



**Paradigm**

## **Supported Decision Making** A guide for supporters

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ISBN Number: 978-0-9543068-6-1

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The information on pages 10 - 13 is taken from Total Communication - Person Centred Thinking, Planning and Practice by Kim Williams, Alison Matthews and Louise Skelhorn. Published by HSA Press (2007)

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This book has been produced with the financial support of the Valuing People Support Team.

We are grateful to the Learning Community for Person Centred Practices for the inclusion and adaptation of some of their material.

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This guide offers people best practice techniques and tools that may be useful when supporting others with their decision-making. This includes those people who make their own decisions and those who may lack the capacity to do so and where decisions are made in their best interest.

The book has been written in accordance with the Mental Capacity Act 2005 and was correct at the time of going to print.

This book is one of a series produced by Paradigm, with support from the Valuing People Support Team. Others in the series include:

- Values for Money – a resource guide to funding for support
- A Handbook on Support Brokerage
- Support Planning – a guide to developing Support Plans
- A Handbook on Individualised Service Design

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Exercising our rights and making choices about how we live makes us all unique and ensures that our lives are directed by us - we are in control.

Making decisions about our lives, like what to eat and drink or whom we want to live with is, for most of us, something that we take for granted and see as a fundamental basic human right.

Decision-making is the key to our autonomy and determines our lifestyle. The ability to make decisions is determined by our mental capacity.

**“Mental capacity is just that - the ability to make your own decisions”**

When faced with a big decision, most people ‘mull it over’, maybe talk it through with their family and friends, discuss the pros and cons and hear other people’s opinions. All of which helps people arrive at a decision they are comfortable with.

Some of the people you support need further help with decision-making. This may be because of the person’s unique communication style or because they need support to explore the information relating to the decision.

However, needing support to make decisions should not prevent people from exercising their rights and controlling their lives.

The personalisation agenda in health and social care continues to develop as more people are choosing to be in control and direct their own support.

We feel that supporting people with decision-making is so important that we must continue to share our learning and understanding about what works for people.

We all have a responsibility to ensure everyone is supported to live their own life and make their contribution as an equal citizen.

**“Citizenship is a right”**



In 2007 the Mental Capacity Act 2005 came into force in England and Wales and applies to people aged 16 years and over. The Act gives a legal framework for the care, treatment or support of people who are unable to make some, or all, decisions themselves.

It is an important piece of legislation and aims to protect both the individual who lacks mental capacity as well as those people who support them, including family members, friends and/or paid workers.

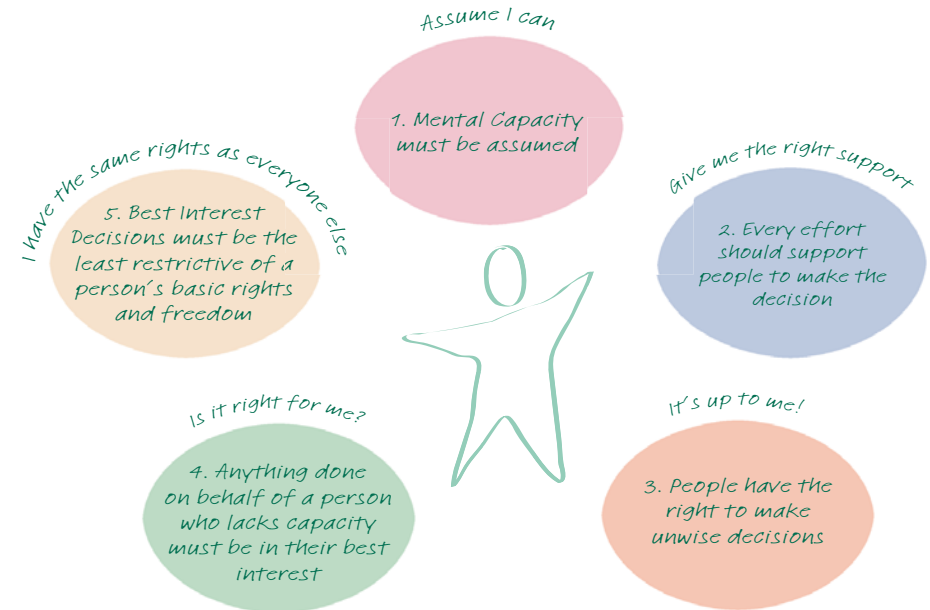
The Mental Capacity Act 2005 is a piece of legislation which puts the individual as the focus. It strives to ensure the person is at the centre of the decision-making process. It supports the involvement of both the person and those people who love and care about them.

