



A Practical Guide to Supported Decision-Making

Paradigm
Pushing boundaries

and partners

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THANK YOU to:

All the people who co-produced this resource – the self-advocates, families, Support Workers, Managers and Commissioners who gave their time and joined us in a series of workshops: Cameron & Janet Swales, Amanda Watson, Liz Wilson, Kate Chate, Mark John-Williams, Kathryn Whitfield, Katie Gibson-Peacock, Robert Sawyer, Michelle McDermott, Nicholas Bettis and James Lewis.

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This is a revamped version of the much used booklet developed by Paradigm in 2008 (Authors: Kate Fulton, Kellie Woodley & Helen Sanderson). If you find any links are not working in the online version, please let us know at hello@paradigm-uk.org.

This booklet is dedicated to:

All those who's right to be supported in making decisions has been ignored or not upheld.

It is dedicated to all those families whose unconditional love for their family member drives all the support they give and to all those supporters who are passionate about getting it right.

We see YOU.

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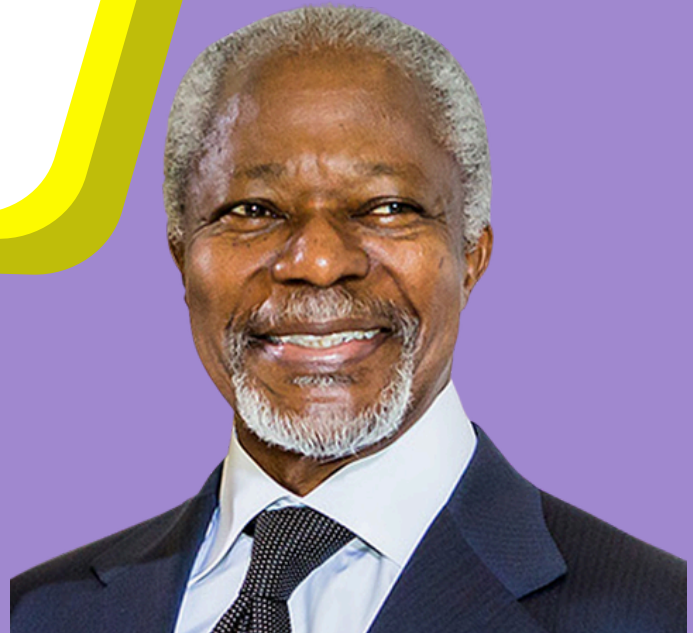


Look out for the pages that have a **light green** background. These pages have case studies on them to bring alive the information for you.

Introduction.

Knowledge is power. Information is liberation. Education is the premise of progress in every society, in every family.

Kofi Annan
**(Seventh Secretary-General
of the United Nations from 1997 to 2006)**



Opening words by Lucy Series

Lecturer in the School for Policy Studies at Bristol University



Most people take for granted that they will make key decisions about their lives – from what they wear and eat, to their relationships with, where they live, and the millions of everyday decisions that go into building a home and a life. We also know that being able to make decisions about our own lives is critical for wellbeing.

Everyone makes decisions within constraints – we cannot always have what we want. And many people draw on their relationships with trusted friends, family and professionals when making decisions – we all rely upon ‘Supported Decision-Making’ sometimes. It makes our lives richer and it makes our decisions wiser.

But people with learning disabilities, autism and other cognitive impairments face a constraint that few others do: being told they ‘lack capacity’ to make key decisions about their lives, and other people making decisions for them in their ‘best interests’ that may not reflect what they want. Mental capacity law is a double-edged sword: it can be used to champion people’s rights to make decisions about their own lives – through Supported Decision-Making, or by maximising a person’s agency through facilitated decision making that is attentive to their wishes and feelings. But if used wrong, mental capacity law can also be used to dismiss a person’s wishes and feelings and rights to decide. This guide will help you to ensure disabled people enjoy legal capacity and rights to decide on an equal basis with others.

'Life is an unpredictable and volatile ride. Strong support helps me to decide.'

**Leon Jordan,
Self-advocate and
poet**



'Sometimes I rush into things and it goes pear-shaped. I don't think everything through.
I want my supporters to help me understand the situation, so that I can think through the right road for me. I want them to help me understand.'

David Jeffrey, Self-Advocate



'We all want the best for our loved ones - be prepared!'

**Cameron Swales,
Father**



'Being able to support people in making decisions in their daily life, is an opportunity to connect with people in a very personal, deep and meaningful way - to work in partnership with families, colleagues and the people you support. It opens up into a beautiful rollercoaster ride with some amazing views.'

**Katie Peacock, Personal Assistant and
Co-ordinator at Exclusively Inclusive**



Our son has the right to be supported to make decisions that are right for him and live the life he wants. As his parents we can't let go until we know the right support is in place and people value and respect him like we do.'

**Amanda Watson, Mother and
Family Rep at Dimensions**



The reason we wrote this guide

Paradigm regularly hears from supporters across the country that people with a learning disability are often NOT genuinely involved in making decisions about their lives. This is unlawful.

Supported Decision-Making is a basic human right that is highlighted in the 'UN Convention on the Rights of Persons with Disabilities' and is part of The Mental Capacity Act 2005 and The Care Act 2014. It is NOT negotiable. We have enormous concern about the principle of Supported Decision-Making being overlooked and the rights of people being denied.

We hope that by co-producing an updated version of the 2008 booklet, we help people to have more more clarity and confidence in how they support others to make decisions.



The 2008 booklet has been the foundation of our family life and taken us through from early teens to adulthood, building my daughter's decision-making skills and holding my hand as I developed an adult relationship with my daughter who has a significant learning disability.

This new resource will give us a 'go-to' resource in supporting families and colleagues to understand the beauty and opportunity of **Supported Decision-Making, the forgotten gem of the Mental Capacity Act.**"

Liz Wilson, Mother



Who is this guide for?

This guide is for anyone who wants to grow their confidence and gain clarity in their role in upholding the rights of people with learning disabilities and all others in making their own decisions. You may be a family member, self-advocate, a paid supporter or a friend. This guide is for you, and we hope you find it helpful.

How to use this guide

You can read this practical guide from beginning to end but you can also explore different sections by using the contents page.

We have included examples to bring Supported Decision Making alive and most of these are accompanied by 'Pause for reflection: Think, discuss, act!' questions. We hope they encourage conversation, discovery and learning. You can learn from these yourself or use them to prompt discussion in team meetings.

You'll find that this booklet is sprinkled with hyperlinks that take you to more information. Any of this information that is in Easy Read, a film or a narrated photostory will have one of these symbols   beside them). If you are reading a printed copy, you'll need to download the online version to access all the great resources via hyperlinks.

We hope this booklet helps you feel confident in supporting people to make decisions!



What is Supported Decision-Making?

Supported-Decision-Making is when you support someone to make a decision for themselves. It sounds simple but sometimes there's quite a lot to it! It involves:

- asking the person how they want to be supported.
- asking if there is anyone they would like (or not like) to help them make the decision.
- making, or locating, accessible information about the decision the person needs to make.
- helping a person to find out about the options available to them.
- supporting the person in understanding and weighing up the pros and cons of each option.
- supporting the person in identifying any risks in any of these options and exploring how they could be addressed.
- supporting the person in expressing their wishes and feelings about each option.

If the person is assessed to have the mental capacity to make the decision, Supported Decision-Making could mean helping them to implement that decision and ensure that others respect it. **It's all about the person being in the 'driving seat'!**



Support should reflect how the person wants to be supported (or our best guess at that). Under the Mental Capacity Act 2005, the 'cut off' for Supported Decision-Making is the point where the person is still thought to 'lack mental capacity', even when 'all practicable steps' to support a person have been put in place.

In some situations, when a person is not able to express a clear preference for their favoured course of action, we use the phrase ‘facilitated decision making’ in line with international human rights approaches that emphasise processes to try and work out a ‘best interpretation’ of the person’s ‘will and preferences’. In other words, we try and work out what the person would be likely to say or what they’d want, if they were able to tell us. Under the Mental Capacity Act 2005, we could call this trying to ascertain their ‘wishes, feelings, values and beliefs, and thinking about factors’ the person would be likely to think about if they were making the decision themselves.



A lot of the time best interests decisions look identical to ‘facilitated decisions’, because they are based entirely on what we think the person would want us to do. In an ideal world, they would always look like this. This is the world the [Conventions on the Rights of Persons with Disabilities](#) would like to see.

However, under the Mental Capacity Act 2005, best interests decisions can involve taking steps or actions that we have reason to believe the person would not want. For example, to keep a person safe, healthy, or to prevent abuse. The Mental Capacity Act 2005 permits best interests decisions that are not entirely based on what the person wants, but this should only take place after careful consideration of the person’s own point of view, and there should be strong reasons justifying this which take into account the emotional impact on the person. It may be necessary to involve independent advocates (p35), liberty safeguards (p38) or even the Court of Protection (p40) in these situations.

To find Easy Read information on Supported Decision-Making click [here](#).



Why is Supported Decision-Making so important?

For many of us, our lives are beautifully varied. Making decisions about our lives, from the little things (like what we want to eat and drink) to bigger decisions (like where we want to live, who we have sex with), is something we can easily take for granted. Decision-making is key to our autonomy, our sense of self, our self-confidence and our sense of belonging. It determines our lifestyle and contributes to our happiness.

When we make decisions in our life, sometimes we take time to ‘mull it over’, sometimes we talk it through with family or friends. We think about the impact a decision will have on us; we discuss the pros and cons and hear other people’s opinions. All of these things help us arrive at a decision that feels right at that moment in time. ALL of us have times when we need support with making decisions in our lives.

It is exactly the same for people with a learning disability. But too often, this is NOT happening. Too often supporters are making decisions FOR people without working with or involving the person with a learning disability or the autistic person. This should not happen.

We must work together to make sure that people are not deprived of their rights and the richness of life. **We must notice that the smallest of moments can erode people’s rights.** It is important to understand more about the law so that we do not act unlawfully or neglectfully.



**“What good is it making someone safer
if it merely makes them miserable?”**

Sir James Munby, one of the most well-known Court of Protection Judges
[Re MM \(An Adult\) \[2007\] EWHC 2003 \(Fam\)](#)

Why are people ignoring Supported Decision-Making?



There are traps we can **all** fall into...

Not knowing the person well enough to be able to support them

Inheriting a culture of 'the way it works'

Not tuning into a person's communication

Presuming what people want

Assuming someone who doesn't use words cannot communicate

Being risk-adverse or biased

Historical worth of people with learning disabilities

Not having time and not preparing well enough

Not keeping the people we support at the centre

Not feeling confident and equipped to do this

Not having built a relationship of trust with the person

Being over-zealous and trying to **SAVE** someone

Misguided loyalty

These are only **SOME** of the traps!



Do YOU recognise any of those?

ALL of those reasons disempower people and erode the control people have in their life.

Each and every one of us has a responsibility to check ourselves and 'call ourselves and our peers out' if we find any of these reasons creeping into the way we support people to make decisions.

We need to create a culture of working together where we can be open, authentic and creative. We must involve ALL people in making decisions about their lives.



'Assumptions can be made that 'these people', 'their' lives are less valuable.

We need to change the narrative'

**Dr Jo Watson,
Researcher in Learning Disabilities.**



PAUSE for reflection

'The police came in to talk to a group of people with a learning disability about being safe and taking care of themselves.

They told people that they couldn't have sex!'



You may be interested in connecting with The Supported Loving Network which you can find [here](#) or the Welsh Sex Education Company which you can find [here](#).

