

# HEALTH IS EVERYONE'S BUSINESS

Plan Ahead 

START



Centre for BME Health



## WHY IS THIS IMPORTANT?

If there is no Advance Decision in place and you have been deemed to lack capacity, the final decision will be made by the relevant specialist (e.g. doctor).

# INTRODUCTION

A guide to advance planning and making decisions about your personal welfare, property and financial affairs.

## WHO IS THIS BOOKLET FOR?



- Carers
- Family members
- Advocates
- Your trusted one
- Close friends
- Emergency services
- Healthcare professionals
- Community workers
- Charities

## KEY WORDS

✓ CAPACITY

✓ MENTAL HEALTH

✓ MENTAL ILLNESS

✓ LEARNING DISABILITY

✓ DEMENTIA

✓ STROKE

✓ BRAIN INJURY

✓ NEUROLOGICAL CONDITIONS

✓ ADVOCATE

✓ ADVANCE PLANNING

This booklet will go through 3 Advance Planning options:

1. 'Advance Decision'  
(Refuse treatment)



2. 'Statement of Wishes  
and Feelings'



3. 'Lasting Power of  
Attorney'



# SECTION ONE

## MENTAL CAPACITY ACT – WHY DO I NEED TO KNOW ABOUT THIS?

The Act has some important considerations that need attention.

### WE ARE CONCERNED WITH:

- Doing things in connection with care and treatment
- Helping you to be able to have your say even if you lose (mental) capacity
- Advance Decisions to refuse treatment

### ADVANCE PLANNING

- This is when you plan for a time when you will not be able to make decisions because you have lost your capacity
- Can involve somebody else making such decisions based on what's in your best interests
- Is about planning what you want to happen to you



## THE FIVE KEY POINTS TO REMEMBER ABOUT THE MENTAL CAPACITY ACT:

1

It must be assumed that everyone can make their own decisions.

2

Support must be given to help people to do so.

3

As long as they are able to do so, no-one should be stopped from making a decision just because others disagree.

4

If someone has to make a decision for somebody who can't do so themselves, the decision must be in the person's 'best interests' (as stated in the Act itself).

5

The person making that decision must try not to restrict the rights and freedom of the person considered not to have capacity.

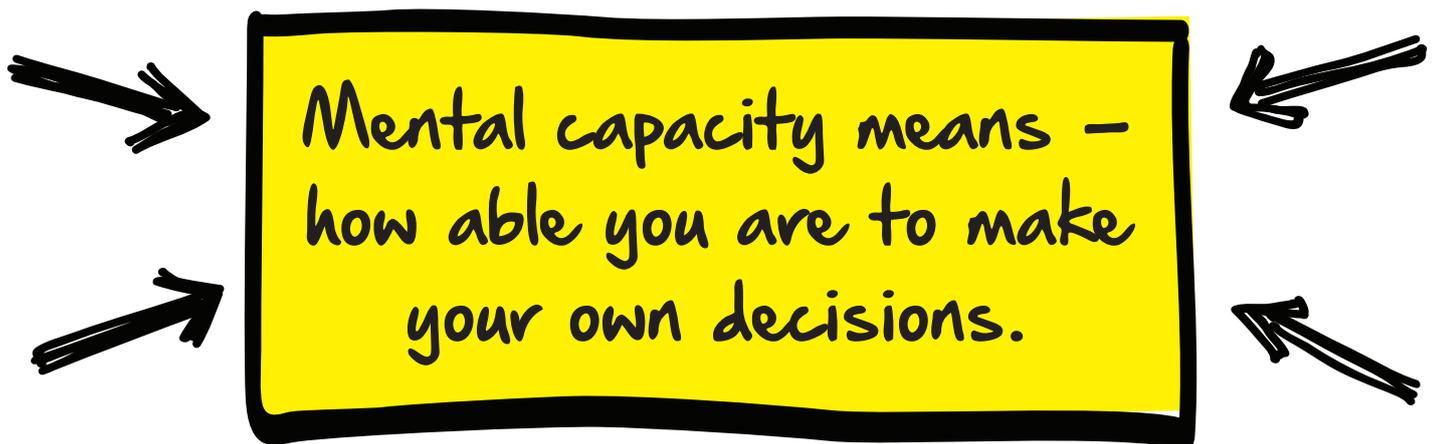
## WHY IS THIS IMPORTANT?