In addition, the Act ensures independent support is available, in the form of Independent Mental Capacity Advocates (IMCA), for those people without family and friends and facing decisions about change of accommodation and/or serious medical treatment.

The Mental Capacity Act 2005 is the first piece of legislation to clearly state that people can no longer make decisions on behalf of others without following a process.

The Mental Capacity Act has five principles, which we have embedded within this book.

## The 5 key principles of the MCA 2005



Good support is all about really understanding people. Giving people support in a way that is right for them can only be done if we work alongside them and really listen. Understanding a person's unique perspective on life can be difficult. It is, however, an essential requirement of a good supporter. In developing good relationships with people, we share information about ourselves to deepen our understanding of each other.

Person centred approaches and tools can help us learn about people in a way that keeps them in control. The tools can help us build a rich picture of who a person is and how they choose to live their life.

**‘Understanding what is important to people, determines the best way to support them’**

We are in a better position to support people in decision-making if we understand who those people are. Exploring answers to the following questions can help deepen our understanding and build meaningful relationships with people.

Remember it is all about what makes sense to the individual. This should look different for different people.



Communication is an integral factor in supporting people well and especially important when supporting people in decision-making.

Communication is a two way process. As with any message, one person expresses it and someone else has to understand and receive it.

Total Communication is a communication philosophy that promotes person centred practice.

*Total communication is a communication philosophy – not a communication method and not at all a teaching method.. Total communication is an approach to create a successful and equal communication between human beings with different language and perception and / or production...*

*To use Total Communication amounts to a willingness to use all available means in order to understand and be understood.*

Hanson, B 1980

## thoughts about understanding

In exploring people's communication we need to consider people's ability to understand spoken or written language. Using total communication means a willingness to supplement the spoken word by using objects, photographs, line drawings, symbols or sign. In order to do this well, we must be person centred. We need to know which method or combination of methods suit each person best.