Think, discuss, act:

Questions for people with a learning disability:

1. Was this okay?
2. Why do you think they did this?
3. If you saw this happening, what would you do?

Questions for supporters:

1. Was this okay?
2. Why do you think they did this?
3. What impact would this have on the people?
4. If you saw this happening, what would you do?
5. What do the police need to understand about capacity?
6. How can we avoid this happening?
7. How would you check a person's capacity to consent to sex.?



Click [here](#) to see a narrated photo story of this.

Key aspects of Supported Decision-Making and how it fits in with the law.



Laws are important. But they can only be effective if the people know about the particular laws.

Waris Dirie
(Human Rights Activist)

The 5 key principles of the Mental Capacity Act 2005:

1. The assumption of capacity: 'A person must be assumed to have capacity unless it is established that he lacks capacity.'

Supported Decision-Making!

2. The support principle: 'A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.'

3. The unwise decisions principle: 'A person is not to be treated as unable to make a decision merely because he makes an unwise decision.'

4. The best interests principle: 'An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.'

5. The least restriction principle: 'Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.'

The legal context

We've focused on the Mental Capacity Act in this booklet which applies in England and Wales but similar practices would fit within the Scottish legislative landscape (excluding there being no 'best interests approach' for adults in Scotland). To find out more about practice in Scotland look [here](#). In 2007, the Mental Capacity Act 2005 came into force in England and Wales, and [Scotland's The Adults with Incapacity Act](#) came into force in 2000.

The Mental Capacity Act applies to EVERYONE aged 16 years and over. The Act gives a legal framework for the care, treatment and support of people who are unable to make some, or all, decisions themselves. It is an important piece of legislation that protects both the person who lacks mental capacity as well as those people who support, love and care for them – family members, friends and/or paid workers. It is the first statute to clearly state that people can no longer make decisions on behalf of others without following a process.

The Act has [5 principles](#) that those working with vulnerable individuals over 16 should adhere to. The 2nd principle says that people MUST be supported to make decisions: **'A person is not to be treated as unable to make a decision unless all practicable steps to help them to do so have been taken without success.'**

The Care Act 2014 (and Social Services and Wellbeing Act 2014, in Wales, and the Social Care (Self-directed Support) Act 2013, in Scotland all create a duty to involve the person in care and support assessments and decisions. The Care Act requires the local



authority to identify an ‘appropriate person’ to represent and support a person for the purpose of facilitating the person’s involvement’ if they would have ‘substantial difficulty’ understanding, retaining, using/weighing information or communicating decisions. If they do not have an ‘appropriate person’ then a Care Act Advocacy Referral should be made and (unlike the MCA) those advocacy regulations explicitly require advocates to:

(a) assist the individual in –

- (i) understanding the function in the exercise of which the person is involved;
- (ii) communicating the person’s views, wishes or feelings;
- (iii) understanding how the person’s care and support, or support, needs could be met by the local authority or otherwise;
- (iv) making decisions in respect of care and support arrangements;
- (v) challenging the local authority’s decisions if the person so wishes;

(b) so far as is practicable, ensure that the person understands the local authority’s duties under Part 1 of the Act and the person’s rights and obligations under that part and any other rights and obligations of the person which may be relevant to those obligations;

(c) make such representations as are necessary for the purpose of securing the person’s rights in relation to the exercise of the function; and *(see overleaf)*

*It's good to
know the law
so you know
what people's
rights are!*

- (d) **where the independent advocate has concerns about the manner in which the assessment or planning function has been exercised or the outcomes arising from it, prepare a report for the local authority outlining those concerns.**

These regulations also say:

- ‘(8) Where the individual does not have capacity, or is not competent, to challenge a decision made in the exercise of the assessment or planning function, the independent advocate must challenge the decision if the independent advocate considers the decision to be inconsistent with the authority’s general duty under section 1 of the Act (duty to promote the individual’s well-being).’**

The Care Act statutory guidance says,

The modern care and support system should routinely enable supported decision-making, where options and choices are presented simply and clearly.’

Care Act 2014 guidance



To find Easy Read information on The Care Act look [here](#).

To find Easy Read information on the Mental Capacity Act click [here](#).

Where every effort has been made to support the person to make a decision and this has not been possible, then an assessment of the person's capacity needs to be completed. This can be done by you. It is important that when you assess a person's capacity, remember that:

DON'T FORGET



1. You are testing capacity for that decision only. (The person may be able to make a decision on something else.)
2. A person's capacity can fluctuate and change over time. E.g. a person may not be able to make a decision first thing in the morning, until they have had breakfast and taken certain medication.
3. A person should not be treated as lacking capacity merely because they are making a decision that others regard as unwise.

To decide if a person has the capacity to make a decision, The 2-Stage Test of Capacity need to be considered (see page 23). But first let's explore capacity! ...

Exploring capacity

The Mental Capacity Act 2005 is based upon 5 principles (see p17) that explicitly explain that a person must be assumed to have capacity unless it is established that the person lacks capacity.

When supporting people with decision-making, it is our responsibility to explore ALL possibilities to enable people to make decisions for themselves. It is our responsibility to think, 'What more is possible?'. Understanding people's communication style is crucial to the principles of the Act, but there are other factors that also need to be thought about when supporting people in decision-making.

Think about a decision you are supporting someone to make. Can you answer all of these questions:

1. Do you understand **what is important to me and my communication?**
2. **Are you the right person** (is there someone else I'd be more comfortable exploring this with?)
3. **Is the information you are giving me, relevant** to the decision?
4. Is the decision being presented to me **in a way I understand?**
5. Are you giving me the **information in the right place at the right time?**
6. Are you **giving me the best chance** to make this decision myself?
7. Is there **anything else you could be doing?**



The 2-Stage Test of Capacity

Stage 1: The Presence of an Impairment or Disturbance

1. Make sure the person can understand the information relevant to the decision (including information about the reasonably foreseeable consequences of deciding either way).
2. Is there an impairment of, or disturbance in, the functioning of the person's mind or brain?
3. If there is, has it left the person unable to make a particular decision?

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** below.

Stage 2: The Functional Test of Capacity

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

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



What should I do if I disagree with a mental capacity assessment decision?

If you disagree with a mental capacity assessment decision there are different ways you can resolve this:

1. **Remember that you can ask to see the notes of how the decision was reached.** However, it is important to note that you do not have a legal right to see them. Families have no legal right to see their relative's notes (unless they are Deputies or Lasting Power of Attorney). The notes should help you to know where to place your challenge.
2. **Make notes of why you think the decision was wrong and how you might suggest re-looking at it** (if you think this would help). E.g. was it the wrong time of day before a person's medication? Make sure your thoughts are clear, calm and collected.
3. **Raise the matter with the person who carried out the assessment and offer to talk it through,** and raise your thinking/concerns. Be clear that you want what is best for the person and that is why you are raising this. Hopefully this'll create a plan of action that addresses your concerns.
4. **It may be necessary to ask for a second opinion** from an independent professional.
5. **If you cannot resolve the disagreement, then you may be able to apply to the Court of Protection (see p40),** who can make a decision as to whether a person has mental capacity. The Court of Protection's aim is to look at what is best for the person but they can only do this with the right information, so make sure that you provide the necessary information. If there is serious disagreement about a medical treatment decision or welfare matter, the public body should be applying to court not waiting for families to do so. It is important families know that if a public body does go to court, then the courts have said they have to do this to resolve this. It can seem adversarial but it's giving everyone a fair say and the judge deciding. [This guide](#) may be helpful.

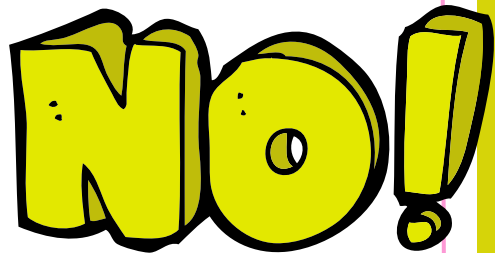


Best Interests Decision-Making

Once a person has been assessed as lacking the capacity to make a particular decision at that time, a decision can be made on that person's behalf. This is called 'Best interests decision-making.' *Please note that there is no 'best interests approach' for adults in Scotland. To find out more about this look [here](#).*

There are some decisions that are excluded from Best Interests Decision-Making. This means that NO-ONE can make these decisions on the person's behalf. The following are decisions that are excluded from Best Interests Decision-Making:

- Voting.
- Consenting 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 partnership.
- Consenting to a child being placed for adoption or making an adoption order.
- Discharging parental responsibility for a child and matters relating to the child's property.
- Giving consent under the Human Fertilisation and Embryology Act 1990.



The Mental Capacity Act recognises that family, friends and paid supporters often make Best Interests Decisions for people everyday. However, there are times when a more formal approach is required, and a Best Interest Decision-Making meeting needs to be facilitated.

This should involve people that know the person well and those who have a particular knowledge in relation to the decision to be made.

With the exception of someone with a [Lasting Power of Attorney](#) (p37), or a [Court Appointed Deputy](#) (p40), the Mental Capacity Act 2005 (MCA) does not identify a particular individual as having legal responsibility for decision-making. It focuses on a collaborative approach to decision-making. Best Interests Decision-Making involves all those involved with or caring for the person. However, it is expected that one person is accountable for the overall decision and that they will record how the decision was reached. Anyone who is responsible for providing care and treatment is potentially liable if they do not ensure that the correct procedures are followed for assessing mental capacity (including supported decision making) and determining best interests (including involving the person, consulting with others and considering their wishes, feelings, values and beliefs).'

However, this does not mean that the clinician can make their decision in isolation. They are required to consult with anyone else involved in the care of the person. Those who know the person well or that the person has indicated to be important in their life should feed into this decision. See the [British Medical Association \(BMA\) guidance](#).

When bringing people to a Best Interests Decision-Making meeting, it is important to embrace dissent (even if it isn't easy) and have open, honest and brave conversations that hold the person and their voice at the heart of what's being decided and to listen to their opinion. To record a Best Interests Decision, you can use [this form](#)



The hierarchy of decision-makers according to the law:

The Court of Protection.

There are some decisions that are so serious they should always be taken by the court. For example, sterilising someone, or an abortion against their wishes or medical treatments a person strongly objects to. Some cases state that if there is disagreement over a serious welfare decision then the court should be involved. If this is the case then you should see a lawyer for advice.

Deputies or attorneys are the 'decision maker' if it is a decision within their power. E.g. a deputy or attorney for property and affairs is not necessarily 'the decision maker' for health and welfare matters. If a deputy or attorney is 'the decision maker', they are also obliged to consult with others involved in caring for the person or care about their welfare.

Those who are responsible for the relevant 'care or treatment': Where the person has no Deputy or Attorney, then whoever is responsible for delivering, arranging, commissioning or funding the treatment has to assure themselves that a valid mental capacity assessment and Best Interests Decision has been made or else they could be liable for unlawful care/treatment without consent. In practice, often there will be many people who take some level of responsibility for the care/treatment, and the new draft Code of Practice says this:





Did you know?

5.22 In all cases involving an organisation there must, however, ultimately be one person who is prepared to take responsibility on behalf of that organisation for the conclusion that the step being taken is in the best interests of the individual concerned. That does not mean that they have the right to take that decision, but simply that they are accountable for it.

5.23 It is important that everyone involved in the best interests decision-making process knows and agrees who the decision-maker is, and that, no matter who is making the decision, the most important thing is that the decision-maker tries to work out what would be in the best interests of the person who lacks capacity. The decision-maker should try to identify any of their own unconscious biases to ensure they do not influence the best interests decision.

So important!

The Aintree case:

There's a case called Aintree about best interests where Lady Hale said:

‘The purpose of the best interests test is to consider matters from the patient’s point of view... in so far as it is possible to ascertain the patient’s wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being.’

‘...in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be.’