If there is no Advance Decision in place and you have been deemed to lack capacity, the final decision will be made by the relevant specialist (e.g. doctor).

He or she should consider not only your feelings but also those of family members. However, you or your family cannot state what will happen.

The final decision rests with the specialist in question.

## TELL ME MORE ABOUT MENTAL CAPACITY



This is particularly important with regard to things such as treatment, finances and other legal matters. The Mental Capacity Act 2007 is the law that relates to this issue.

## **WHO DOES THE MENTAL CAPACITY ACT AFFECT?**

- People aged 16 years and over
- People living in England and Wales

## **WHAT DOES THE MENTAL CAPACITY ACT TELL US?**

- The Act shows how to work out if a person is well enough and able to make decisions
- If they can, but find it difficult, the Act states that they should be given as much support as they need to help them do so
- If, however, there is evidence that a person cannot do this, the Act demonstrates how decisions can be made in their best interests and on their behalf
- The Act states how a person can make decisions 'in advance', so that their wishes are known at any stage even if they lose 'capacity'



This is particularly important with regard to things such as treatment, finances and other legal matters.

The Act shows how to work out if a person is well enough and able to make decisions.



## **HOW IS MY MENTAL CAPACITY ASSESSED?**

No one can assume you lack capacity because of:

- Your age
- How you look
- The way you act
- An illness or disability you have
- Your inability to make other difficult decisions
- You not being able to make similar decisions in the past

## **HOW DOES SOMEONE KNOW IF I DO NOT HAVE CAPACITY TO MAKE A DECISION?**

- You have a condition that affects the way your mind works
- You are unable to make a particular decision because of that condition
- You are unable to properly understand any information that is given to you about the particular decision that needs to be made
- You are unable to remember any information that you are given long enough for you to be able to make the decision
- You are unable to weigh up the information that has been given to you when making the decision
- You can't communicate the decision that you want to make, either by talking, using sign language, or other means

## HOW IS THE MENTAL CAPACITY ACT USED TO DECIDE WHETHER SOMETHING IS IN MY BEST INTERESTS?

The Act gives some important instructions to the person making that decision for you. He or she must:

- Encourage you to take part in the decision-making as much as you are able
- Find out about your wishes and feelings, both in the past and the present
- Find out if you have any particular beliefs that are relevant to the decision being made
- Think about whether you will have capacity to make the decision in the future. (If that is the case, it may be appropriate to postpone making the decision until that time or to limit its effect if a decision has to be made now)

### REMEMBER:

*Anybody having to make a decision for you because you are considered not to have capacity, has to do so in your best interests.*



## SECTION TWO

# HOW CAN I MAKE AN ADVANCE DECISION TO REFUSE TREATMENT?

- An Advance Decision to refuse treatment is legally binding
- You must be at least 18 years old
- If you wish, for example, you can simply tell the doctor that you want to make an Advance Decision to refuse a particular treatment. The doctor should **make a note** of your wishes so it is clear that you are **refusing** treatment
- It is recommended you **make an Advance Decision in writing** and have it witnessed to avoid any confusion about what treatment you want to refuse and when you want to refuse it

### REMEMBER:

An Advance Decision can only be used to tell people what treatment you **do not** want and when you **do not** want it. It doesn't cover what treatment you do want to receive.



## WRITING AN ADVANCE DECISION – THINGS TO INCLUDE IN YOUR DOCUMENT

It is personal so every document will be different. However, it should include the following information:

- Name
- Address
- Date of Birth
- Contact details (telephone number & email address)
- Doctor's name and address
- Date of when the Advance Decision was made
- The treatment that is being refused
- The circumstances when this is to happen
- Name and signature of witness

### REMEMBER:

You can refuse treatment that is intended to save your life but you **MUST** do this in writing and you must clearly say that you want to refuse treatment even if your life is at risk.