## thoughts about expression

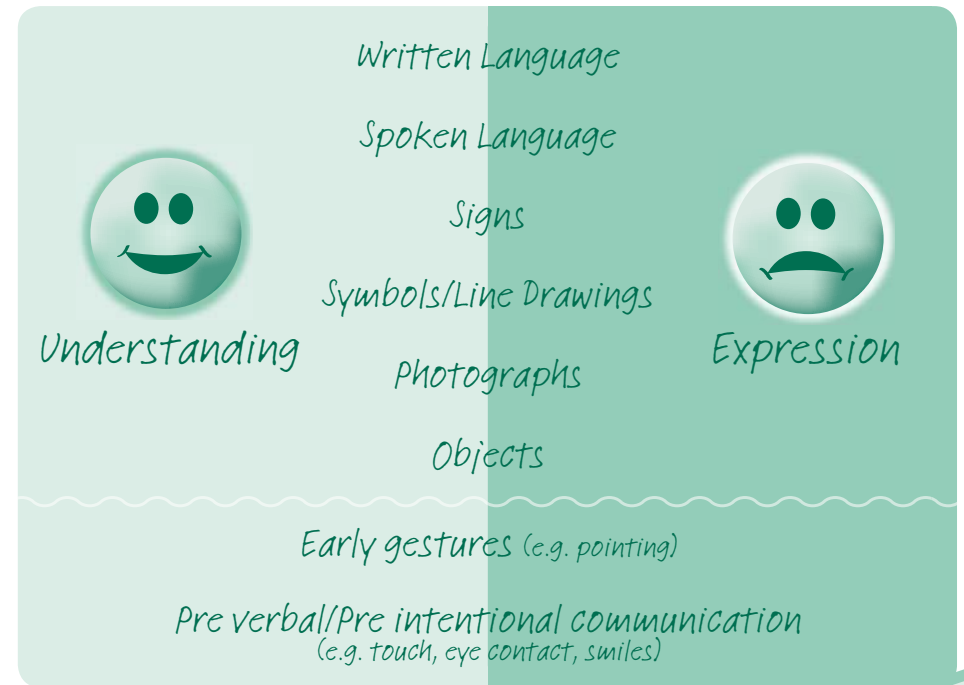
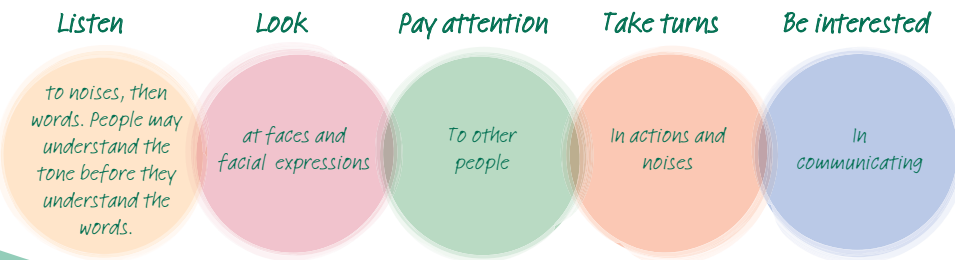
Expression is the act of transferring what is inside your head: your thoughts, feelings, desires, wants and wishes to another person. All people have their own way of expressing themselves; for some people, this may mean using other methods than speech alone. Objects, photographs, line drawings, symbols, signing and /or body language may be used to express information. In total communication all of these are equally valid forms of expression and need to be interpreted as such.

Our responsibility, when supporting people adopting a person centred approach, is a commitment to continually listen to, and learn with, the person. This includes striving to support the person's communication, ensuring they can direct their own life, interact with us and other people, and make their contribution as an equal citizen.

Best practice in supporting people's communication includes the desire to really hear a person and learn how the person communicates with you and how you communicate with them.

When supporting people we need to work hard to develop our own skills and understanding of communication and develop into a skilled communicator.

Skilled communicators need to be able to:



Many people use informal communication styles that are unique to them and they are sometimes heavily reliant upon the people who know and understand them well. It is really important that a person's unique communication style is recorded to ensure that those around the person can learn their particular style.

**Lucy's Story**

Lucy is a young woman who does not use words to communicate her wishes; she uses sounds and gestures. It is important for Lucy to spend time with her family, friends and her paid supporters.

Over time Lucy began to demonstrate anxiety and distress. Her family and friends had growing concerns and felt they were not understanding Lucy and began to explore why this may be.

During discussions it became apparent that each individual both interpreted and responded differently to Lucy. In any given week this could mean Lucy communicated with sixteen different people and received sixteen different responses. This meant Lucy's communication had lost its meaning. Everyone agreed to share and record their understanding of Lucy's communication.

<i>At this time / in this situation</i>	<i>Lucy does or says this</i>	<i>We think it means</i>	<i>You should do this</i>
<i>Anytime</i>	<i>Grabs at your arm or clothing and is smiling.</i>	<i>Lucy wants a hug and is initiating some fun.</i>	<i>Acknowledge Lucy, let her put her arm around you and offer her a fun activity.</i>
<i>Anytime</i>	<i>Starts to shout in high pitched noises. May begin to tug at her hair.</i>	<i>Lucy is upset or anxious.</i>	<i>Stop what Lucy is doing hold her hand and explain what is happening.</i>