[Aintree University Hospitals NHS Foundation Trust v James \[2013\] UKSC 67](#)

'The person facing the decision contributes by expressing their will and preference, using a range of informal communication methods such as body language, facial expression, gesture and physiological reactions (e.g. changed breathing patterns).

Supporters contribute to the process by responding to these expressions of will and preference, through acknowledging (as opposed to ignoring), interpreting and acting on this expression.'

Dr [Jo Watson](#),
Researcher in Learning Disabilities





PAUSE for reflection

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. They worked through the Best Interests Checklist on p48 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 and together they explored significant events in her life to help the group when think about the decision. For example, Jane had a great time at a week-end break in Devon last year but 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 with her friend but they would make sure that Jane had transport to return, should she want to. Once this decision was made, Jane's staff continued to attempt to involve her in the planning and organising of the holiday.

The Best Interests Decision-Making Checklist is on p48.

Think, discuss, act:

Questions for people with a learning disability:

1. Do you know about Circles of Support?
2. Why did Jane's Circle of Support help Jane with this decision?

Questions for supporters:

1. How could you use the Best Interests Decision-making checklist on p48 more?
2. Would it be helpful to people in your team? How would it be helpful?



Click [here](#) to see a photo story of this.



Checklist points :

- ☐ Don't base thinking simply on a person's condition, appearance or behaviour.
- ☐ Who should be involved? Is there anyone they would like to be consulted?
- ☐ What's important to the person?
- ☐ What are their views/wishes about other decisions in?
- ☐ What were the important factors to be considered?
- ☐ What are the pros and cons?
- ☐ How can you keep the person involved?





PAUSE for reflection

We explained to Anna that her infection would get worse if she didn't go to hospital. Every time we made another appointment Anna became hugely distressed and refused to go. This deeply impacted her ability to weigh up the pros and cons of going to hospital.

In the end, after rather intense liaisons between Anna, her Support Worker and the GP and trying different options, the GP made a Best Interests Decision to administer sedative so that Anna felt calm enough to go hospital.



Think, discuss, act:

Questions for people with a learning disability:

1. What do you think of this?
2. What could have helped Anna to not feel so scared?

Questions for supporters:

1. What do you think of this?
2. What was Anna communicating?
3. If the GP made this decision, what does that say about her capacity to make the decision?
4. Could sedation have been avoided?
5. What reasonable adjustments could have been offered/considered?
6. How would you check Anna's capacity in advance of her ill health?
7. What difference would that have made?



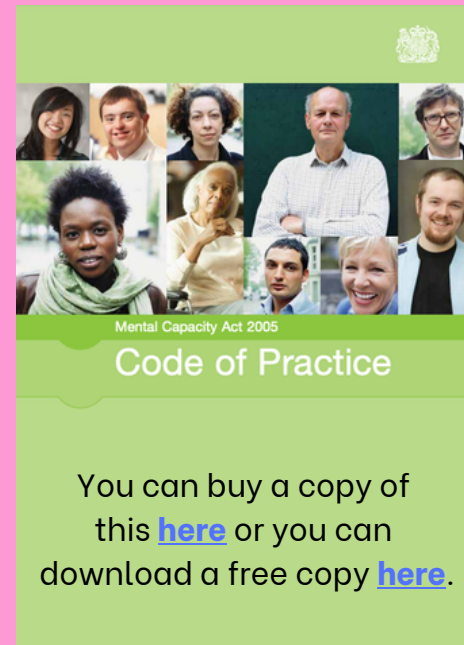
Click [here](#) to see a narrated photo story of this.

The Mental Capacity Act Code of Practice

This [Code of Practice](#) gives guidance to people who work with people who can't make a decision for themselves. It supports The Mental Capacity Act. The Mental Capacity Act 2005 (MCA) says certain people **MUST** follow its guidance when they act or make decisions on another person's behalf:

- **an Attorney** appointed under a Lasting power of Attorney (see p37)
- **a Deputy** appointed by the Court of Protection (see p40)
- **an Independent Mental Capacity Advocate** (IMCA p35)
- **a person who acts in a professional capacity for, or in relation to, people who can't make decisions for themselves**
- **a person who is paid to act for or in relation to people who can't make decisions for themselves**

IMPORTANT TO KNOW!



As two co-producers of this practical guide emphasised, it is important when thinking about making a Best Interests Decision to **consider how a decision may impact on the whole of a person's future life**. A decision can affect more than just that moment in time.

‘Respect my tomorrows as well as my todays. Families often walk the line of best interests decisions every day and work hard to get others to understand that there will be no tomorrows if we don't look at the big picture, past, present and future when we support people in making decisions.’

Amanda Watson, parent and Family Carer Rep at Dimensions and Liz Wilson, parent



A limitation of The Mental Capacity Act is that it treats each decision in isolation. In some situations, it might be worth considering making a Lasting Power of Attorney (see p37) or seeking a Deputy (see p40) to ensure continuity over many decisions across time in different areas of a person's life.



When is an Independent Mental Capacity Advocate (IMCA) needed?

An IMCA only supports a person when they have no family or friends to consult, when they only have paid supporters, and when they are 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 also be told to support someone in:

- Adult protection cases, whether or not family, friends or others are involved.
- Their care review, if no one else is available to be consulted.

What will the IMCA do? They will:

- Support the person who lacks capacity. They will try and work out what the person's wishes, feelings, beliefs and values may be.
- Represent the person in discussions to work out if the suggested decision is in the person's best interests.
- Use information to help work out what is in the person's best interests. This could involve looking at different options to the suggested decision.
- Ask questions or challenge decisions if they don't seem to be in the person's Best Interests.
- Write a report that provides decision makers with information about their investigations, representing their client's situation.





PAUSE for reflection

Chhaya has lived in a home for many years and she is needing more and more help each day. Her support team feel they can no longer offer the right support.

Chhaya does have a niece and nephew but they don't live locally and she has little contact with them.

Chhaya's Social Worker and Community Nurse assess Chhaya and find she lacks the capacity to make the decision to do with the change in where she lives. Her Social Worker contacts her niece and nephew who both say they do not want to be involved in any decisions.

Chhaya's Social Worker makes a referral to their local Independent Mental Capacity Advocacy Service. Chhaya is given the support of an IMCA and together they begin to explore her options in line with the Best Interests Decision-Making Checklist (p48).



Click [here](#) to see a narrated photo story of this.

Think, discuss, act:

Questions for people with a learning disability:

1. Why did Chhaya need an IMCA?
2. What do IMCAs do to help people?
3. How would you find an advocate?

Questions for supporters:

1. Do you know where your nearest IMCA service is?
2. It is often good in these situations to have a 'go to' person that you trust the opinion of and seek their support. Who is this person for you?
3. If a person has no family or friends, how could you develop a Circle of Support to avoid this situation?
4. What would you do if the Social Worker made a bad decision only on cost?



Lasting Power of Attorney

A Lasting Power of Attorney (LPA) is a legal document. It enables individuals to give someone they trust the power to manage their affairs if they lack capacity to make certain decisions for themselves in the future. This person who has Lasting Power of Attorney will then make decisions in the person's best interest.

There are 2 types of Lasting Power of Attorneys. One for each:

- property and financial affairs
- health and welfare

You can find guidance on Lasting Power of Attorney [here](#).

If a person does NOT have the capacity to manage their finances and a Lasting Power of Attorney is not in place, you can apply for to the Court of Protection for a Financial Deputy to be appointed.

This Financial Deputy can then make decisions on the person's behalf. A Health and Welfare Deputy can also be appointed by The Court of Protection to make decisions. You can find more information about this [here](#).

More people with learning disabilities could be supported to appoint LPAs, as this is the only way they can choose who makes major best interests decisions about their lives. It gives their chosen supporters/Attorneys clearer legal status when dealing with organisations likes banks, hospitals, councils etc.



Deprivation of Liberty (DoLS) & Liberty Protection Safeguards

Sometimes a person's freedom is limited to give them the care they need, or to prevent them from any harm or danger. For example, staff in a residential home may need to stop a person from leaving the building at night and walking into a nearby main road (as the person does not have capacity to understand). This is called a Deprivation of Liberty.



In June 2026, a Supreme Court ruling changed the law about how we decide when someone is deprived of liberty. The acid test no longer applies and instead a 'multifactorial' test is considered. You can find out more about this [here](#).

At the moment, if a person is deprived of their liberty in a care home, nursing home or hospital, it can be authorised by the Council using The Deprivation of Liberty Safeguards. The care home or hospital has to apply for authorisation. If a person is deprived of their liberty in supported living or a home setting, then it can only be authorised by the Court of Protection. In the future, new Liberty Protection Safeguards will give Councils and NHS bodies powers to authorise Deprivation of Liberty in all settings, including people's private homes, without having to go to court. A Deprivation of Liberty can only be authorised after independent checks have been done on the person's care arrangements. It also usually requires that the person has a representative, or advocate (or both), to help them understand their rights and keep in touch with them.

If you are supporting someone and are not sure if they are deprived of their liberty or not, then you should contact the Council's 'Deprivation of Liberty Safeguards' Team for advice. If you think there may be an unlawful deprivation of liberty then raise the concern with the provider, or the council. Click [here](#) for info on a man unlawfully deprived of his liberty.

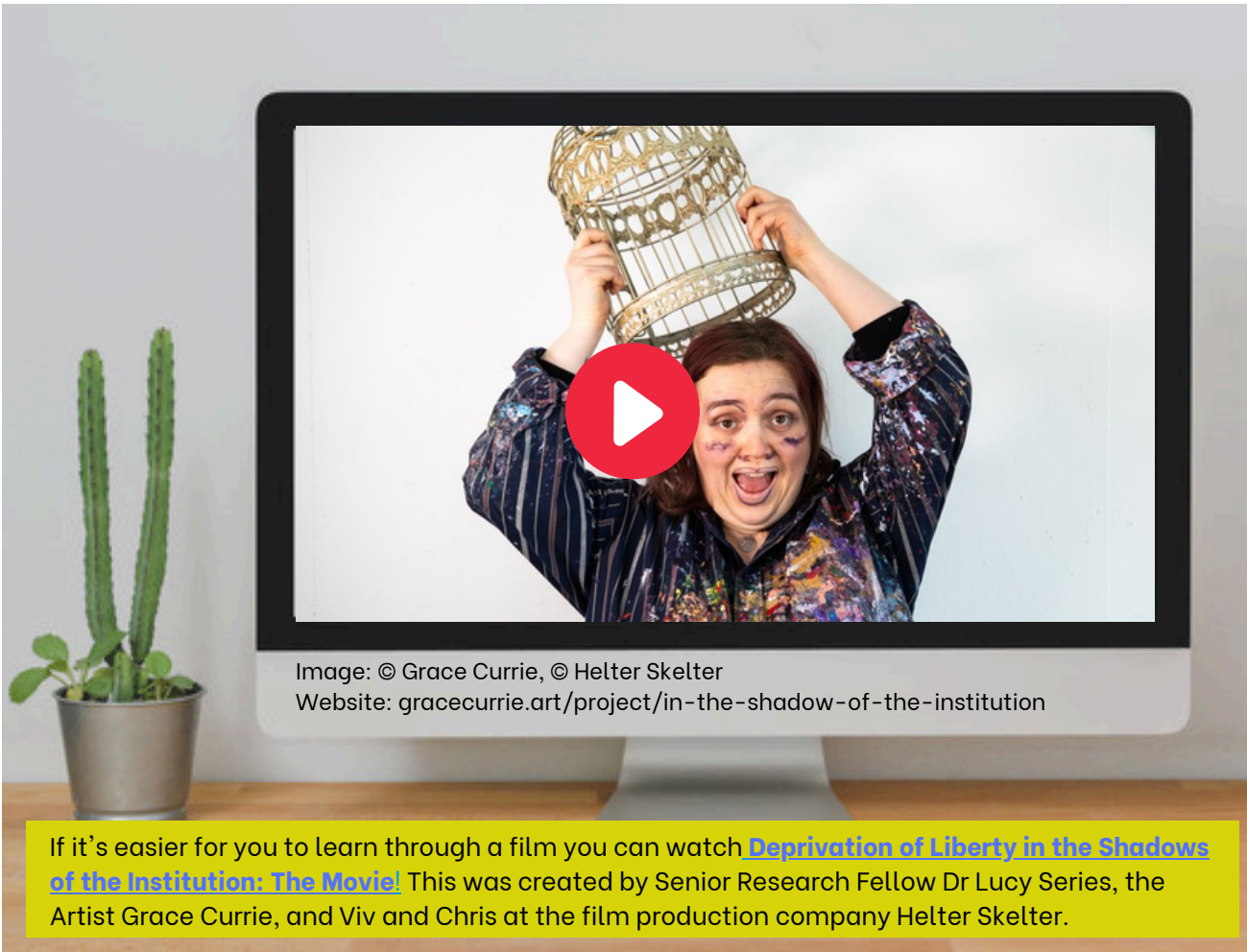


Image: © Grace Currie, © Helter Skelter
Website: gracecurrie.art/project/in-the-shadow-of-the-institution

If it's easier for you to learn through a film you can watch [Deprivation of Liberty in the Shadows of the Institution: The Movie!](#) This was created by Senior Research Fellow Dr Lucy Series, the Artist Grace Currie, and Viv and Chris at the film production company Helter Skelter.

