

Carers and the Assisted Decision-Making (Capacity) Act 2015

Frequently Asked Questions

What is the Assisted Decision-Making (Capacity) Act 2015 and how might it affect me as a family carer?

The Assisted Decision-Making (Capacity) Act (sometimes referred to as the 'Capacity Act' or 'ADM') was signed into law in December 2015, however it is not yet fully commenced. The Act recognises that, as far as possible, all people have the right to live a life of their choosing and to play an active role in decisions about their personal welfare, property, and affairs. It repeals the Lunacy Regulation (Ireland) Act 1871 which means that the Ward of Court system will be abolished. Once commenced, there will be no new Wards of Court, and existing Wards will all be reviewed within 3 years and moved out of Wardship with the appointment of a decision supporter, if required.

While the Act is rightly focused on people with diminished capacity or those whose capacity may be called into question in the future – aka the 'Relevant Person' – there are many other groups of people who are relevant to the Act and to ensuring its principles are respected. One of the most important groups are family carers - the family members and friends who care for a person due to their illness, frailty, disability, a mental health difficulty or addiction and who are the most likely person to bring the legislation to life by assuming the role of a decision supporter. If you care for an adult who has difficulty making decisions without support, or for someone who may experience difficulty in the future, then it is important that you understand the protections and provisions contained within the Act, and how they can support you and the person you care for.

What does the Act mean when it refers to the 'Relevant Person'?

The Relevant Person (RP) is the central person under the Act. An RP is the person who lacks capacity to make a particular decision or who may lack capacity in the future. Capacity is assessed relative to the decision that needs to be taken.

What does the Act mean when it refers to decision-supporters?

The term decision-supporter is not actually mentioned in the Act but we use it to refer to any person or persons who have been appointed as either a Decision-Making Assistant, a Co-Decision-Maker, or a Decision-Making Representative (appointed by the Circuit Court), Attorney under an Enduring Power of Attorney or a Designated Healthcare Representative under an Advance Healthcare Directive. Ideally, this person will most often be a family member or trusted friend. In cases where a person has no family member or friend to act as a Decision-Making Representative, then a person can be appointed by the court from an expert panel held by the Director of the Decision Support Service.

What are the Guiding Principles set out in the Act?

Section 8 of the Act contains the Guiding Principles of the legislation. These principles are based on human rights principles, they create a best practice guidance for all interactions with a person whose capacity is in question or may shortly be in question,

1. A person is presumed to have capacity unless it is shown otherwise using a functional approach to capacity.
2. A person should be given all possible support to make their own decision. This means that all relevant information about the decision is given to the person in a way that is appropriate to their own circumstances, considering the persons means of communication, the time and place that best suits the person, and using appropriate communication aids to assist the person.
3. A person is not considered unable to make a decision merely because they have made or are likely to make an unwise decision. If a person makes an unwise decision it does not mean that the person lacks capacity to make the decision.

4. No action/intervention should be taken unless it is necessary for the person based on their individual circumstances.
5. Any action/intervention taken for a person should be the least restrictive of their rights and freedom. Any action should respect the person's dignity, bodily integrity, privacy, autonomy, and right to control over their financial affairs and property.
6. A person should be permitted, encouraged, and facilitated to participate in any action/intervention taken for them. Any action/intervention taken for a person should follow the person's past and present will and preferences, and should take account of their beliefs and values, particularly those expressed in writing.
7. The views of people engaged in a caring role for the person, people with an interest in the welfare of the person or healthcare professionals may be considered when taking an action/intervention on behalf of a person.
8. If an intervention is proposed for a person who is considered to lack the capacity to make a decision about the matter themselves, consider if the person will recover capacity to make their own decision and consider if the intervention is urgent or if it can wait for the person to be able to make their own decision.
9. An Intervener should obtain relevant information only, use the information only for the purpose of making the action/intervention, keep the information secure and dispose of the information safely when no longer required.