<i>At this time</i>	<i>When you want Lucy to know or do this</i>	<i>You should say or do this</i>
<i>At the weekend</i>	<i>When you want Lucy to know her Mum is coming.</i>	<i>Show Lucy Mum's photo and say Mum is coming.</i>
<i>On a Friday night</i>	<i>Her friend Kellie is coming to pick her up to go to the pub.</i>	<i>Her friend Kellie is coming to pick her up to go to the pub.</i>

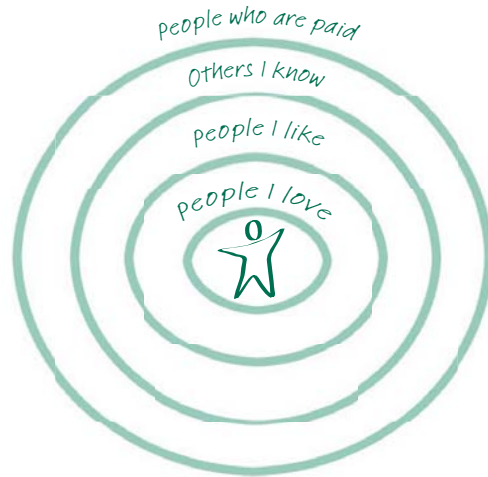


We all have important relationships in our lives, with people we like, admire and respect. We draw upon some, if not all, of these people when making important decisions. They can offer us their perspective, in the context of knowing and understanding us well.

It is vital that we both know and acknowledge who the important people are in the lives of those we support.

If people need support to make decisions it is crucial to work alongside them to establish their own relationships circle.

It is important to remember that we don't always use everyone in our life to help make a decision. We often choose people depending on the decision being faced. Some people may need support to figure out who these individuals are.



Joe was facing a decision about moving home.

His supporters helped him establish his relationships circle using photographs. They then spent time with him, exploring who he wanted to involve in this decision.



Joe chose:

- Marie - his niece
- Bob - Joe's brother, one of the most important people in his life
- John - Joe's supporter and friend

Together they worked through Joe's options and supported him to visit different properties and make his decision.

## to make decisions

**The Mental Capacity Act 2005 is based upon five principles, which explicitly promote the notion that a person's capacity should be assumed, and every effort should be made to support the person in making a decision.**

When supporting people with decision-making it is your responsibility to explore all appropriate ways to enable people to make decisions for themselves.

Although understanding people's communication style is crucial to the principles of the Act, there are other factors that also need to be considered when supporting people in decision-making.

The following are examples to consider; think about the decision you are supporting the person to make. Can you answer all of the questions?

<i>Do you understand what is important to me and my communication?</i>	<i>Are you the right person?</i>	<i>Is the information you are giving relevant to the decision?</i>
<i>Is it being presented to me in a way I understand?</i>	<i>Are you giving me the information in the right place at right time?</i>	
<b><i>Have you given me the best chance to make this decision my self?</i></b>		

Where every effort has been made to support the person to make a decision and this has proved unsuccessful, then an assessment of the person's capacity needs to be completed.

### Remember, when assessing a person's capacity:

- It is based on **that** decision only
- People's capacity can fluctuate (can change over time)
- A person can make unwise decisions



In order to decide if a person has the capacity to make a decision, the following two questions need to be considered:

### The two-stage test of capacity

- Is there an impairment of, or a disturbance in the functioning of the person's mind or brain?
- If so, has it made the person unable to make a particular decision?

### Mental Capacity Act 2005

If the answer is yes...

To determine the person's capacity to make this decision at this particular time, you need to work through the Functional Test.

**The Functional Test of Capacity**

The Act says that a person is unable to make a decision if they are not able to:

- Understand the information relevant to the decision
- Retain the information
- Use or weigh up that information as part of making the decision
- Communicate the decision (whether by talking, sign language or any other means)

The following graphic demonstrates one way of exploring Jane's capacity to consent to spend money on a holiday.

