

NOTHING ABOUT YOU / WITHOUT YOU

A guide to the Assisted Decision Making (Capacity) Act 2015



New legislation signed by President Higgins on 30th December 2015

Repeal of Lunacy Regulation (Ireland) Act 1871

The Assisted Decision Making (Capacity) Act 2015 will strengthen the rights of all individuals but it will have particular relevance for people with intellectual disabilities, older people with diminished capacity or dementia and people whose capacity has been affected by traumatic injury. It will also ensure that people with capacity can register in advance their wish not to receive treatment which they perceive as futile in the event that they lose capacity to make decisions. Central to the legislation is the establishment of a Decision Support Service and the introduction of new roles: Decision-Making Assistant; Co-Decision-Maker; Decision-Making Representative. The legislation will be

'commenced' by the end of 2016 and this has been confirmed by the Minister for Justice in response to parliamentary questions. The system of Wards of Court will be phased out over a three year period.

Presumption of Capacity

Throughout our lives we seek advice from others about various matters before we make a decision for ourselves. But sometimes, perhaps due to illness, injury or a disability we may need a little more than just advice; we may also need support. There is international law, and now Irish law, which provides for the support we should be given. The Assisted Decision Making

(Capacity) Act respects the right of everyone to make choices for themselves and at all times to be treated with dignity and respect. The old 'status' approach to an individual's capacity to make decisions is replaced by a new 'functional' approach which has at its heart a simple question: "In relation to this specific issue, at this time, does this person have capacity"? It follows that question with another: "what level and type of support might be needed in order to assist this person make a decision"? The focus is now on the positive, on enhancing whatever level of capacity exists, even where it is considerably diminished, and there is a statutory presumption of capacity unless there is clear evidence to the contrary.

PRESUME CAPACITY

WHAT DOES SUPPORT MEAN

The Assisted Decision Making (Capacity) Act 2015 recognises that support may mean different things to different people, depending on their needs.

- Support may take the form of needing things explained in a clear easy to understand manner, a manner which is appropriate for the person.
- Support may alternatively mean that assistance is needed in gathering information to enable a person make an informed decision.
- Sometimes a person may need someone to make decisions with them.
- At other times, even when a person is not in a position to take part in the decision making process, decisions may nonetheless have to be made. The person's input is still valuable and must be respected as the law states that the decision made must be one which the person would have made for themselves, if able. A person's desires, preferences, beliefs and values must be known and used when making decisions on their behalf.



Who's on her side?
When she is under pressure to make a decision

A STEP BY STEP GUIDE

STEP 1

STEP 2

STEP 3

STEP 4

STEP 1

Unsure about ability

If you are not quite sure about a person's ability to make a decision for themselves, follow the approach below to support both of you in the decision making process.

Before you begin make sure the person making the decision is aware that:

- It is their right to make the decision
- It is your duty to ensure they exercise that right
- You are concerned that they may be finding that difficult
- It is your role to support them in whatever way they need to ensure that they are helped to make the decision for themselves.

• Offer the person options in the context of choices available.

Example:

- “Do you realise that there are various different options available to you about X?”
 “Have all of the various options (such as A/B/C) and the information you need about them been given to you?”
 “Do you understand all of the options?”
 “Would you like me to go through them with you again OR what would make them easier for you to understand them eg writing it down/drawing it out?”
 “Do you need any further information in relation to any option?”
 “Would you like to appoint someone else to assist you in getting that information for you?”

• Establish if the person has a reasonable understanding of possible foreseeable consequences.

Example:

- “Do you have particular fears or concerns about option A/B/C (go through each individually)?”

• Ensure the person has voluntary choice and the ability to weigh up the information/ options/

Example:

- “What is of most importance to YOU right now?”
 “What do you wish to do to achieve that?”

• Consider, with the person, if this is the right time for them to make this decision.

Example:

- “Are you happy to make this particular decision now or perhaps later when you feel more up to

it/feel better/ have thought more about it/ have discussed it with your family?”

“Is there any part of this decision that you fully understand and feel able to make now?”

• Consider and offer other assistance that may support the person to make decisions.

Example:

“Would you like someone to assist you? For example a decision making assistant or a co-decision maker” (see more on this below)

• Clarify, with the person, if there is anyone influencing their decision.

Example:

“Who thought of that solution?”
 “What were the other possible solutions you considered?”
 “How did you decide which was the right solution for you at this particular time?”
 “What do you “feel” deep down now about that particular solution now that I have repeated it back to you?”

ALERT

Establish the persons understanding of the decision(s) and choice(s) being asked of them by using the **ALERT** Method

ASK

LISTEN

EXPLAIN

REALITY CHECK

TELL ME

Example:

ASK - “tell me what is your understanding about X (particular issue), and the decision you are being asked to make about it?”

LISTEN - (to the words, the feelings and watch the body language)

EXPLAIN - “would you like me to explain X again to you? (explain/inform/clarify)

REALITY CHECK – (paraphrase, summarise, reflect back to check understanding & information retention)

TELL ME “tell me what is your understanding now about X? (listen again)

Always remember:

- If a person can remember information for a short time only that is not an indication of their inability to make a decision.
- An apparently unwise decision made by a person is not to be regarded as a sign of their inability to make a decision.

If the decision in question cannot be made at this point move to Step 2

STEP 2

If a person has planned ahead

People have the right to plan ahead and appoint another person to make future decisions on their behalf for a time when they may not have the ability to make decisions for themselves.

If you are considering providing for your own future decision making you could put an **Advanced Healthcare Directive** and/or an **Enduring Power of Attorney** in place.

