for him/herself, but there is reason to believe the patient has an advance decision, staff should make reasonable efforts to obtain a copy by:

- Contacting any person nominated by the patient;
- Contacting the patient's GP;
- Checking for a MedicAlert emblem (bracelet or necklet)

MedicAlert is an international charity specialising in the transfer of medical data to health professionals in emergency situations. Patients can register their advance decisions with MedicAlert, and will wear an emblem which states 'has advance decision' and provides MedicAlert's 24-hour telephone number. MedicAlert will fax a copy of the advance decision to the health professional on request.

Recording and communicating the existence of the advance decision

4.4 The advance decision should be placed in a prominent position in the patient's healthcare record and the health professional with overall responsibility for the patient's care should ensure that all members of the multi-disciplinary team are informed of the advance decision. The same person should ensure that staff in different departments, wards or institutions are informed of the advance decision, if the patient's care is transferred.

Compliance with the Mental Capacity Act

4.5 The health professional with overall responsibility for the patient's care may wish to check that the advance decision meets the requirements of the Mental Capacity Act (see Part One: boxes 2 and 3, above). However, this is not a requirement of the Act and it would be hard for a doctor to be sure that an advance decision meets the requirements of the MCA when the person still has capacity and the situation is yet to arise when it will be required.

See Chapter 5 part B for further information on advance decisions belonging to patients who lack capacity.



5. Caring for patients with advance decisions

Part A: Patients with capacity

5.1 Good communication between health professional and patient is very important in end-of-life decision making. If the patient still has capacity, the advance decision to refuse treatment should be understood as an aid to, rather than a substitute for, open dialogue.²⁰

A discussion between the patient and health professional regarding the content of an advance decision to refuse treatment can:

- Assist the patient's understanding of his/her diagnosis and prognosis, the available treatment options, and the implications of accepting or refusing these options;
- Clarify exactly what the patient's wishes are;
- Enable the health professional to elicit and understand the patient's wider goals of care, which may clarify the way to proceed in grey areas.

Such discussions will need to be ongoing to reflect changes in the patient's condition and preferences.

5.2 The goal of any conversation should always be to clarify the patient's position on any treatment as well as on which life-sustaining treatments he/she wishes to refuse (or consent to), and in which circumstances. Health professionals should conduct any such conversations with reference to the guidance set out in Chapter 3.

5.3 Patients are not legally required to discuss their decisions, nor accept offer of advice from a health professional. That an advance decision has not been discussed with a health professional does not render it invalid.

5.4 A person's needs and preferences can often change over time. What someone states while relatively well, may change radically as their condition, the support they receive and personal circumstances change. Healthcare professionals will be involved in assessing the needs of the patient, and agreeing a care plan. The care plan could also include reviewing an advance decision to refuse treatment in the light of changes.

5.5 The details and outcomes of any such conversation should be recorded in the patient's medical notes. Any amendments to the advance decision that follow as a result of a discussion must be properly recorded in accordance with the criteria set out in the Mental Capacity Act. If the patient has lodged a copy of the advance decision with his/her GP, solicitor or other, that person may need to be contacted to ensure consistency.



Assisting the patient's understanding

5.6 Research suggests that patients with advance decisions to refuse treatment do not always understand the life-sustaining treatments mentioned in them, which can lead to confusion for health professionals attempting to implement the advance decision to refuse treatment.²¹ If a patient is willing and able to discuss the content of an advance decision to refuse treatment, health professionals should ensure this occurs before an emergency situation arises.

5.7 The health professional's role is to provide factual, accessible information with which the patient can assess the benefits and burdens of life-sustaining treatments, within the context of his/her own condition. Health professionals should provide simple and honest information on the patient's diagnosis and prognosis; the likely illness trajectory; an explanation of the common forms of life-sustaining treatments; the benefits and burdens of such treatments for the particular patient; and the implications of refusing these treatments.

Clarifying exactly what the patient's wishes are

5.8 Ambiguities in the wording of an advance decision to refuse treatment can not only lead to a lack of clarity about exactly what the patient wants, and under what circumstances, but also can render the advance decision to refuse treatment invalid.²²

5.9 Pro-forma advance decisions often simply decline "life-sustaining treatments" in general, in the event of serious illness or permanent loss of cognitive function. Health professionals should encourage the patient to consider life-sustaining treatments individually since there may be different benefits and burdens attached to each treatment.