## THINGS TO REMEMBER

- You must first keep a copy for yourself in a safe place
- Give a copy to anyone that you think should know about it (doctors, family and friends)

## CAN I MAKE CHANGES?

- You can make any changes that you like
- If you wish, you can also withdraw it altogether if you decide that you would like to receive treatment that you previously refused
- However, you can only make changes to your Advance Decision if you have capacity
- Remember to inform all relevant parties

## ONCE COMPLETED

If you have made an Advance Decision to refuse treatment correctly, a doctor has to follow it and not give the treatment that you have refused unless:

- You have consented to the treatment covered by the refusal (in other words you've changed your mind) and have capacity to do so
- The treatment is under the Mental Health Act

**SEE APPENDIX 1 FOR EXAMPLES OF ADVANCE DECISIONS TO REFUSE TREATMENT**

### THINGS TO REMEMBER:

Sign the document yourself and also get it witnessed and signed by another adult of your choice.



# SECTION THREE

## HOW CAN I MAKE A STATEMENT OF MY WISHES AND FEELINGS?

- A **Statement of Wishes and Feelings** is **NOT** legally binding, but does need to be taken seriously by someone making decisions for you
- Such statements are a way that you can express your wishes, feelings and opinions about almost any aspect of your life
- They are used by a person that needs to make a decision for you in your best interests when you have lost capacity
- A Statement of Wishes and Feelings is a good way of telling people what you think and would like to happen



Medical Treatment – any treatment that you would or would not like to receive.



People who should and should not be told that you are ill.



Diet – for example, you may be a vegetarian or only be able to eat certain foods because of your religious beliefs.

## EXAMPLES OF WHAT YOU CAN WRITE ABOUT

### KEY INFORMATION TO THINK OF:

- The list on page 16 only has a few examples of what you can include in your Statement of Wishes and Feelings. Each person is different, so please think very carefully about what you want to say and include
- The Statement of Wishes and Feelings does not have to be in writing. However, writing it down can give it a sense of formality that can be helpful in avoiding debate or any confusion as to what your wishes are
- And do remember to tell people such as your doctor, your family and your Attorney, including providing copies of written wishes. If you want the wishes taken into account, the decision-maker needs to know about them
- Whoever makes the decision has to do so in your best interests and after talking to anyone mentioned in a Statement of Wishes and Feelings

**SEE APPENDIX 2 FOR AN EXAMPLE OF A STATEMENT OF WISHES AND FEELINGS**



# SECTION FOUR

## WHAT IS A LASTING POWER OF ATTORNEY (LPA)?

A LPA is a legal document that allows you to **SELECT** somebody to make certain decisions for you, if you do not have the capacity to make those decisions yourself.

- You must be at least 18 years old
- You must make a LPA in writing
- Your LPA has to be registered with the Public Guardian, which incurs a cost
- You must clearly say that you understand how to make a LPA and that you want it to be used when you do not have capacity
- You must write the names of people who you think should and should not be told about your LPA

**UNLESS YOU ARE EXEMPT, YOU HAVE TO PAY TO REGISTER EACH LPA:**  
[www.justice.gov.uk/about/opg](http://www.justice.gov.uk/about/opg)

## THE ATTORNEY

- Can be anybody you know personally who is over the age of 18, for example, a family member or friend
- You should select somebody you trust
- They do not need to have a legal background or knowledge
- The Attorney must follow the five key points of the Mental Capacity Act at all times (Section One, page 6)
- The Attorney can **ONLY** make the decisions you've defined in the document
- If you want this to happen, put it in the document! And if you want your Advance Decision to be followed by the Attorney, put that in also!