<i>Exploring Capacity</i>	<i>Jane's example</i>
<i>What is the decision?</i>	<i>The decision is to spend £250 on a weekend break to Scotland.</i>
<i>Who was involved?</i>	<i>Key worker and Rachael (staff member) who has a close relationship with Jane.</i>
<i>When did you present the choice or decision?</i>	<i>On Monday 23/4/07 and Wednesday 25/4/08 in the evening, when other people were not around.</i>
<i>How did you present the information to the person?</i>	<i>Used photographs of last break, played Jane's video of last holiday, talked through what the break will involve.</i>
<i>How did you explore the person's understanding?</i>	<i>Following Jane's communication plan – Jane didn't indicate yes or no.</i>
<i>How did you explore the person weighing-up the pros and cons?</i>	<i>Jane didn't indicate either way in accordance with her communication plan.</i>
<i>How did the person let you know their decision?</i>	<i>Jane didn't indicate a decision.</i>
<i>What is the outcome of the capacity test?</i>	<i>Jane doesn't have the capacity to make this decision at this time.</i>
<i>When will this be reviewed?</i>	<i>We will begin the process of best interest decision-making. We will review for next holiday.</i>

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**Remember:**

- Capacity is decision specific
- People's capacity can fluctuate (can change over time)
- People can make unwise decisions



**Unwise Decisions**

It is important to remember that people can and do make unwise decisions and lack of capacity should never be used as a rationale for preventing the person from carrying out their decision. The Functional Test protects people against this happening if followed correctly.

The following example illustrates this:

Reg lives with three other people. Reg is considered to be a 'big drinker' and most evenings drinks four cans of lager. Reg, when drunk, can sometimes behave inappropriately, with both his other housemates and his supporters, walking into other people's bedrooms, behaving in an abusive manner etc.

Often, after Reg has had a 'heavy' night, he is unable to get up for work on time and this results in considerable sick time. Support staff around Reg feel he shouldn't drink the amount that he does and have recently explored his mental capacity to understand the decisions he is making.

Exploring Capacity	Reg's Example
What is the decision?	The decision is to drink 4 cans of lager every night.
Who was involved?	Reg, Tim (Reg's friend for many years) and Julie (Service Manager) were involved.
When did you present the choice or decision?	Saturday afternoon. Reg chose to talk in his room away from other housemates.
How did you present the information to the person?	Talked through Reg's drinking. We discussed the benefits and risks, drawing them on one sheet of paper. Reg contributed to the discussion and final lists.
How did you explore the person's understanding?	Reg was very clear that he knew the risks and benefits.
How did you weigh up the pros and cons with the person?	In Reg's words: 'Drinking makes me ill and I know people can get sick if they drink too much. I am an adult and I want to drink - my dad did and no one told him he couldn't.' Reg also explained that if he were to lose his job, he would seek another with a later start time.
How did the person let you know their decision?	Reg was really clear that he wants to spend his money on drink and wants to continue.
What is the outcome of the capacity test?	Reg clearly has the capacity to make this decision.
When will this be reviewed?	This decision will not be reviewed.

## decision-making

Once a person has been assessed as lacking the capacity to make a particular decision at that time, you are then able to explore the decision on that person's behalf; this is called 'Best Interest Decision-making.'

The Act recognises that family, friends and paid supporters are making best interest decisions for some people, on a daily basis.

Best Interest Decision-making draws on best practice in supporting people to make decisions. The Best Interest Checklist provides a framework for you to work through on the person's behalf. It provides clear steps to ensure the person is central to the process.

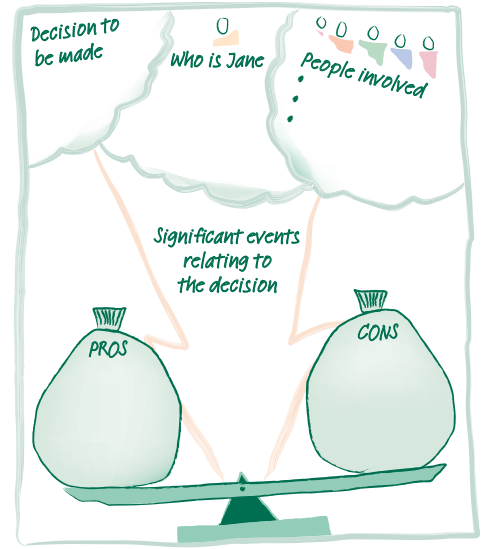
## excluded decisions

There are some decisions that are excluded from Best Interest Decision-making and no one can make these decisions on the person's behalf. These decisions are listed at the back of the book. The Best Interest Decision-making Checklist is listed overleaf and a graphic, designed to support people to work through the checklist, is also provided.