5.10 Words such as 'severe', 'serious', and 'grave' can be particularly difficult to interpret.²³ Health professionals should try to establish what situation the patient envisages when he/she considers these words. For example, a patient might refuse life-sustaining treatments in the event that he/she develops 'severe brain disease'. Different patients will have different ideas on what constitutes 'severe'.

5.11 Patients may also use the word 'terminal' very loosely. Health professionals should try to establish what stage the patient would consider the 'terminal' stage in a chronic progressive illness. Would the patient want the advance decision to refuse treatment to apply even if he/she had a prognosis of six months to live? Or 12 months?

5.12 Health professionals might sensitively pose a number of hypothetical questions to avoid misunderstandings at a later date. While it may be difficult to answer these questions, and patients' wishes may have changed over time, these questions are included as a guide. For example, did the patient intend to refuse Cardiopulmonary Resuscitation (CPR) altogether, or were there certain circumstances in which he/she would accept it? What if the doctor felt that there was a 50% probability that the patient could regain normal cognitive function? Or if there was a 10% probability? Would the patient be willing to receive mechanical ventilation for a trial period of a week? Would the patient find a nasogastric tube more acceptable than a gastric PEG?

Understanding the patient's wider goals of care

5.13 Advance decisions can never account for every eventuality. The clinical scenario a patient finds him/herself in may be entirely different from the one envisaged in the advance decision. It is the case that valid advance decisions are legally binding, it is nevertheless the case that health professionals can and do get involved in discussions about a patient's general values and attitudes towards health, quality of life and end-of-life care. This can be helpful for doctor and patient. A broad conversation of this nature may also be appropriate for patients who are unable or unwilling to participate in the more detailed type of discussion outlined above.

5.14 A discussion of the patient's values need not necessarily lead to clinical instructions being recorded; instead it is an opportunity for the health professional to engage with the patient's goals, hopes and fears, and understand the patient as a person. A conversation in non-medical language may help a patient communicate his/her general treatment preferences, which may indicate the appropriate course of clinical action at a later stage.²⁴ Uncomplicated, sensitive questions such as 'what for you makes life enjoyable?' may be all that is needed to begin the discussion.



Part B: Patients without capacity

5.15 Patients who have already lost capacity will not be able to clarify any ambiguities in their advance decisions to refuse treatment. Health professionals must therefore take a different approach. The first step will be to establish that the advance decision to refuse treatment meets the Mental Capacity Act's general requirements, as set out in Box 2 above, and its specific criteria for validity and applicability, as set out in Box 3. Health professionals may provide or continue treatment until they are completely satisfied that an advance decision to refuse treatment meets all of the Act's requirements, provided that the treatment is in the patient's best interests. See Chapter 6 on 'resolving disputes' for further information.

5.16 The patient's next of kin, partner or significant other may be able to provide valuable information as to the patient's thinking when he/she made the advance decision.

Box 5. Relatives or friends of patients without capacity may be able to provide information on:

- When the advance decision to refuse treatment was drafted and how regularly it has been updated;
- The situation envisaged by the patient when he/she drafted the advance decision to refuse treatment;
- The patient's illness trajectory and his/her views at each stage;
- The patient's attitudes towards and understanding of his/her condition;
- The patient's awareness of and attitudes towards the available medical treatments; and factors that may have shaped those attitudes.

5.17 The patient's GP and healthcare record may also provide evidence that can be used to determine the validity and applicability of an advance decision.

5.18 The details and outcomes of any relevant conversations should be recorded in the patient's medical notes and where relevant, communicated to the patient's GP.



6. Resolving disputes

6.1 There is potential for disagreement on the validity and applicability of an advance decision to refuse treatment. Members of a multi-disciplinary team may interpret the patient's wishes, or the severity of his/her condition, in different ways. The family may not share the patient's attitudes towards end-of-life care and may urge health professionals to override the advance decision to refuse treatment.

The Mental Capacity Act Code of Practice guidance (paraphrased):

6.2 Ultimately it is for the health professional with overall responsibility for the patient's care when the treatment is required (likely to be a hospital consultant) to decide whether there is a valid and applicable advance decision. In the event of a disagreement, either between health professionals or between health professionals and family members (or others close to the patient), the senior health professional must consider all the available evidence. He or she may need to consult with relevant colleagues and others who are close to or familiar with the patient. All staff involved in the patient's care should be given the opportunity to express their views. The patient's GP may also have relevant information.