Court of Protection and Deputies

The [Court of Protection](#) makes decisions on financial or welfare matters for people who can't make a decision at the time the decisions need to be made i.e. when a person 'lacks mental capacity'. The Court of Protection:

- decides whether someone has the mental capacity to make a specific decision themselves.
- appoints [Deputies](#) to make ongoing decisions for people who lack mental capacity.
- gives people permission to make one-off decisions on behalf of someone else who lacks mental capacity.
- deals with emergency/urgent applications for when a decision must be made on behalf of someone else.
- makes decisions about a Lasting Power of Attorney and considering any objections to their registration.
- makes decisions about when someone can be deprived of their liberty under the Mental Capacity Act.



Under the law, parents are responsible for their children up until they become adults, at which point best practice shows that decisions on their behalf should be taken collectively by everyone interested in their welfare, and the family should only be appointed as Welfare Deputies in 'the most difficult cases'. In 2019, the Honourable Mr Justice Hayden, Vice President of the Court of Protection, handed down judgment ruling that there should not be a starting presumption AGAINST such an appointment of a Welfare Deputy. This acknowledges the importance of family members' (particularly mothers and fathers of adults lacking capacity) involvement concerning matters involving their loved one's welfare.

Tools, thinking and ideas.

Life is a series of small and big decisions that feed into what our 'every days' and our future. We all need support at different points to create and steer the lives we want.

Sally Warren, Paradigm's MD



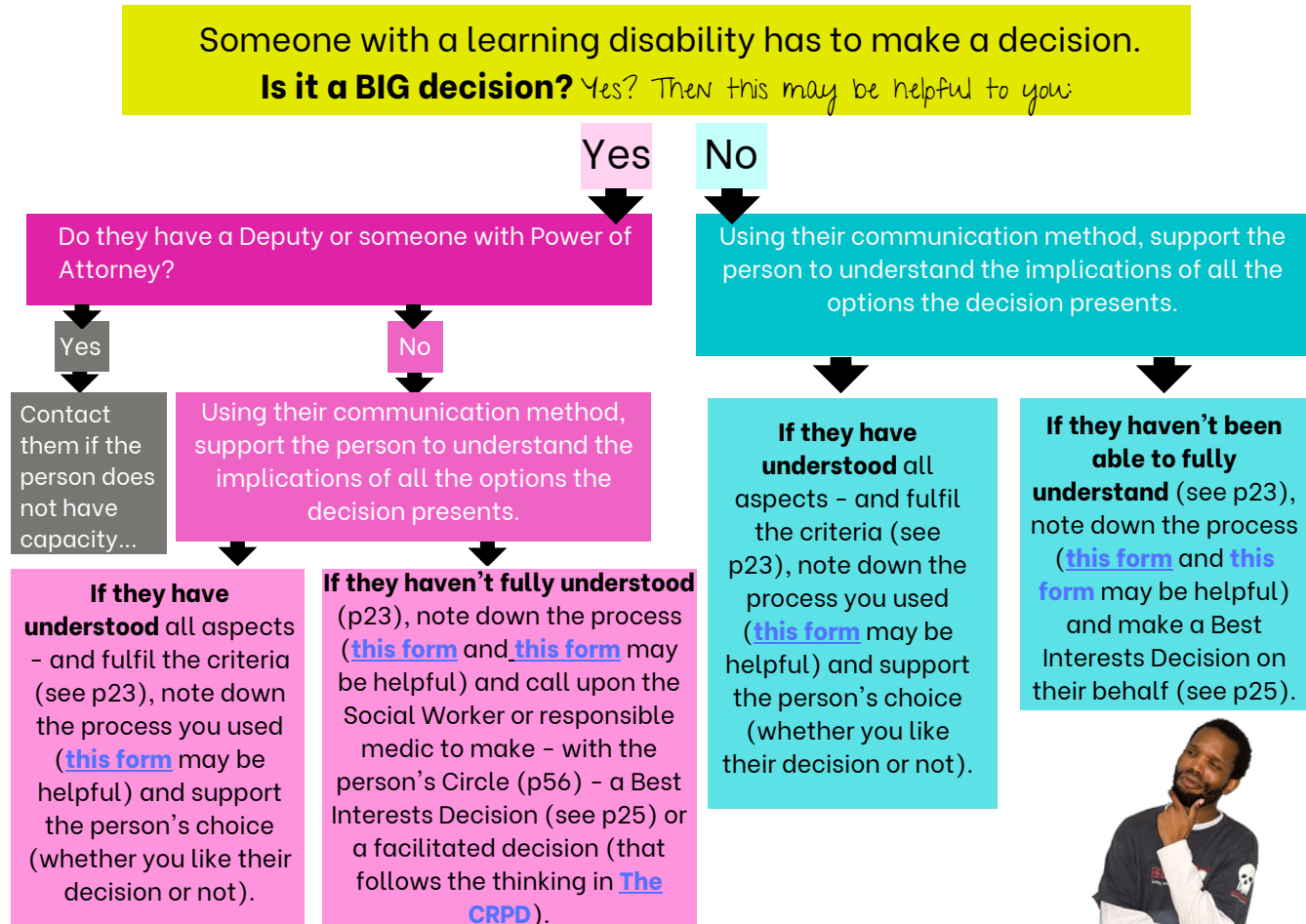
This section has lots of things in it to help you when you are supporting someone to make their decision...

By failing to prepare,
you are preparing to fail.

Benjamin Franklin
(Inventor, scientist, politician, peace-maker)



A Decision Flow Chart to help you think through the process



What is the decision to be made?

If we are thinking about the formal process of Supported Decision-Making, so not about using an umbrella or taking the bus instead of walking, but where to move to, for example. It is important to have absolute clarity about the **specific decision** to be made and why it is needed.

Once, you have clarity on what the decision is, **consider ALL the options** – this is very important! For each one: what are the risks, benefits, what does the person feel about it, how will it affect their life, what are the pros and cons, and what the consequences are of making or not making the decision? (Sometimes decisions can get blurred amongst other ‘stuff’ in life!)

One of the issues that comes up a lot in case law is the importance of checking out all the ‘options’ that a person can choose from. Often people will be offered one option only, for example to move into a residential care home, and other options are not explored. The courts have said that Local Authorities should not start with a ‘blank slate’ but should properly explain all the options for a person to choose between.

You can use [this Supported Decision-Making Agreement form](#) to help you keep clarity and keep the person at the centre of their decision-making.



What you should think through

How the person would like to be supported?

This won't always be possible, but this is important. Supported Decision-Making **MUST NOT** become yet another thing 'done to' a person. [New NICE guidelines on mental capacity and decision making](#) say:

'1.2.1 Find out from the person how they want to be supported in decision-making in accordance with principle 2 of the Mental Capacity Act 2005. If they would like someone to support them, find out from the person who needs support who this should be. Be aware of the possibility that the nominated person may be exercising undue influence, duress or coercion regarding the decision, and take advice from a safeguarding lead if there is a concern.'

What information is needed to help?

This will depend on the nature of the decision. If it is about medical treatment or care options, then there may be [duties on the NHS or Local Authority or Care Provider](#) to ensure that there is accessible information. The NHS has duties to provide accessible patient information and Local Authorities and Care Providers are bound by The Equality Act to make reasonable adjustments. So supporters and advocates may want to locate accessible information and remind providers of their duties to provide it.



Who is the best person/people to help the individual make the decision?

Who would the person like to support them (p54)? Do they have a Circle of Support they would like to involve (see p56)? It is important that supported decision-making doesn't become yet another thing that is 'done' to a person. It may be helpful to look at the [new NICE guidelines on mental capacity and decision making](#).

'1.2.1 Find out from the person how they want to be supported in decision-making in accordance with principle 2 of the Mental Capacity Act 2005. If they would like someone to support them, find out from the person who needs support who this should be. Be aware of the possibility that the nominated person may be exercising undue influence, duress or coercion regarding the decision, and take advice from a safeguarding lead if there is a concern.'

What is the best way to communicate with the person?

Check if the person has a [communication document](#) to share. Ask them (or those who know them well) what works for them in terms of communication –some people prefer videos, Easy Read, sign language, singing. Some times we forget to be curious and ask this!

Communication Chart belonging to: _____

Supported by: _____
Should be shared with: _____
Signed: _____

To be reviewed:

At this time / in the situation	How the client communicates from words/sign language	How they if they communicate	How should do this	At this time / in the situation	What you want them to know or do this	How should say at this time

Does the person need to be in a certain place?

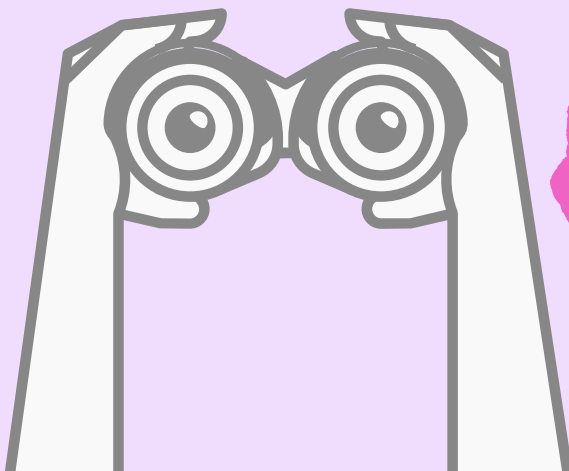
Is there somewhere they prefer to be because they feel more comfortable, relaxed and in control? Some people need to be in a place that has no distractions or where there aren't sensory sounds/lights that will compete for their attention. Ask the person where they would prefer to be.

Does the person need help to prepare?

Certain things may need to be done to help a person prepare for making a decision. For example, if a person is thinking about moving out of home, would it be helpful for them to visit different housing options to see how they work and feel, and maybe speak to people who live there already. Talk through different ideas that could be helpful.

What is the best process for the decision-making?

Ask the person what would work for them. Talk through different ways in which it could work. Give the person as much control and choice as possible. Do they need to meet numerous times and have things broken down into stages, e.g. exploring one option per meeting. Do they need support in processing it afterwards?