## best interest decision making checklist

- ✓ Cannot be based simply on the person's condition appearance or behaviour
- ✓ All relevant circumstances should be considered
- ✓ Every effort is made to encourage the person to take part in the decision
- ✓ Consider if the person is likely to regain capacity
- ✓ Special considerations apply about life sustaining treatment
- ✓ The person's past and present wishes, feelings, beliefs and values are taken into account
- ✓ Views of the people close to the person are considered and taken into account

*Mental Capacity Act 2005*



Best interest Decision agreed  
 .....  
 Date .....

# decision-making best interest

## Jane's Story

The decision for Jane to spend her money on a weekend break to Scotland was explored with her. Her supporters found that Jane lacked the capacity to make this decision at this time.

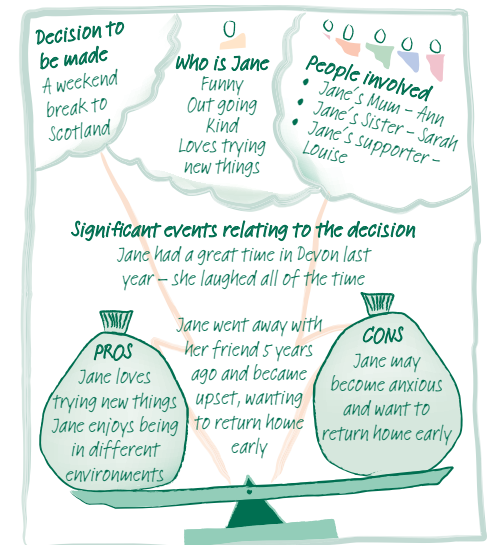
Jane's supporters worked through the Best Interest Checklist to make the decision on Jane's behalf.

The team began by using Jane's circle of support to identify the right people to explore the decision on her behalf. Jane was part of this gathering.

They discussed who Jane is. Together they explored significant events in her life to help the group when thinking about the decision e.g. Jane had a great time at a weekend break in Devon last year; however, Jane's mum explained that around 5 years ago, Jane went away with a housemate, became upset and had to come home early. The group then weighed up the pros and cons.

Together they made the decision that Jane would go on the weekend break to Scotland and made sure that she had transport to return, should she want to.

It is important to remember that once this decision was made, Jane's staff continued to attempt to involve her in the planning and organising of the holiday.



Best interest Decision agreed  
Jane should go on her weekend break to Scotland, with transport available should she decide to return early.  
Date 25/4/08

# decision-making agreement

As we know, it is really important for people to have as much control as possible over the decisions in their lives. With the right support many people can make decisions, and where people lack capacity to make a particular decision at a particular time, we follow the Best Interest Checklist to ensure the best possible decision is made on the person's behalf.

As capacity is decision specific i.e. a person may make decisions about what to eat and drink, but may lack capacity to make a decision about having an operation, we must be clear about how decisions are made in the person's life.

The Decision-making Agreement enables people to be clear about the decisions the person is making, as well as any decisions made in that person's best interests. We know that a person's capacity can fluctuate - an example may include being under the influence of drugs; therefore, it is important to remember that Best Interest Decisions should be reviewed.

The Decision-making Agreement offers clarity to all those involved in the person's life, to make sure we offer the right support for them to be in control.