6.3 The point of such discussions should not be to try to overrule the patient's advance decision but rather to seek evidence concerning its validity and to confirm its scope and its applicability to the current circumstances. Details of these discussions should be recorded in the patient's records.

The Court of Protection

6.4 As a last resort, where there continues to be genuine doubt or disagreement about the existence, validity or applicability of an advance decision to refuse treatment, a declaration can be sought from the Court of Protection.

6.5 The Court does not have the power to overturn a valid and applicable advance decision. It does have the power to make declarations as to:

- Whether a person does or does not have capacity to consent to or refuse treatment at the time the treatment is proposed;
- Whether an advance decision is valid;
- Whether an advance decision is applicable to the proposed treatment in the circumstances that have arisen.

6.6 Information on when and how an application to the Court of Protection should be made will be available from the Office of the Public Guardian. See also Chapter 8 of the Mental Capacity Act Code of Practice.





References

1 The Act was implemented in two stages. In October 2007, the clauses related to advance decisions and Lasting Powers of Attorney came into effect, and the new Court of Protection, Public Guardian and the Office of the Public Guardian became operational for England and Wales. The independent mental capacity advocates (IMCA) and some directly related elements of the legislation, the code of practice to provide guidance, and the criminal offence of ill treatment and willful neglect came into place in April 2007.

2 General Medical Council, Withholding and withdrawing life-prolonging treatments: Good practice in decision making, London: 2002

3 Airdale NHS Trust v Bland [1993] 1 All ER 821 at page 860 per Lord Keith and page 866 per Lord Goff. Also Re MB [1997] 2 FCR 541 and Re JT (Adult: Refusal of Medical Treatment) [1998] 1 FLR 48 and Re AK (medical Treatment: Consent) [2001] 1 FLR 129. Confirmed as an absolute right in St George's Healthcare National Health Service Trust v S (No 2): R v Louise Collins & Ors, Ex Parte S (No 2) [1998] 3 WLR 936

4 For example see: Uhlmann RF, Pearlman RA, Cain KC: "Physicians' and spouses' predictions of elderly patients' resuscitation preferences" J Gerontol 1988; **43**: M115-M121; Teno JM, Hakim RB, Knaus WA, et al: "Preferences for cardiopulmonary resuscitation: Physician-patient agreement and hospital resource use" J Gen Intern Med 1995; **10**:179-186

5 The SUPPORT Investigators, "A controlled trial to improve care for seriously ill hospitalised patients", JAMA 1995; **274 (20)**: 1591-98

6 Schiff R, Sacares P, Snook J et al, "Advance decisions and the Mental Capacity Act: a postal questionnaire survey of UK geriatricians", Age and Ageing 2006; **35**: 116-121; Thompson TDB, Barbour RS, Schwartz L, "Health professionals' views on advance directives: a qualitative interdisciplinary study", Palliative Medicine 2003; **17**: 403-409

7 Heyland D, Tranmer J, O'Callaghan C and Gafni A, "The seriously ill hospitalised patient: preferred role in end-of-life decision making?", Journal of Critical Care 2003; **18 (1)**: 3-10