Checklist points :



Don't base thinking simply on a person's condition, appearance or behaviour!

☐

Who should be involved? Is there anyone they would like to be consulted?

☐

What's important to the person?

☐

What are their views/wishes about other decisions in?

☐

What were the important factors to be considered?

☐

What are the pros and cons?

☐

How can you keep the person involved?



You can use the forms on p51, 77, 78, 79 and 80 to help you and the person you support think this through in more detail.

Remember: the assumption of capacity principle

This Act says that you must start from an assumption that the person has the capacity to make the decision. If someone is concerned that they might lack capacity, then it is up to them to establish that fairly and objectively, including making sure the person has had the right support to make the decision for themselves.

Remember: We are often supporting people to make decisions everyday

Before we start looking at the 'formal' decision making process, let's be clear, as a supporter, you are probably already supporting people to make decisions on an 'everyday' basis. You may have gone to support someone who usually goes to a music class but find out that they have decided that as it is raining, they do not want to go. Did you simply say 'okay' or did you chat about:

- using a brolley or taking a bus instead of walking.
- how they might feel if they miss seeing their friends?
- if there is a hidden reason, beyond the rain.
- if there is a way to get over the dislike of rain e.g. good waterproofs.

We support the people we care about to make better decisions all the time. We don't have to call somebody's capacity into question to suggest alternatives, raise concerns about risks, and help them think things through.

People who care about each other do this all the time. It's just part of natural every day 'goings on'.

We need to trust our gut and get the balance right for when we use a formal Supported Decision-Making process. We mustn't stop people's lives. The following example shows how someone's life could have been stopped if the right support hadn't been given, if their feelings hadn't been noticed, listened to and responded to ...





PAUSE for reflection

Tim doesn't use many words to communicate. He is supported each week to go swimming. However, each week they were unsuccessful, and the support session usually ended with one of the Support Workers telephoning Tim's home to explain that they were having difficulties and that Tim would be returning home.

One of the home team who knew Tim well was asked to go along to observe what was happening to be able to help interpret Tim's communication. As they drove away from the home Tim was obviously happy to be venturing out. He was expressing this by clapping and cheering and saying 'car'. This cheerful communication continued until they got to the road that led to the swimming pool. Tim very quickly became upset. His distress continued to escalate rapidly but the Support Workers stuck at it. When they got to the pool, one of the staff got out of the car to get Tim's wheelchair whilst the other member of staff attempted to remove his seatbelt. Tim was clearly very distressed, and the Support Worker said they should return home.

The person who knew him well asked the Support Workers if they had considered that he did not want to go swimming - that maybe he didn't need to return home but try something different. She asked Tim if he would like to go for a drive as he had been so clearly enjoying the journey. Tim almost instantly stopped shouting and repositioned himself in the car to ready himself to continue the drive. As they drove away Tim shouted hooray! The Support Worker turned to Tim 'Oh you didn't want to go swimming?! Why didn't you tell us you didn't want to go?!'

Under the '[Convention for Persons with Disabilities](#)' (a human rights treaty of the United Nations intended to protect the rights and dignity of persons with disabilities') this would be called facilitated decision-making because it involves interpreting a person's 'wills and preferences' where it is unclear.

Think, discuss, act:

Questions for people with a learning disability:

1. What do you think would help them to understand Tim better and make sure that all of his support workers don't make mistakes like this again?

Questions for supporters:

1. What was the turning point in understanding what Tim was communicating?
2. If Tim has a long history of loving swimming, what has changed? Was it the new staff he didn't like, a new sound at the pool? Should another pool be tried?
3. Tim's mum is worried about the change. How can you reassure her that you have explored why the change has happened?
4. What other function might swimming have had in Tim's life? E.g. physio.
5. If Tim is clear that he doesn't want to swim at the moment, what other options could there be if he needs to stretch his limbs in a supported way?



Click [here](#) to see a narrated photo story of this.



Are YOU the right person?

Relationships are what matters in life. When they are right, everything else is more likely to be right. Everything the support person does is communication and we need to be tuned in with that and learn the individual's language to be in a good relationship.

[Gettalife](#), an organisation supporting people with complex learning disabilities in Coventry



The UN Human Rights Treaty 'Convention for Rights of Persons with Disabilities' emphasises that the person should be in the driving seat in choosing who supports them and how. For people who can express a choice, it can be helpful to draw up a '[Supported Decision-Making Agreement](#)' where the person can express who they want to support them in making particular decisions and things that are important to them in how they are supported. For example, if the person wants to be reminded of particular goals, or it's important not to be spoken to in a particular way. Think of supporters as like a life coach: the person chooses the coach, chooses the goals and then the coach helps them get there.

Supported Decision-Making Agreement

My name is: _____
This is my form about: the decisions I want to make.

The person or persons supporting me need to be able to understand what I want to do.

I want to have people I choose to help me with:

The people who will be my Supporters:

My Supporters are not making decisions FOR me. I make the decisions.

I would like my Supporters to:

1. Get all the necessary information to help me make decisions.
2. Think through any choices so I can make a choice.
3. Record what my Supporters think.
4. Help (me) with my decision.

The people I want to support me are:

Name of Supporter: _____

Address: _____

Phone number: _____

Email address: _____

I want this Supporter to help me with making choices about:

- ☐ food, clothing, money and where I live.
- ☐ my physical, mental and emotional health.
- ☐ how I spend my time or leisure.
- ☐ choosing who and
- ☐ something else.

I do not want them to help me with: _____

easy read

For some people, who may not be able to express a choice as clearly or make a support agreement, the approach tends to emphasise 'relationships of trust' and the individual's ability to express like or dislike. There's a stress on the quality of the relationship and communication.

It is important to value the importance of long-term support relationships and that it can be very important not to treat decisions in isolation. Longer-term Supported Decision-Making may focus on supporting a person in identifying goals and achieving them through a series of decisions over the longer-term.

If you feel that a particular Supporter may actually get in the way of a balanced exploration, e.g. because the person wants to please the Supporter, it important to consider the impact this could have and how free a person feels in their decision.

The importance of discovering and getting to know who a person is

‘The starting point is not a test of capacity, but the presumption that **every human being is communicating all the time and that this communication will include preferences**. Preferences can be built up into expressions of choice and these into formal decisions. From this perspective, where someone lands on a continuum of capacity is not half as important as the amount and type of support they get to build preferences into choices.’

Beamer and Brookes in 2001 (p4)



We are in a better position to support people in decision-making, no matter how small or big these decisions are, if we understand and are curious about who people are and how they choose to live their life.

All too often people who receive paid support have their ‘needs assessed’ and little time is spent on truly discovering who people are, what they love and don’t love about life and their hopes for the future. This is particularly true for people who don’t use words to communicate.

[Jo Watson’s](#) work describes the importance of narrative storytelling between the person with profound disabilities and their supporters. She asks people to look beyond the constraints of the person’s disability to create a story of who they are and how they would want to live their life. This is based on the deep knowledge of those who know and love the person. Having such conversations with the person and those that know and love them is crucial to ensure that the person is truly heard. ‘If Nathan could eat, what would he eat?’. “If a person you support had complete control over their life, what music might they listen to, what car might they drive or what clothes might they wear?”

Person-centred approaches and [tools](#) can help us learn about people and keeps them in control (if used well). The tools can help us build a rich picture of who a person is and how they choose to live their life.



These tools can help support decisions because:

- they can highlight where supporters need to identify different options.
- they can help a person weighing up the pros and cons of options.
 - they might help the person to communicate the options.
- they could help link up lots of decisions to help achieve a person's goals.

If the person 'lacks capacity' then [these NICE considerations](#) must be taken into account by best interests decision-makers as they are part of the person's wishes, feelings, values and beliefs and 'the other factors that he would be likely to consider if he were able to do so.'

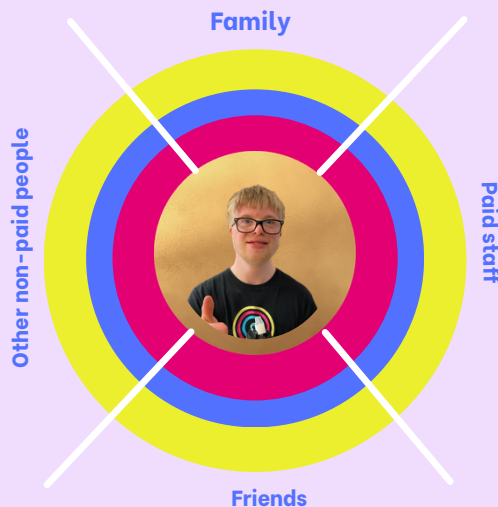
Discover WHO is important to a person

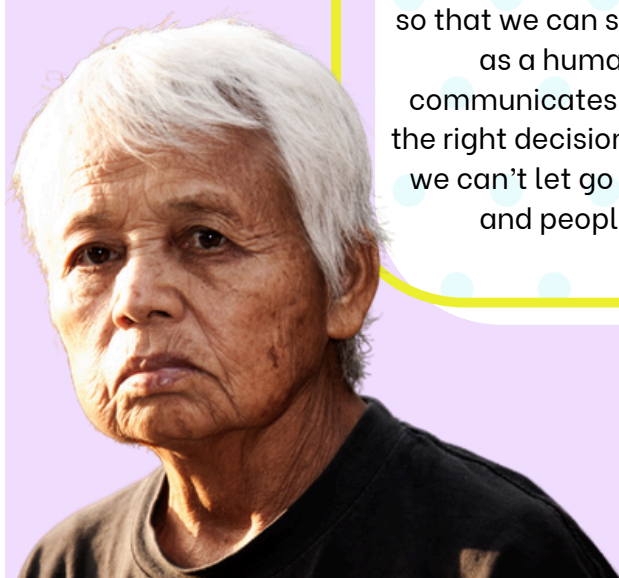
It is so important for the person to choose (where possible) who supports them – which usually comes down to people they like and trust. It may be a family member, a Support Worker, a friend, a neighbour or someone from their local community.

Very often, family members know the person in a way that most other people in the world do not. They have known the person longer than anyone else – from birth to now. They have been through the rollercoaster of life together with the person. They know the person's nuances and have experienced what works and what doesn't work. It may be hugely important to tap into their knowledge and experience and work together.

So often the individuals that are important to a person and individuals who know them well – whether these are family members or friends – can be sidelined by professionals and this valuable knowledge is then ignored or lost. Research, inquiries, court cases, ombudsman complaints, safeguarding reviews find this over and over again. For example, sometimes family members are excluded from capacity assessments. Where this happens, it's worth highlighting that [NICE guidelines](#) referenced above do emphasise asking the person who they want to support them.

It is also, of course, important to discover if there are individuals that a person does NOT want or does not want/trust to support them in making a decision. We can love someone yet still feel under pressure to make a certain decision. We can love someone yet want privacy.





‘We’ve had to fight our whole lives for what is right for our son. The system has let us and him down badly so many times. We are tired. Tired of being seen as the ‘bad guys’ or ‘the obstacle’. We aren’t. We want what is best for our son. We love him. He deserves to be supported well by others and we want to work with those people.

All we want is to be able to trust and work alongside people so that we can share our knowledge and experience of him as a human being and the subtleties of how he communicates. He has the right to be supported to make the right decisions and live the life he wants. As his parents, we can’t let go until we know the right support is in place and people value and respect him like we do.’

Family member

There may be times where family may not be the best people to be involved in a decision but it’s important to have open, safe, honest conversations about this.

It might be that the person has a Circle of Support, sometimes called a [Community Circle](#), that could support the person in making a decision.

A Circle of Support is a group of people that a person has chosen or seems to like and trust. They meet together on an ongoing basis to help a person they know plan and make decisions about their life. They may include family, friends, a neighbour, someone from a support organisation or a professional with a particular expertise. The person should be directing the circle and the support people give as far as possible.