### REMEMBER:

An Attorney **CANNOT** make decisions unless you have given them permission in the document to do so. That includes medical decisions – even ones about treatment that could save your life. It's your choice – put it in the document!

## WHAT DOES A LASTING POWER OF ATTORNEY FOR PERSONAL WELFARE COVER?

The Attorney can make decisions based on:



Your medical treatment, including medicines and operations.



Your accommodation:  
where you should live.

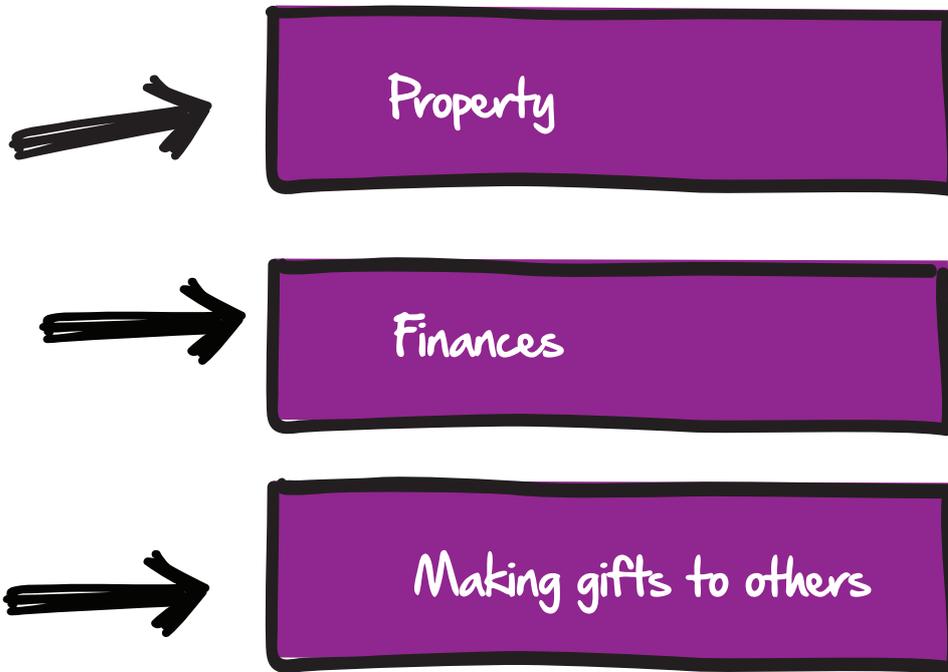


Day-to-day decisions about your life: who can visit you; whether you should go on vacation.



# WHAT DOES A LASTING POWER OF ATTORNEY FOR PROPERTY AND AFFAIRS COVER?

The Attorney can make decisions based on:



# SECTION FIVE

## TOP TIPS



REMEMBER:  
MAKE MORE THAN  
ONE COPY OF A  
DOCUMENT.

- 1 Think carefully about who to involve.
- 2 Seek relevant advice.
- 3 Tell relevant people what you want them to do and say.
- 4 Where necessary, keep things in writing and have what you say witnessed.
- 5 Keep a record of the decisions you make and your wishes and feelings.
- 6 Make sure your plans and records are clear, thorough and unambiguous.
- 7 Keep copies of documents in a safe place.
- 8 Make any changes you wish to make as soon as you need to.
- 9 Keep relevant information to hand.
- 10 Let people know that you have made advance plans and what they are. Important people to consider are doctors and attorneys as well as family members and trusted friends.
- 11 Ensure that you have the correct contact details available for anyone involved in your advance planning.
- 12 Make sure you know the legal requirements, for example, registering a Lasting Power of Attorney, or refusing treatment that is intended to save your life.

# SECTION SIX

## BE AWARE

### IMPLICATIONS

If you lose mental capacity and do not have an Advance Decision statement or a Lasting Power of Attorney all decisions on your medical treatment, financial or legal matters will be made by someone NOT of your choosing. Your family or carers will be asked about your wishes and feelings, but they can only actually make decisions for you if you've appointed them under a Lasting Power of Attorney.