- 8 Tilden VP, Tolle SW, Nelson CA, Fields J, "Family decision making to withdraw life-sustaining treatments from hospitalised patients", *Nursing Research* 2001; **50 (2)**: 105-115; Seymour J, Gott M, Bellamy G, Ahmedzai S and Clark D, "Planning for the end-of-life: the views of older people about advance directives", *Social Science and Medicine* 2004; **59**: 57-68
- 9 Hardin SB and Yusuf YA, "Difficult end-of-life treatment decisions: do other factors trump advance directives?", *Arch Intern Med* 2004; **164**: 1531-1533; Toller CA and Budge MM, "Compliance with and understanding of advance directives among trainee doctors in the United Kingdom", *Journal of Palliative Care* 2006; **22 (3)**: 141-6
- 10 *Airdale NHS Trust v Bland* [1993] 1 All ER 821 at page 860 per Lord Keith and page 866 per Lord Goff. Also *Re C* [1994] 1 WLR 290
- 11 *Burke v General Medical Council* [2005] EWCA 1003 (Civ)
- 12 There are, however, certain restrictions on who can be an attorney in relation to financial and property affairs for example, a bankrupt individual would not be permitted. See Chapter 8 of the Mental Capacity Act Code of Practice for detailed information on Lasting Powers of Attorney.
- 13 *Re Ms B v a NHS Hospital Trust* [2002] EWHC 429 (Fam)
- 14 See for example *General Medical Council, Withholding and withdrawing life-prolonging treatments: Good practice in decision making* (London:2002); *British Medical Association, Advance statements about medical treatment* (BMJ Publishing, London:1995); *British Medical Association, Withholding and Withdrawing Life-Prolonging Medical Treatment: Guidance for decision making*, 3rd edition, 2007 Hammicks/BMA; *British Medical Association, Resuscitation Council (UK) and Royal College of Nursing, Decisions relating to cardio pulmonary resuscitation*, 2007 (<http://www.bma.org.uk/ap.nsf/Content/CPRDecisions07?OpenDocument&Highlight=2,cpr>).
- 15 BMA 2001, *ibid*, Page 7. The Mental Capacity Act defines life-sustaining treatments at section 4 (10) as "treatment which in the view of the person providing health care for the person concerned is necessary to sustain life."
- 16 *Airdale NHS Trust v Bland* [1993] 1 All ER 821
- 17 Confirmed in Section 1(2) of the Mental Capacity Act 2005
- 18 GMC *Good Medical Practice*, (London: May 2001) Paragraph 21
- 19 *Re T (adult) (refusal of medical treatment)* [1992] All ER 649 at 653, (1992) 9 BMLR 46 at 50. per Lord Donaldson.
- 20 Teno JM, Stevens M, Spornak S and Lynn J, "Roles of written advance directives in decision making" *J Gen Intern Med* 1998; **13**: 439-446
- 21 Thorevska N, Tilluckdharry L, Tickoo S, et al, "Patients' understanding of advance directives and cardiopulmonary resuscitation", *Journal of Critical Care* 2005; **20**: 26-34
- 22 Upadya A et al, "Patient, physician and family member understanding of advance decisions", *Am J Respir Crit Care Med* 2002; **166**: p 1430-1435
- 23 Thompson T, Barbour R and Schwartz L, "Adherence to advance directives in critical care decision making: vignette study", *British Medical Journal* 2003; **327**: 1011-18
- 24 Docker C, "Decisions to withdraw treatment: values histories are more useful than advance directives", *BMJ Letters* 2000; **320**: 54; Demoratz MJ, "Advance directives: getting patient to complete them before they need them", *The Case Manager* 2005 (January) 61-63; Pearlman R, "Are We Asking the Right Questions", *Hastings Center Report Special Supplement* 1994; **24(6)**: S24-S28

Notes

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IMCA REFERRAL FORM

VoiceAbility can provide an Independent Mental Capacity Advocate (IMCA) to people who are physically in areas that VoiceAbility is commissioned to provide IMCA, when a decision is being made about either their:

- 1) Serious medical treatment or
- 2) Long term move (more than 28 days into hospital / 8 weeks into a care home)

and it is considered that the person **does not have the capacity** to make **that** decision **and** they have no family or friends *'appropriate'* to consult with

We may also be able to provide an IMCA where a person lacks capacity to agree to arrangements in;

- 3) Care reviews where there are no family or friends able to support and represent the person.
- 4) Safeguarding proceedings, where the person is victim or alleged perpetrator, regardless of family and friend involvement

Section 1 – Personal Details

1	Referred person's full name		Date of Birth		M		F		Funding Local Authority	
2	Usual address								Postcode	
		Phone				Local Authority				
3	Address at <u>now</u>, if different to usual address								Postcode	
		Phone				Local Authority				

4	Ethnicity	White British		Black Caribbean		White/Asian		Indian	
		White Irish		Other Black background		Other mixed back ground:		Other Asian background	
		Other white background		White/Black Caribbean		Bangladeshi		Chinese	
		Black African		White/Black African		Pakistani		Other (please state)	
5	Client Group	Learning disability		Autistic Spectrum Disorder		Mental Health needs		Serious physical illness	
		Dementia		Acquired brain injury		Unconscious		Other (please state):	
6	Primary communication	English		Other language:		Gestures/ vocalisations/ facial expressions		Other (please state):	
		Pictures/symbols/ Makaton		BSL		No obvious communication			