A Circle of Support can be a very powerful way to give very holistic support and to make sure that the person gets the best support to make decisions in the right way, at the right time, by the right people.

A person's Circle are also important people to consult about a person's wishes, feelings, values and beliefs for any best interests decisions (a key requirement of The Mental Capacity Act).

Tom's Circle of Support





PAUSE for reflection

As a family, many years ago, we were looking to the future, thinking about my brother, Andrew, who has a learning disability. We wondered about the risk of him not having a friends and family around him in the future- about him only being with paid staff. We decided to take a 'positive risk', with him being in charge of this, with our support, **(Supported Decision-Making)** to invite together and build a circle of support. He carefully invited together a selected group of family, friends and previous support people. Nobody had a DBS check (CRB back then), so some people might say that is too risky!

Andrew's Circle flourished and besides helping him to develop and strengthen his relationships, it also put him more in charge of his life **(Supported Decision-Making)**. He developed his own Plan for the future and one opportunity that came up, was for him to go on an amazing trip to the Himalayan Mountains, trekking up to Everest base camp. We talked this over together, as there were obvious health risks involved. We helped Andrew to check these risks out **(Supported Decision-Making)** and the trip was planned, over a year in advance. He went and had an amazing time, but it was also very, very challenging. Some people dropped out and he also lost a lot of weight and had struggles. If you ask him, if he'd do it again he'd say 'No', but he would also say he achieved an amazing thing. He learned from his experience.

Some years later, Andrew had some difficult times with his health and ended up in Hospital with a nasty bout of pneumonia. Because of the Circle he had built up, Andrew's network of friends was now massive and there were people popping up all over the place saying - 'where is he, we are worried about him'. He now has eyes and ears out in the community who care for him and support him. Because Andrew was supported to take a 'positive risk' all those years ago, he is now safer than he has ever been, because he has that safety net of relationships. This does not replace staff and a monitoring regime, but some of us would suggest that it's a better way of enabling someone to be safe and to be liberated.



Click [here](#) to see a narrated photo story of this.





PAUSE for reflection

Justin was a very able man who had his own car, but he had become so anxious that he could not leave his house, which was causing a lot of stress for his family.

With help, he chose a few friendly faces to come together as his Circle of Support one evening. When he was talking about his future to them, he said his dream was to be a truck driver.

One of his friends said they knew someone who worked as a lorry driver. He contacted them and they said he had talked to his boss who was happy for Justin to have some work experience as a Truck Driver's Assistant.

He had to overcome a lot of anxiety to do this, but did it and this gave him the confidence to go for his HGV Theory and Practical test. He passed the Theory and is booked for his Practical – watch this space.

Another contact through his Circle of Support linked Justin up to an Annual Truckers Convoy. Justin took himself along, was invited into one of the trucks and joined the Convoy!

Think, discuss, act:

Questions for people with a learning disability:

1. Do you know what a Circle of Support is?
2. How was the Circle helpful to Justin?
3. Do you have a Circle of Support?
4. If yes, who could help you set one up?

Questions for supporters:

1. What was the most powerful aspect of Justin's Circle of Support coming together?
2. How did the people in the Circle support Justin to make decisions?
3. What do you need to record so that Justin can be better supported in the future?
4. If Justin had gone to his Social Worker, would he have got the same result?
5. What is the difference in the possibilities created here?
6. Do you know anyone who would benefit from a Circle of Support?
7. How could you help this happen?



Click [here](#) to see a narrated photo story of this.





PAUSE for reflection

Akuba was unhappy living with her paid carer. She didn't know what to do, but she thought she could have a go at having her own place. Her carer was against this idea and didn't think it could work.

Akuba met with her Circle of Support to ask for their advice. Akuba's Circle consisted of her mum, her friend Xavier, her old teacher and support worker (but not her sister Afia and she has a deep rivalry with Afia).

They offered to help Akuba with a **PATH planning** session to map out how this might work and what her options were.

After some exploring and a lot of intense chats and planning, 9 months later Akuba moved into her own flat!



Click [here](#) to see a narrated photo story of this.

Think, discuss, act:

Questions for people with a learning disability:

1. How did Akuba's Circle of Support help her to make a decision?
2. Do you have a Circle of Support? If not, who would be in yours and who could help you set it up?
3. Why do you think Akuba did not want her sister in her Circle of Support?
4. Is there anyone you would not want in your Circle of Support (and why)?

Questions for supporters:

1. What are the benefits of having a Circle of Support?
2. Do the people you support have Circles of Support in place?
3. How could you help make this happen?
4. How would you check someone's capacity for making a decision to move house?
5. Is it true that a person who needs support with some decisions can't have their own tenancy?
6. If Akuba didn't have the capacity to make a decision to move into her own place, what could you do?





'People should have natural support around them to help them make decisions.

In my mind, **it's not about power over.**'

Mark John-Williams, brother and Planning and Development Officer at Flintshire County Council

Are we really listening to what a person is communicating?

Communication, whether verbal or not, is an integral part of supporting people well and it is especially important when we support people in making decisions.

As Supporters we need to really listen to and notice what a person's whole communication is expressing. Is a person saying 'yes' to fit in or because they feel that giving the answer 'yes' is what is expected of them. We must be willing to explore the complexity of people's feelings around this. We must be willing and ready to engage with integrity. Sometimes working together with a Circle of Support can be a very powerful way to make sure we are noticing all we can in a person's communication and how we interpret it. We must also be careful to not unduly influence people we support. We need to keep checking ourselves – our interpretations, our communication and our roles. There is a lot of concern in The Mental Capacity Act law and in law cases about people exercising 'undue influence; over a person so that they cannot express their true wishes.

'This requires us to be in a relationship of integrity and authenticity with the person. One where we support from a place of truly caring for or loving the person. A relationship where we listen to explore, and respond to a person, await their responding communication and then listen, explore and respond again. It is a 2-way relationship that can only work well if we are truly invested in it.'

Dr [Jo Watson](#), Researcher in Learning Disabilities



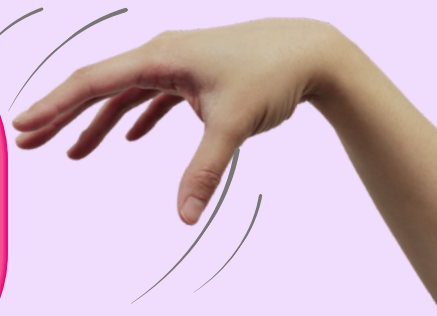
Sometimes, it isn't clear what a person is expressing, and we have to take the time to be brave, try something and see what happens (as in the stories on p63-65).

'Total Communication' is often used with people who are non-verbal. Total Communication is all about finding and using the right combination of communication methods for each person. Total Communication: helps a person to connect and interact with others well and creates the best environment/way for people to understand situations and meanings and make decisions.

It may be important to use **'Intensive Interaction'** in the way you communicate. Intensive Interaction is a practical way of interacting with people with learning disabilities who do not find it easy communicating or being social.

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."

Kim Williams, Principal Speech and Language Therapist





PAUSE for reflection

Mark was really struggling to make a decision about a holiday. He had the money but his mum didn't know how to help him make the decision.

As a friend of the family, I sat with Mark and his mum and helped them look at YouTube, photos and brochures on the internet. He was not interested in planes, boats or beaches but got visibly very excited when he saw clips of railways and trains.

This led to a conversation about a possible holiday on the Orient Express! Plans for this are underway!

Think, discuss, act:

Questions for people with a learning disability:

1. What helped Mark when thinking about where to go on holiday?
2. What helps you when you need to make an important decision?

Questions for supporters:

1. What creative ways have you used to help people make decisions?
2. Is there anyone you support who might benefit from a more creative way of supporting in their decision-making?



Click [here](#) to see a narrated photo story of this.





PAUSE for reflection

Imad has a moderate learning disability with complex autism. He can find it very hard to process what he sees, hears, and senses. He communicates mostly by expressing his needs through pointing and things like eye movements. If Imad is experiencing high anxiety and stress, it can impact on his ability to process information and communicate his needs. Sometimes he just needs time and simple definitive options.

Imad needed a haircut. His usual hairdresser was very busy and noisy, so his team felt it wasn't the best place to go. They drove him to a different hairdresser and sat outside in the car. They asked if he would like to get his haircut, and showed him where he would be going. He signed yes and got out of the car. But when he got to the door of the new hairdresser's, he got 'stuck'. He couldn't pass through the doorway and started to get anxious and agitated, banging the doors and windows. So he was asked if he would like to go back to the car, and he signed yes, which he did. Rather than simply drive off and leave, his team waited with him in the car for a while. When he was settled again, they asked him again if he would like to have his haircut or go home. Imad chose the haircut, and the second attempt went very well.

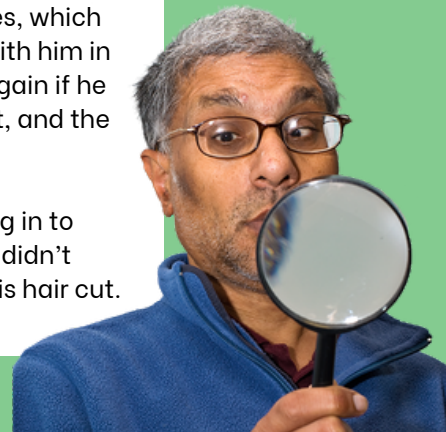
Imad had been given time to process the fact that he was walking in to somewhere different and was able to prepare himself. The team didn't assume the agitation and banging meant he no longer wanted his hair cut.

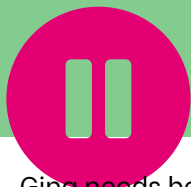
Think, discuss, act:

1. What enabled Imad to have his haircut?
2. How could the situation have been different?
3. What would supporters need to know about Imad to support him well?
4. What would you do if you weren't sure what someone's behaviour meant?
5. Would it be helpful for new supporters if the Communication Chart like on p67 was completed and shared?
6. Do you know anyone who would find the Communication Chart helpful?



Click [here](#) to see a narrated photo story of this.





PAUSE for reflection

Gina needs help with all aspects of her life, including feeding herself. (She used to be able to feed herself but can no longer do this.) Gina is totally dependent on her Support Workers. Gina's mum, Semina, has observed that Gina becomes apprehensive in unfamiliar circumstances, especially with people who she doesn't know. This can be a problem with agency and newer members of staff.

A few years ago, a new member of staff reported that Gina had not eaten breakfast or lunch. This was assumed to be Gina's choice and therefore the meal was removed.

Gina's Key Worker, Cheryl, spoke with Gina's mum, Semina, and they decided that Cheryl would offer the food to Gina herself and see what happens. Gina happily ate it all. Cheryl and Gina's mum then decided that Cheryl should observe Gina with staff she didn't know. Gina didn't eat her food. It seemed that this wasn't about not wanting the food, it was about Gina being anxious around people she didn't know.

It was agreed that wherever possible, Gina should be supported to eat her meals by people she is familiar with until she gains confidence in the new staff.

Think, discuss, act:

Questions for people with a learning disability:

1. Is it easy to explain why you don't want to do some things?
2. Who knows you well enough to support you when you make decisions?
3. Would you choose different people to explain different things to you?

Questions for supporters:

1. What would you have done if this hadn't worked?
2. Have you ever thought you were offering choices but you did so badly or in the wrong way?
3. How did an open, supportive culture in the provider service, help this situation?
4. Who would you have turned to for support?
5. What person-centred and supported decision making tools would help Gina communicate 'I don't like this food' and 'I want someone I know'?



Click [here](#) to see a narrated photo story of this.