A family or carer would have to apply to the Court of Protection to appoint someone to make these decisions that are in your best interests.

### YOUNG PEOPLE

Decisions for children under 16 years of age are the responsibility of the child's parents or registered carer. They are responsible for making decisions that are in the best interests of their child.



### FINALLY...

Ensure that any statements you make in relation to your care, treatment, financial and legal matters should be written down, signed and dated.

### KEEP A COPY

**REMEMBER:**  
Children and young people are subject to special rules. Good practice is to take their views into account. BUT if you want legal enforceability, YOU probably want to get specialist legal advice on this.

# SECTION SEVEN

## FURTHER READING AND INFORMATION

This information pack has been written specifically to provide you with information about how the Mental Capacity Act (2005) and Advance Decision making is relevant to mental illness, learning disability, dementia, stroke, brain injury and other neurological conditions. However, other reading material on this topic exists and you may find it helpful to read some or all of it in addition to this information pack. References are given below.

### REFERENCES

The Mental Capacity Act 2005 – Published by The Stationery Office (23rd April 2007); ISBN No: 011703746X; can be downloaded online at: [http://www.opsi.gov.uk/acts/acts2005/ukpga\\_20050009\\_en\\_1](http://www.opsi.gov.uk/acts/acts2005/ukpga_20050009_en_1)

The Mental Capacity Act Code of Practice 2007 – Published by The Stationery Office (23rd April 2007); ISBN No: 9780117037465; can be downloaded online at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/497253/Mental-capacity-act-code-of-practice.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf)

Advance Decisions to Refuse Treatment Specialist Guidance (Adult) – Published by NHS East Midlands Health and Social Care Community (April 2007); can be downloaded online at: [https://www.derbyshire.gov.uk/images/ADRT%20Guidance%2013%204%202007%20-%20FINAL\\_tcm44-7240.pdf](https://www.derbyshire.gov.uk/images/ADRT%20Guidance%2013%204%202007%20-%20FINAL_tcm44-7240.pdf)

Advance Decision to Refuse Treatment – <https://www.nhs.uk/Planners/end-of-life-care/Pages/advance-decision-to-refuse-treatment.aspx>

Lasting Power of Attorney – <http://www.gov.uk/power-of-attorney>

## USEFUL ORGANISATIONS TO CONTACT:

Alzheimer's Society  
[www.alzheimers.org.uk](http://www.alzheimers.org.uk)

Bipolar UK  
[www.bipolaruk.org](http://www.bipolaruk.org)

Citizens Advice Bureau  
[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

Dementia UK  
[www.dementiauk.org](http://www.dementiauk.org)

Headway  
[www.headway.org.uk](http://www.headway.org.uk)

Mencap  
[www.mencap.org.uk](http://www.mencap.org.uk)

MIND  
[www.mind.org.uk](http://www.mind.org.uk)

Office of the Public Guardian  
[www.justice.gov.uk/about/opg](http://www.justice.gov.uk/about/opg)

Rethink  
[www.rethink.org](http://www.rethink.org)

Stroke Association  
[www.stroke.org.uk](http://www.stroke.org.uk)

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This guide was produced by The Centre for BME Health East Midlands, East Midlands Academic Health Science Network and Collaboration for Leadership in Applied Health Research and Care East Midlands, and is part of a wider programme of work in this area. For more information see:

- <http://ourhealthourway.org.uk>
- <http://www.emahsn.org.uk>
- <http://www.clahrc-em.nihr.ac.uk>

# APPENDIX 1

## ADVANCE DECISIONS TO REFUSE TREATMENT

### EXAMPLE 1

NAME: Joe Bloggs

Date of Birth: 02/06/1976

Address: A Street, Wolverhampton, West Midlands

Tel: 0123 456789

This document explains the treatment that I wish to refuse in the event of my losing capacity and the circumstances in which I want the refusal to take effect.

Treatment to be refused: Electroconvulsive Therapy (ECT)

Circumstances: In all circumstances, even when all other types of treatment have been tried and have not worked.