Section 2 – Case Details

7	Decision to be made:	Serious Medical Treatment		Long term move		Care review		Safeguarding Procedure	
8	Person lacks the capacity to make the decision in Q7:	A Mental Capacity Act test has been done by the decision-maker			A Mental Capacity Act test has been done by another professional but decision maker agrees the person lacks capacity to make this decision				
9	When does the decision need to be made?	Please list deadlines and meeting dates:							
10	Decision-makers (DM) recommended cause of action?								
11	Are there friends/family?	Yes, but this is an Adult Protection Proceedings referral		There are no family/friends		Yes, but DM considers they are not 'appropriate' to consult			
12	Please clearly state reason(s) why family / friends are considered not 'appropriate' to consult.								
13	Please ensure family/friends are informed of the	I have informed the family/friends of IMCA involvement				I will inform the family/friends of IMCA involvement			

	involvement of an IMCA				
14	Please list contact details of relevant people e.g. Decision maker (if not referrer) G.P, Care Manager, Key worker, Day centre etc				
15	Risks to personal safety – Detail any information needed to ensure the safety of the advocate and the referred person, including risk management procedures in place:				

Section 3 – Referrers’ Details

16. Referrers’ Name		Referrers’ Team	
Relationship to referred person; (E.g. Care Manager, GP, social worker, consultant)			
Address			
Email address		Tel:	Fax:
How did you hear about this service?		Are you the decision maker?	Yes No (DM details given in box 14)

<p>17. I would like VoiceAbility to provide an IMCA. They can keep, and put on computer the information on this form, and other information I provide needed to do the work.</p> <p>I am providing this information and asking for this referral in the referred person’s best interests and in line with the Mental Capacity Act.</p> <p>I consider that the referred person lacks the capacity to make the decision referred for and has no family/friends ‘appropriate’ to consult with / this is an Adult Protection Proceedings referral (delete as appropriate)</p>			
Referrers Signature (if not DM)		Date	
Decision Makers signature		Date	

Please Return to: Total Voice Northamptonshire c/o Voiceability, Victory House, 400 Pavilion Drive, Northampton Business Park, Northampton, NN4 7PA or Telephone: 020 33 55 88 46 Fax: 01604 521394

******* Please call the hotline after sending referral to ensure it has been received *******

Contacts

Contact us in confidence for more information about our services or to access support.

Our service is open Monday to Friday between 9am and 5pm.
Our referral telephone line is open Monday to Friday between 10am and 3pm.

You can call us directly on:



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or write to us at:



totalvoicenorthamptonshire@voiceability.org



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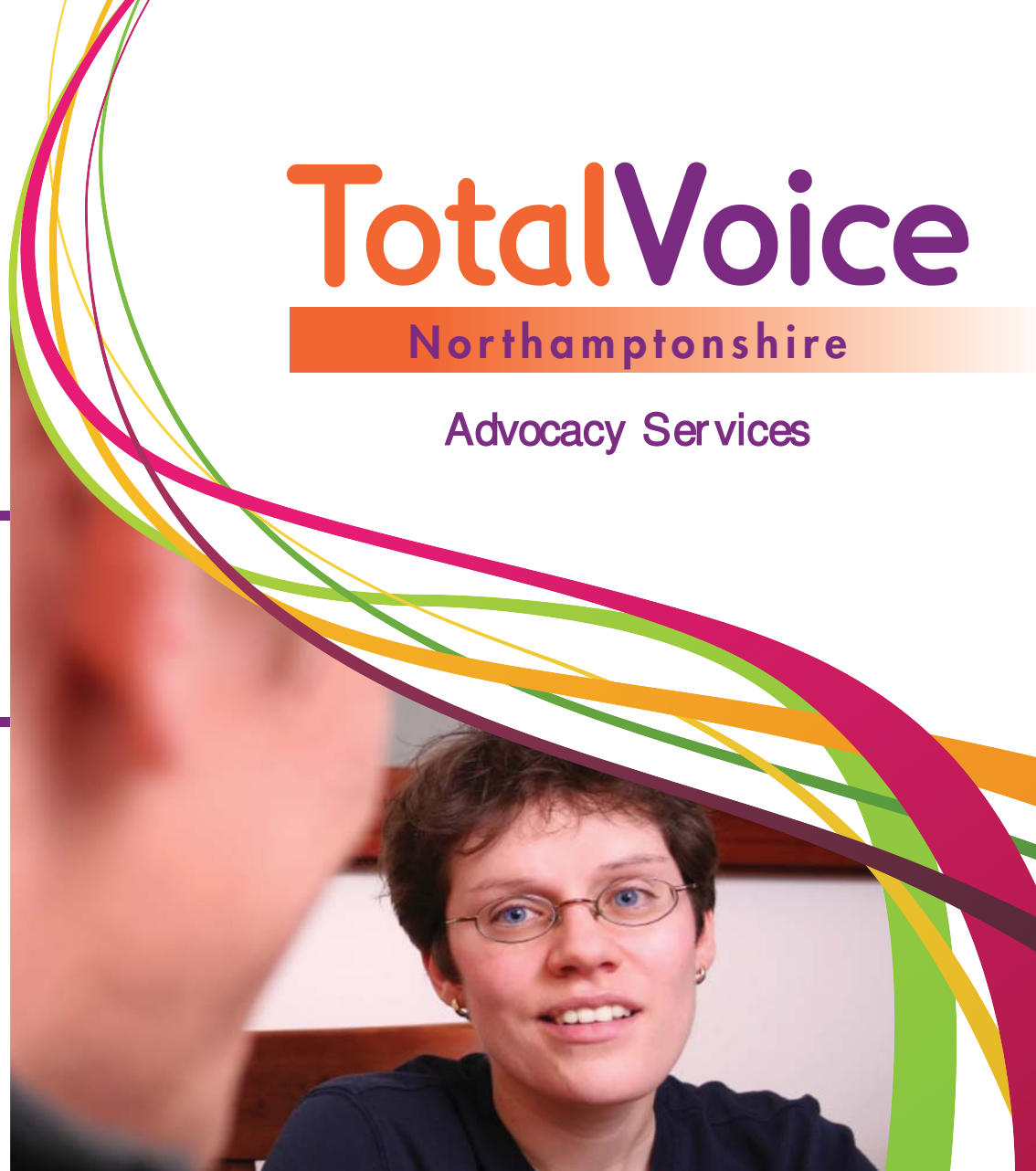
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TotalVoice

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Advocacy Services



Free, independent and confidential advocacy services for people who are using Adult Social Care or Health Services and their carers.



Total Voice Northamptonshire

Advocacy is about speaking up

Our service is:

- Free
- Independent
- Confidential



We can help

Total Voice is an advocacy service providing independent advocacy for people who are using Adult Social Care or Health Services.

We will support you to make sure your voice is heard.

Or represent you, if you are unable to represent yourself.

We will work with you on issues about your mental health and or social care.



We offer

- We support you to have choice and control over your life.
- We support you to understand your rights and responsibilities.
- We support you, if you have been detained under the Mental Health Act, to challenge your treatment if you feel it is not appropriate.



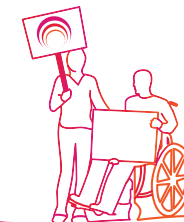
Total Voice

We provide advocacy support to adults with disabilities including statutory advocacy*. We also provide advocacy to carers, older people and disabled young people accessing adult services.

** Independent Mental Health Advocacy Independent Mental Capacity Advocacy Deprivation of Liberty Safeguards*



Strengthening voice, championing rights, changing lives



KEY DOCUMENTS

INFORMATION BOOKLETS ON THE MENTAL CAPACITY ACT

These booklets provide introductory information on the Mental Capacity Act.

- [Making Decisions...about your health, welfare or finance. Who decides when you can't? \(English Version\)](#)
- [Making Decisions. A guide for family, friends and unpaid carers \(English Version\)](#)
- [Making Decisions. A guide for people who work in health and social care \(English Version\)](#)
- [Making Decisions. A guide for advice workers \(English Version\)](#)
- [Making Decisions. Easy-Read Version \(English Version\)](#)
- [Making Decisions. The Independent Mental Capacity Advocate \(IMCA\) Service \(English Version\)](#)

MENTAL CAPACITY ACT 2005 INFORMATION LEAFLET

An information leaflet - 'Making decisions about your health, welfare and finances ... Who decides when you can't?' - has been designed to help raise awareness of the Mental Capacity Act 2005. It gives some basic information about how the Act could affect you and is available in the following languages:

- [Welsh](#) [PDF 166kb, 8 pages]
- [Arabic](#) [PDF 397kb, 8 pages]
- [Bengali](#) [PDF 222kb, 8 pages]
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