Making sure that everyone has a shared understanding of a person's communication

All those around a person need to have a shared understanding of their communication. If we don't clearly record and share the person's communication with those involved in the person's life, there could be a very negative impact on the quality of the person's life. Have a look at this story below. Look at how the important ways of communication were captured in the table on the following page.



PAUSE for reflection

Ted does not use words to communicate his wishes. Ted had begun to show anxiety and distress. His family and friends were getting worried and felt they were not understanding Ted. They began to explore why. It became clear that each person was interpreting and responding differently to Ted. This could mean that Ted was communicating with sixteen different support people in one week and they could all be interpreting his communication in different ways! Ted's communication was losing its meaning. Everyone agreed to share and record their understanding of Ted's communication in a communication chart that they all then used. This made things much better for Ted who was better understood and much happier!

Think, discuss, act:

Questions for people with a learning disability:

1. How do you think Ted felt when people weren't understanding him?
2. Do you feel like people listen to you carefully?

Questions for supporters:

1. How can you make sure that a person's communication is not lost?
2. Do people you support have or need communication passports/records?
3. If yes, how often have you read it?
4. How much training would you need to reach the same level as the person you support?
5. How can you highlight the importance of this in your team?
6. What other person-centred tools could be helpful?



Click [here](#) to see a narrated photo story of this.

Ted's Communication Chart

You can get a blank template [here](#)

At this time / In this situation	He does this/makes these sounds	We think it means	You should do this
Anytime	Grabs at your arm or clothing and is smiling.	He wants a hug or is initiating some fun	Acknowledge Ted. Let him put his arm round you. Offer fun activity.
Anytime	Shouts in high voice. Might tug his hair.	Ted is upset or anxious	Stop what Ted is doing. Hold his hand, explain what's happening.

At this time / In this situation	When you want Ted to know or do this	You should say or do this
At the weekend	When you want Ted to know his mum is coming.	Show Ted mum's photo and say that mum is coming.
On a Friday night.	His friend Kellie is coming to pick him up to go to the pub.	Show Ted the picture of Kellie and the pub and say Kellie is coming.

Exploring unwise decisions

The key message, in law, is: A person should not be stopped from making a decision merely because OTHERS think it is unwise. But if a decision seems unwise or very risky, it's important to check out what is going on for the person. Does the person understand the risks and options? Perhaps they need some support to think through the different options. Or perhaps they need some help finding better options. Often people might be choosing an 'unwise' decision because the options available to them aren't great or they aren't being well supported.

The Mental Capacity Act says if a person can understand and use and weigh the decisions, they have the capacity to make even risky decisions, **BUT** it is important they are well supported to make the decision.

We all take risks, and sometimes they work, sometimes they don't or ... sometimes they have an outcome we don't expect. It's what helps us learn and grow as human beings. The important thing is that people are supported to make their own decision as far as is possible.

Very often people with a learning disability are 'allowed' to make decisions as long as they have made the 'right' decisions. If they don't make the 'right' decision, too often they are deemed to lack capacity to make the decision. The law says that if you have capacity, you can make a decision, and a person doesn't lack capacity merely because someone else thinks their decision is unwise.

The [LEDER reports](#)  (on premature deaths of people with learning disabilities) have highlighted concern in how staff are interpreting and following The Mental Capacity Act which has put people's lives in danger. 'Unwise decisions' is a commonly misunderstood part of The Mental Capacity Act.

WATCH OUT

You need to get this right!

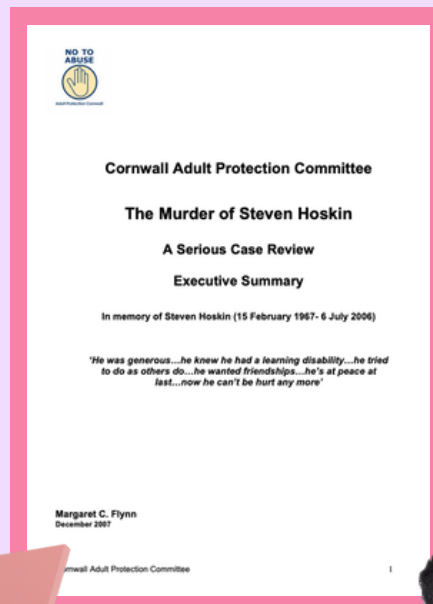
This can be seen in [Margaret Flynn's Safeguarding Adults Review](#) about the deaths of three adults at Cawston Park Hospital).

A flippant and ungrounded 'he lacks capacity' should never be used as a rationale for preventing the person from carrying out their decision. The 2-Stage Test of Capacity on p23 protects people against this happening if followed correctly.

Another example is the murder of Steven Hoskin. Steven was 'befriended' by a gang, who moved into his flat and used it as a base for drug dealing and worse. He thought they were his friends. With their encouragement, he cancelled his support visits and the council stopped them without any further checks about what was going on. The gang tortured Steven and murdered him.

[The Safeguarding Adults Review](#) argued that the Council should have properly checked out Steven's decision to refuse support.

There is an example on the next couple of pages that touches on capacity and how Supporters can work through and assess a person's decision-making...





PAUSE for reflection

Reg lives with 3 people. People describe him as a 'big drinker' as he'll drink 3 or 4 cans of lager every night. When Reg gets drunk, he'll walk into people's bedrooms behaving in an abusive way.

Often, after one of his 'heavy' nights, Reg struggles to get up in time for work and this means he's taken sick leave again. Reg's support staff don't think he should drink as much as he does. They have recently explored his capacity to understand the decisions he is making.

Look at the next page to see how Reg's Supporters thought through his capacity...

You can find a blank version of the form [here](#).



Click [here](#) to see a narrated photo story of this.

Exploring capacity	Reg's example
What's the decision about?	Reg carrying on drinking 4 cans of lager every night.
Who was involved and why?	Reg - its his capacity being checked! Xav (friend and flat mate for many years) - knows Reg well, how he communicates and can convey things from his point of view re options Agnes (me) (favourite Support Worker).
When and where did you meet and why?	Saturday afternoon 15.01.22 - Reg chose this time so he could sleep in and have adjusted to a hang over. Reg chose to talk in his room for privacy but also because he feels comfortable there.
What information was needed to help the person?	• Easy Read Tenancy Agreement Reg signed on flat responsibilities re other tenants, paying bills on time, eviction. • Job details/consequences if he carries on taking 'sick' days. • Video on what drinking this amount of alcohol does to your body over time. • Xav, having prepared before what he wants to say about the impact on him and the other flat-mates.
How did you present the different options in a way to help the person understand, including reasonably foreseeable consequences of the different options?	We used flip chart papers- one for each option - carrying on drinking 4 lagers an evening; the other not to....exploring what could be another option (reduced amount). See flip chart photos stapled to this - this should be all in Reg's file and Reg has a copy). As you can see, used mixture of drawings, words to capture flow of conversations and questions. We all added to it - so all engaged. (Used videos etc as detailed above- captured response to this.) You'll see it captures exploration of possible consequences.

Use extra paper or attach, photos etc to help record a person's capacity on this decision. Remember that you are looking at their capacity just on this decision.

How did the person use and weigh up the information to make a decision?

The photos of the flip chart papers clearly capture that Reg could weigh up the information and understand the consequences eg. hearing from Xav about him falling asleep across the sofa and snoring loudly all evening 'takes over the space'. Reg understood that and was embarrassed to hear that. Reg wants to carry on drinking and together they have agreed that Reg would sit in the armchair in the evenings (so he didn't take up the whole space) and that his flatmates could nudge him to go to his room if he was snoring loudly... so they could use the space. He agreed to not be grumpy when he wakes. See photo that captures all Reg's weighing up on info on flip chart paper eg eviction if things escalate badly or losing his job. Reg looking for a job that starts later.

Could the person retain the information in order to make the decision?

Yes very clearly as captured on photos of flip chart papers.

How did the person communicate their decision ?

Clearly verbally - Reg said he wanted to carry on drinking for the moment as it relaxes him and stops him worrying about work. (We talked about him feeling unhappy at work and how this might be impacting on Reg. We are going to talk through the work stuff in more detail and how these unhappy feelings and worries can be addressed.... and ways that can help Reg relax.)

Do you need to meet at another time to explore anything further ?

I am hoping that Reg will, with other support and ways of dealing with the work issue, reduce his alcohol intake. He said the video did scare him a bit. BUT if Reg's drinking increases, and agreements aren't kept to, or Reg's health declines, it may be good to revisit this to check his alcohol intake is not affecting his capacity and to check that he understands the impact of any change on his body, flat mates, work, homelife etc.

What is the outcome of the capacity test?

Reg clearly has capacity to make this decision to carry on drinking 4 lagers a night.

Signed by:
Date/time and role:

Agnes Amecchi
2pm 29 July 2022. Support Worker at Paradigm Lives

Use extra paper or attach, photos etc to help record a person's capacity on this decision. Remember that you are looking at their capacity just on this decision.



PAUSE for reflection

There is a case about a man with learning disabilities and his capacity to make decisions around sex. The Supreme Court found that he did not understand that the other people needed to consent to sex and that they could withdraw their consent during sex. The Supreme Court held that if a person lacks capacity, others can intervene to prevent sex in their 'best interest' [Re JB \[2021\] UKSC 52](#)).



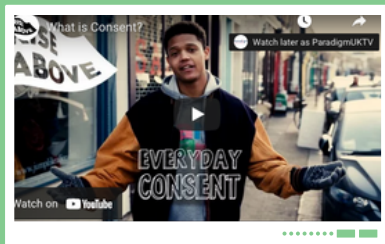
Think, discuss, act:

Questions for people with a learning disability:

1. What does the word 'consent' mean to you?
2. Why is it important in sex?

Questions for supporters:

1. How could you support people to understand about the importance of consent in sex?
2. How could you help someone understand the risks?
3. What would help set the scene and create an open and safe environment within which to learn about this?
4. Where can you find resources to help you with such important conversations?



You can find some videos on consent [here](#) and some other resources [here](#) on The Supported Loving website.



Click [here](#) to see a narrated photo story of this.



PAUSE for reflection

Chi Chi, a black woman with a learning disability, often struggles with her ethnicity not being represented and supported more in different situations.

In May 2020, she was acutely aware of the rising voices of people against the George Floyd murder in America. Protests were happening all around the world. The pandemic was in place and there were lots of restrictions on the public and what they could do.

Chi Chi was keen to go on one of the London protests about what had happened and speak out against racism. A friend spoke to Chi Chi about the risks of going – like not following the Covid guidelines and being so close to people who may have coronavirus.

Chi Chi understood this and chose to go on the march anyway. She said she would wear a mask and stay as safe as possible. She came back buzzing from having made her stand and being part of a bigger voice against racism. Luckily Chi Chi was safe and did not catch coronavirus. This may not have been the case, but she was prepared to take that risk.

Think, discuss, act:

Questions for people with a learning disability:

1. What would you have done in this situation?
2. Have you had times where your Support Workers haven't agreed with what you have done? Why was this?

Questions for supporters:

1. What would you have done in this situation?
2. Would you have wanted to seek guidance from anyone else?
3. Who would this have been?
4. Chi Chi's dad was upset that she had been allowed to do this. How could you have proven that she had capacity to make that decision?
5. How would you explain the Mental Capacity Act to Chi Chi's dad?



Click [here](#) to see a narrated photo story of this.



Thinking about your own life, what decisions have YOU made that others may have thought to be unwise?

Why did you do this?