Treatment to be refused: Haloperidol

Circumstances: If I need to be given anti-psychotic medication during manic phase of bipolar disorder. I am specifically refusing Haloperidol and not all types of medication.

Signed:

Date:

Witnessed by:

Note: These examples have been taken from the original "Advance Planning for People with Bipolar Disorder" booklet.

## **EXAMPLE 2**

NAME: Joe Bloggs

Date of Birth: 02/06/1976

Address: A Street, Wolverhampton, West Midlands

Tel: 0123 456789

When I am experiencing depressions, I do not ever want to be given Venlafaxine because it makes me feel like being sick and also makes me put on weight, which makes me more depressed.

Signed:

Date:

Witnessed by:

## **EXAMPLE 3**

NAME: Joe Bloggs

Date of Birth: 02/06/1976

Address: A Street, Wolverhampton, West Midlands

Tel: 0123 456789

I do not want to be given Electroconvulsive Therapy in any circumstances, even if it is an emergency and my life is at risk.

Signed:

Date:

Witnessed by:

# APPENDIX 2:

## STATEMENTS OF WISHES AND FEELINGS

NAME: Joe Bloggs

Date of Birth: 02/06/1976

Address: A Street, Wolverhampton, West Midlands

Tel: 0123 456789

I have bipolar disorder. It will be easy to tell when I am in the middle of a high phase. When I am high, I make claims that Paul McCartney died in a car accident in 1966 and that I replaced him in the Beatles. This is not true, but if anybody says that they do not believe me, I become very irritable and aggressive, although I have never hurt anybody. If I become irritable or start shouting, please do not shout back at me and tell me that I am mad, crazy or whatever. This only upsets me more. If I make claims about being Paul McCartney's replacement in the Beatles, the best way to calm me down is to just say, "Are you sure about that?" You may need to say this a few times. This makes me think about whether I am correct or not.

I also spend a lot of money, which I may not be able to afford. I particularly buy a lot of CD's and DVD's, so if you see me with a lot of them suddenly, this may be a sign that I am high. Please take away my bank cards and keep them somewhere so that I don't spend any more money. When I am not ill, I go to bed every night at 11pm. When I am high, I will still be up at this time and sometimes do not sleep at all.

When I am having low periods, I talk a lot about death and think out loud about the best ways to end my life. If I start talking like this, do not encourage it, but please do not shout at me either. It means that I am in a crisis and need somebody just to be with me and support me.

Please tell the following people when I become ill;  
Mr James Bloggs, my father – 0123 456789 (telephone) or jamesbloggs@email.com  
Mrs Jane Bloggs, my mother – 0123 456789 (telephone) or janebloggs@email.com  
Mr Wayne Bloggs, my brother – 0987 654321 (telephone) or wbloggs@email.com  
Dr Johnathan Doe, my GP – 01902 333444 (telephone)  
Dr Linda Smith, my psychiatrist – 0181 811 8182 (telephone)

Please do not tell the following people that I am ill in any circumstances:  
Sarah Bloggs, my sister – we had an argument 10 years ago and haven't seen each other since.

I am taking these medications at the moment: Lithium and Valproate.  
If I am ill please give me the following medications if possible: Lithium and Valproate.

I do not want to have the following treatments under any circumstances:  
Haloperidol – I have had problems with side effects before.  
Any benzodiazepines - I am worried that they will become addictive.

I am currently going to group therapy every Wednesday and find this helpful.

#### Food and diet:

I am Hindu and strict vegetarian. This means I do not eat any meat or fish. I do eat eggs and dairy products so am happy to be given these. I enjoy Brand X Baked Beans. If Brand X is not available then please do not give me baked beans to eat at all.

#### Other things:

Please do not call me 'mate'. I particularly hate it when people I don't know call me this. I love going for a walk every evening at 7pm, even if it is cold or raining.

# YOUR NOTES

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**CLAHRC East Midlands**

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