If you are supporting a person's decision making process about their healthcare matters,

you must first establish if the person has signed an **Advanced Healthcare Directive**. If they have, the content of that document may assist with the decision, or the document may appoint a **Designated Healthcare Representative** who has responsibility to make the decision.

If there is no **Advanced Healthcare Directive** in place and the person has signed an **Enduring Power of Attorney** the attorney appointed **may** have the authority to make the

decision in question, depending on whether or not the **Enduring Power of Attorney** has been registered (with a solicitor) and what kind of decisions the attorney is authorised to make.

If the decision in question cannot be made at this point move to Step 3



As you get older who will you trust to carry out your decisions?



STEP 3

If a person has not planned ahead

A person may not have considered or planned in advance who may make decisions on their behalf should they have difficulty or be unable to do so for themselves.

The Assisted Decision Making (Capacity) Act has created three separate decision support arrangements, depending on the level of decision making support a person requires. Each must be considered in turn.

FIRST ESTABLISH IF THERE IS A DECISION-MAKING REPRESENTATIVE APPOINTED.

If a person has a **Decision-Making Representative** who has been appointed by the Circuit court for the purpose of making this decision it is the responsibility and duty of the **Decision-Making Representative** to make the decision in question.

IF THERE IS NO DECISION-MAKING REPRESENTATIVE APPOINTED ESTABLISH IF THE PERSON HAS SIGNED A CO-DECISION-MAKING AGREEMENT.

A **Co-Decision-Making Agreement** is an agreement whereby a person has appointed

another person (who has full capacity) to make decisions jointly with them. If there is such an Agreement check it covers the decision in question and consult with the **Co-Decision Maker**.

IF THERE IS NO RELEVANT CO-DECISION MAKING AGREEMENT ESTABLISH IF THE PERSON HAS SIGNED A DECISION-MAKING ASSISTANCE AGREEMENT.

A **Decision-Making Assistance Agreement** is an agreement whereby a person has appointed another person (who has full capacity) to assist them with certain specified decisions. The **Decision Assistant** will obtain/explain relevant information, ascertain the

desires and preferences of the person about the decision to be made and assist the person to make, express and implement their decision. If there is such an Agreement in place, check it covers the decision in question and consult with the **Decision-Making Assistant**.

FINALLY AT THIS POINT CONSIDER IF THE PERSON COULD NOW SIGN EITHER A DECISION-MAKING ASSISTANCE AGREEMENT OR A CO-DECISION MAKING AGREEMENT.

If the decision in question cannot be made at this point move to Step 4

STEP 4

No capacity and no plans in place

If the decision to be made is significant in terms of the change it would make to the person's life (for example where the person is to live) but not extremely urgent then consider either an application to the Circuit Court for the appointment of a Decision Making Representative OR to the Decision Support Service for guidance.

If the decision is extremely urgent OR is not significant in terms of the change it would make to the person's life, (for example with whom the person should go on holiday) then make the decision in accordance with the following principles:

- **Take in to account:**
 - the person's own known past and present wishes and preferences so that the decision is as close as possible to the decision the person might have made for themselves
 - their beliefs and values
 - any other factors which they would have been likely to consider if able to do so
- **Consider the views of others as to who the person might wish to be consulted**
- **Act at all times in good faith and for their benefit only**
- **Consider all other circumstances which it would be reasonable to regard as relevant**
- **Consider the views of any carer/ person with a genuine interest in their welfare/ healthcare professionals**
- **Consider the likelihood of the person recovering the ability to make the decision for themselves against the urgency of the matter to be decided**
- **All decisions (interventions) taken should be decisions which:**
 - least restricts the person's rights and freedom
 - is most respectful of the person's dignity, bodily integrity, privacy, and continued right to have control over their financial affairs and property
 - is proportionate to the significance and urgency of the matter
 - shall be in place for as short a time as possible

Who would you trust?

- ... with your money
- ... with your life
- ... with where you live
- ... with whom you live
- ... with choosing who cares for you



KEY TERMS AND DEFINITIONS



Decision Making Capacity

A person's ability to understand, at the time a decision is to be made, the nature and consequences of the decision in the context of the available choices at that time. This ability is to be distinguished from cognitive ability which is a medical assessment.

Decision Support Service

Supervisory and regulatory body for all those supporting decision making.

Advanced Healthcare Directive

Planning ahead regarding decisions to be made about your healthcare at a time when you are unable to make them yourself.

Designated Healthcare Representative

A person appointed by another who has power to make healthcare decisions for the appointer.

Decision-Making Assistant Agreement

An agreement whereby one person appoints another person to assist them in making specified decisions. The person appointed is called a Decision-Making Assistant.

Co-Decision Making Agreement

An agreement whereby one person appoints another person to make specified decisions jointly with them. That person is called a Co-Decision Maker.

Decision-Making Representative

A person appointed by the Circuit Court to make one or more specific decisions for another person who lacks the ability to make that specific decision/s.

Enduring Power of Attorney

An agreement whereby one person appoints another person to make certain decisions for them at a future date when they may themselves lack the ability to make those decisions. The person appointed is called an attorney.

FEEDBACK

This is the second edition of 'New Times' – A Guide to the Assisted Decision Making (Capacity) Act 2015. The next edition will benefit greatly if we can have your feedback about this guide. How useful was it to you? What is still unclear? What would you like more information on? It will also carry news of developments in the implementation of the legislation and about emerging challenges and opportunities.

Please email your comments and suggestions to Mary Condell, Legal & Financial Coordinator with Sage mary.condell@sage.thirdageireland.ie

To organise a briefing on the legislation please email: bookings@sage.thirdageireland.ie

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