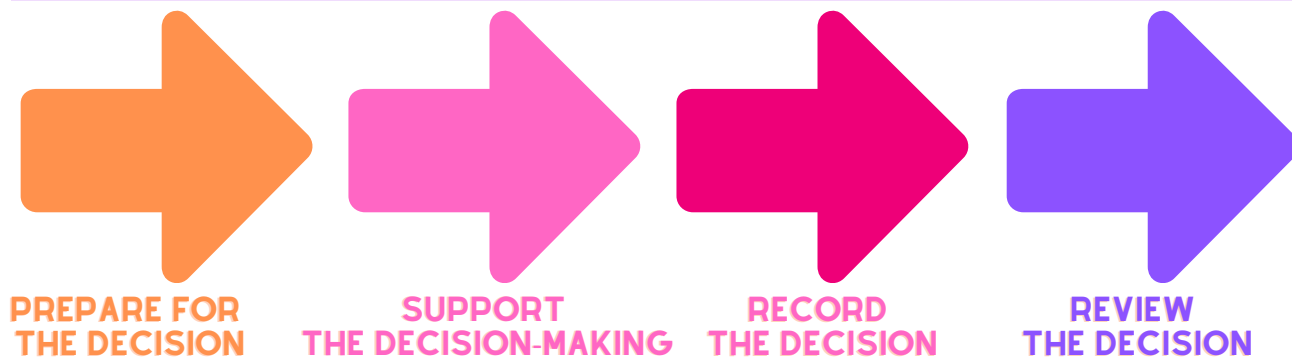
What did you gain from it?

Would you make the same decision again?

Recording the decision-making process

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. Obviously not all these decisions need to be recorded (e.g. what a person wore in the morning) BUT for more important decisions it can be helpful and important.

Recording the decision-making process helps to make sure that there is clarity in who is involved and how. It makes sure that a person is offered the right support and that they have as much control as possible. There's guidance on this in the [new draft code from p106](#) onwards. Best Interests Decisions should be checked and reviewed as appropriate, as a person's capacity can fluctuate (e.g. due to timings of medicines).



The forms on the next 2 pages may be helpful for recording the decision-making process.

A useful tool to help you record a person's capacity:

Recording capacity		Person's name:	Paradigm
The capacity decision about is:			
Who was involved and why?			
When and where did you meet and why?			
What information was needed to help the person?			
How did you present the different options in a way to help the person understand, including reasonably foreseeable consequences of the different options?			

Use this form to record a person's capacity to help record a person's capacity on this decision. Remember that you are looking at their capacity just on this decision.

How did the person use and weigh up the information to make a decision?	
Could the person retain the information in order to make the decision?	
How did the person communicate their decision?	
Do you need to meet at another time to explore anything further?	
What is the outcome of the capacity test?	
Signed by:	
Date and role:	



You can find a blank version of this form [here](#).

You can also use questions from this '[Recording the process of My Decision-Making](#)' form or this '[Recording a Best Interests Decision](#)' form to help guide your conversation.

Make sure you ask about the person's feelings about different options and what they value about them and what is important to them. These questions are often missed out!



You can download [this form](#) to record a person's decision-making process.

Recording the process of MY decision-making

What my decision is about:

Why is this decision important?

Who is helping me and why:

Where we are meeting:

Why we are meeting here:

When we are meeting:

Why it is at this time/day/date:

Recording the process of MY decision-making

What is the process for making my decision

This section was written by:

Signed by:

Supporter Name: Signed: Date:

My name: Signed: Date:

Supporter Name: Signed: Date:

Supporter Name: Signed: Date:

Supporter Name: Signed: Date:

Option 1 for MY decision on:

What's good about this?

What's NOT good about this?

How will affect my life?

What are the risks?

What do I think about this at the moment?

What are my feelings about this?

What are my values/beliefs on this?

Closing thoughts on the decision?

If you need more space, you could write on the back of this sheet.

Recording the process of MY decision-making

What I have decided:

What do I/we need to do to make this happen?

What needs to happen?

Who needs to help (if anyone)?

1

2

3

4

If you need more space, you could write on the back of this sheet.

Who should know about my decision?

Should this decision affect the future? If yes, why?

easy read

Please make sure that you photograph the form and give me a copy and add it to my file.

There's an important case, [CC v KK](#), where the council only assessed a person's capacity to choose to live in a care home, but did not explain properly what support would be available if she went home, meaning she could not properly evaluate each option as they were only really considering one option (the care home). So detailed consideration of each option separately is sometimes useful.

Here is a **Best Interests Decision Agreement tool** you can use to help guide the conversation, help everyone feel engaged and keep the person at the heart of your conversations:



To capture this in more detail you can use the 'Recording a Best Interests Agreement' form [here](#) which you can see on the next page.



You can download [this form](#) to record a Best Interest Decision:

Paradigm
Recording a Best Interest Decision with/for:

Option 1 for the

What is the process for making this decision?

This section was written by:

Signed by:

Supporter Name: _____
Signed: _____
Date: _____

Person's Name: _____
Signed: _____
Date: _____

Supporter Name: _____
Signed: _____
Date: _____

What are the person's values/beliefs on this?

What's **good** about this?

What's **NOT good** about this?

How will affect the person's life?

What are the risks?

What are people's feelings about this including the person if possible?

Describe any dissent.

Closing thoughts on the decision?

If you need more space, you could write on the back of this sheet.

What I (*name*) have decided:

What do I/we need to do to make this happen?

What needs to happen?	Who needs to help (if anyone)?
1	
2	
3	
4	

If you need more space, you could write on the back of this sheet.

Who should know about this final decision?

Should this decision be thought about again in the future? If yes, when and why?

Please make sure that you photograph or scan my completed form and give me a copy and add it to my files.

easy read

Sharing the information with the right people

Once you have supported someone in their decision-making, it is important to think about who may need be informed about this. Are there team members who need to know so that they can support the person well? Are there family members, neighbours or friends that need to know so that the decision is implemented effectively? What do they need to do?

There is no point in doing all the preparatory explorations, planning and careful supporting of the person making the decision, if the right people are not aware of the person's decision. Potentially, if you do not share the decision with the right people at the right time, the outcome of the decision may not work or may have a detrimental effect.



Recording who may need to know about the decision and what their role is may be helpful - see p76 to p80.



PAUSE for reflection

Bhavna is a new supporter joining a small, motivated team of people supporting Nigel, a disabled man with profound disabilities. Nigel communicates mostly through humming sounds, facial expressions, gestures and body language, so it was really important when Bhavna joined that she quickly got a sense of his communications and who he is.

Part of this was done by shadowing another team member but what also helped was a document that captured a brief summary of the types of daily decisions Nigel would be involved in making and how he should be involved in making these decisions. It included things like:

1. The decision to be made (e.g. on food shopping, what Nigel does during the day, the music he wants to listen to)
2. How Nigel should be supported to make his decision e.g. are certain resources needed or should Nigel be in a certain place to make the decision?
3. Should particular people be involved?
4. How often should this be reviewed?
5. Who should this information be shared with?

Think, discuss, act:

Questions for people with a learning disability:

1. What would you want a new supporter to know about you and how you communicate?
2. How could they learn that really quickly?

Questions for supporters:

1. If you support people with profound disabilities, how do you make sure that you (or your team) are updated with the most up-to-date information that is part of helping people make decisions?
2. Is there anything that could keep people more at the heart of the decisions you are supporting them to make?
3. What can you say to people who insist someone 'does not have capacity' when you think they do?



Click [here](#) to see a narrated photo story of this.



Closing words.



Wow! That's been a lot of information! But ...

... Information is power.

Information empowers.

**Information is powerless
if not applied.**

Saji Ijiyemi (Coach, blogger & author)



Each and every one of us should be the driver of our own lives as much as possible. We must use The Mental Capacity Act to uphold people's rights to make decisions whether this is through smaller everyday decisions (like what to do, or what food to eat) or bigger decisions such as where to live and who to live with.

Some people with a learning disability can be supported to make decisions more easily and quickly, and others, for example people with more profound disabilities, may require much more in-depth support that perhaps needing detailed preparation, creativity, thoughtfulness, facilitation and navigation.

Supporting people to be able to make their decision isn't always easy to do. Things aren't always clear. It can take time; it can take creativity and preparation; it can take careful mediation; it may involve taking risks and also making mistakes; and it may involve some difficult conversations.

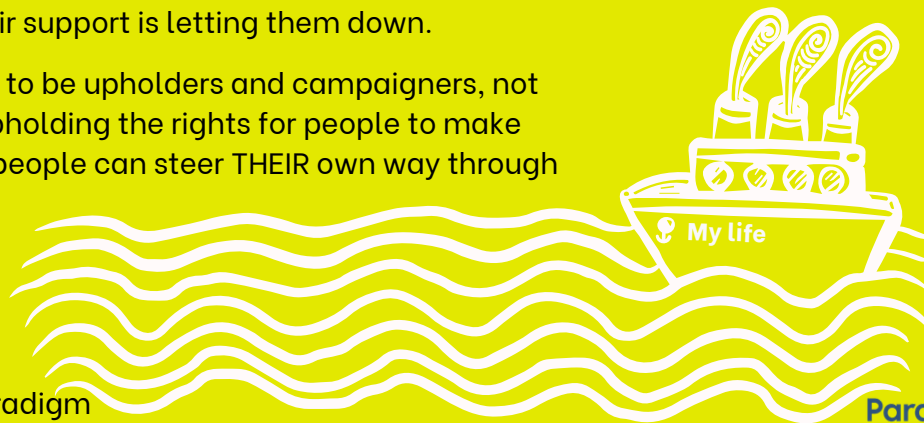
The list of qualities you may need to support people well so that they can make their own decision can be long. You may have to be a critical friend, a navigator, a mediator, assertive, a risk taker, a questioner, a challenger, tenacious, a person who can sit with discomfort and sometimes a person who is hugely brave. **Very often we can't do it alone, we have to work together with others.**



If we don't support people with integrity and according to the support that they legally have a right to, we become part of an institutionalised system that groups people together – one that tells people in group homes that they all need to get changed into their pyjamas at 9pm as the night shift Support Workers are coming in at 10pm. Then we aren't treating people with a learning disability as equal citizens as described in [this video 'Declaration of Independence'](#) by the Standards of Wrexham Services group and TAPE . We become part of a system that erodes away people's rights and allows people's person-hoods to fade away into a distant mist. We become part of a system that pretends and dishonours.

No matter what somebody's learning disability is, each person CAN be part of making decisions about their lives, steering their lives and having their preferences acted and built upon. If the support around them is not given in the right way, by the right people, at the right time, their support is letting them down.

Together we need to be upholders and campaigners, not gatekeepers, in upholding the rights for people to make decisions so that people can steer THEIR own way through the sea of life as much as possible.



Sally and Jo at Paradigm

Paradigm
Pushing boundaries

'It is important for people with a learning disability to be supported to make their **own decisions**. For me, it's about having control of my life. They are **my** choices to make and it's **my right!**'

Michelle McDermott, Self-advocate, Co-Chair for Thera Trust and Paradigm Reach Co-Trainer



To find out more
about Paradigm, see
www.paradigm-uk.org

Paradigm
Pushing boundaries



(Kept for printing reference for now)

A5 Wiro Bound Short Edge Bind 210mm x 148.5mm

**Remember to delete or hide
this layer.**

T: 01702 460047



Bleed Area

Anything here will be trimmed off, but remember to extend any colouring or images into this 3mm bleed area to avoid white lines appearing during the print finishing stages.

Trim

Your job will be cut on the solid black line, any images or text placed in this 3mm area may be trimmed off incorrectly.

Safe Area

Keep all your information inside the white area. Remember to use high resolution images (300dpi) for the best results.

Wiro Binding Area

Anything here might be cut off when the holes are punched for the wiro binding, but remember to extend any colouring and/or images past this area and into the bleed to avoid a large blank area.