Important decisions in my life?	How must I be involved?	Who makes the final decision?	When will this be reviewed?
Food shopping	Record favourite foods. Sue to be involved in the shopping. Ensure Sue has the chance to explore the food on offer.	Best Interest Decision agreed 10/4/08.  Direct Supporter - Julie	Weekly
What I do during the day	Pictorial timetable always available. If Sue indicates 'no' to an activity, her decision is respected - this can happen during the activity.	Sue	Annually

Independent Mental Capacity Advocates (IMCA) provide independent safeguards for people who lack capacity to make certain 'important' decisions.

### When will an IMCA be appointed?

An IMCA **must** support a person when they have **no family or friends to consult, only paid supporters**, and when the person is facing the following decisions:

- An NHS body is proposing serious medical treatment.
- An NHS or Local Authority is proposing to arrange, or change, hospital or care home accommodation, and the person will be staying in hospital for longer than 28 days, or in a care home for more than 8 weeks.

An IMCA **may** be instructed to support someone concerning:

- Care reviews, where no one else is available to be consulted.
- Adult protection cases, whether or not family, friends or others are involved.



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## what will the IMCA do?

- Provide support for the person who lacks capacity by trying to ascertain what their wishes, feelings, beliefs and values may have been had they been capable.
- Represent the person in discussions to determine if the proposed decision is in their best interests.
- Provide information to help work out what is in the person's best interests – this could be looking at alternatives to the proposed decision.
- Raise questions or challenge decisions that don't appear to be in the person's best interests.

### Mary's Story

Mary has lived in a residential home for many years and due to an increase in the level of assistance she needed, her support team felt they could no longer be supportive. Mary has a niece and nephew who don't live locally and with whom she has little contact. Mary's social worker and community nurse assessed Mary and found she lacked the capacity to make the decision regarding her change of accommodation. Mary's social worker contacted her niece and nephew who both indicated they did not want to be involved in the decision. Her social worker then made a referral to their local Independent Mental Capacity Advocacy service. Mary was given the support of an IMCA and together they began to explore her options in line with the Best Interest Decision-making Checklist.



Supporting people to live their lives can be fulfilling, although at times challenging, especially when we want to support them in the best possible way.

Being in control of your own life is vital, and as this book demonstrates it requires commitment and creativity to ensure people are at the centre of all decision-making that affects their life.

The Mental Capacity Act 2005 is in its infancy and we must continue to share our learning and develop best practice in supporting people with decision-making.

We hope this book has given you some ideas in relation to one of the most important responsibilities when providing support.

Thank you

The following are decisions that are excluded from best-interest decision-making (MCA 2005):

- Consent to marriage or civil partnership
- Consenting to sexual relations
- Consenting to a decree of divorce on the basis of 2 year separation
- Consenting to dissolution of a civil partnership
- Consenting to a child being placed for adoption or making an adoption order
- Discharging parental responsibility for a child and matters not relating to the child's property
- Giving consent under the Human Fertilisation And Embryology Act 1990.

Note: The Mental Capacity Act 2005 should be applied in conjunction with other legislation that affects people who may lack capacity in relation to decision-making.

#### References

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### **Further Reading**

Resource Guides about the Mental Capacity Act 2005 can be found at [www.dca.gov.uk/legal-policy/mental-capacity](http://www.dca.gov.uk/legal-policy/mental-capacity)

Information about IMCA can be found at [www.actionforadvocacy.org.uk](http://www.actionforadvocacy.org.uk)

### **Acknowledgements**

The Communication Chart on page 13 was developed by The Learning Community for Person Centred Practice

## About Paradigm

Paradigm is one of Europe's leading human service consultancy and development organisations. We work with local, national and international government agencies, provider organisations, campaign groups, people who use services and their families. We work in the UK, Europe and across the World. We were one of the first organisations in Britain to really promote person centred approaches and self directed support, and have been leading their development ever since.

## Website

We have an excellent website at [www.paradigm-uk.org](http://www.paradigm-uk.org) which provides regularly updated information affecting health, social care, education, housing and community services – government policy, articles and links to websites across the world.

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