What levels of decision support does the legislation provide for?

The Act sets out a three-tier framework of 'Decision Supporters'. The level of support the person you care for needs will depend on their individual decision-making capacity.

- (i) Decision-making Assistant (the relevant person still makes the decision),
- (ii) Co-Decision- Maker (joint decision making),
- (iii) Decision-Making Representative (an application made to the Circuit Court - person, most often a family member, is appointed by the Court to make decisions on the relevant person's behalf).

The Act also provides tools for planning ahead while you still have capacity. This can be done by way of making an Enduring Power of Attorney and/or an Advance Healthcare Directive.

What are the key responsibilities of a Decision-Making Representative and what sanctions, if any, exist for breaches of decision support and how are these determined?

The responsibilities of a DMR will be set out in an order by the circuit court (called a decision-making representation order). It could include decisions in relations to the RP's personal welfare or property and affairs or both. The DMR must act within the court order, also having regard to the Guiding Principles and Codes of Practice. The DSS will examine complaints where it is alleged that a DMR has acted, is acting, or is proposing to act outside the scope of his or her functions as specified in the court order. In addition, the DSS can examine complaints regarding the suitability of a DMR. If a complaint is considered well-founded, the DSS can refer the matter to court to have the DMR removed from the role.

How does a family carer register or apply to be a Decision-Supporter?

At the lower tiers of support, it is the relevant person who appoints their Decision-Making Assistant, or Co-Decision-Maker. Information will be available from the DSS (from the Information Service or on our website) for family carers who wish to assist the person they care for to register a decision support arrangement. There will also be information for people who wish to apply to court to be appointed as a Decision-Making Representative.

Are there any costs involved?

The cost of registering an arrangement with the DSS has not yet been decided, but information will be available on the DSS website or from the DSS Information Service. It is intended that costs should not be a barrier for anyone seeking to access supports under the Act.

How is capacity assessed?

The Act uses a functional approach to capacity, rather than the old '*all or nothing*' status approach previously used. The functional approach is not one based on any medical assessment, but rather focuses on *whether the person has the capacity to decide a particular thing at the time when they need to decide it*. Under the functional approach, a medical condition or diagnosis does not presuppose decision-making limitations, but rather only matters if it affects decision-making.

The functional test for capacity finds that a person will lack capacity to decide if he or she is unable:

- (a) to understand the information relevant to the decision;
- (b) to retain that information long enough to make a voluntary choice;
- (c) to use or weigh up that information as part of the process of making the decision; and
- (d) to communicate his or her decision by whatever means (whether by talking, writing, using sign language, assistive technology).

How long is a functional test of capacity valid for?

There is no requirement to have a functional capacity assessment before making a decision-making assistance agreement. However, it will be necessary to provide a capacity statement when registering a co-decision-making agreement. The Act requires a review of a person's functional capacity within 15 months of registration of the agreement and at intervals not exceeding 3 years after that. Where the court has made a declaration that a relevant person lacks capacity, an application for a review of the declaration may be made to the court at any time by the relevant person or others, with the consent of the court. In any event, the court must in every case review a declaration at intervals not more than 12 months, or not more than 3 years if it is satisfied that the relevant person is unlikely to recover his or her capacity.

What's the difference between an Enduring Power of Attorney (EPA) and a Decision Supporter on the new three-tier framework? If one is in place do I need the other?

An EPA is a tool for advance planning. It allows someone who has capacity (the donor) to plan ahead and to appoint a trusted person (the Attorney) to make decisions for them in the future. The EPA only comes into effect when a person (the donor) is no longer able to make decisions. The Attorney then acts as the donor's agent, having regard to his or her known will and preferences. Attorneys are obliged to follow the Guiding Principles and Codes of Practice relevant to them. It is a good idea to have an EPA in place as it could avoid the need for a court appointed DMR.

I already have an Enduring Power of Attorney in place; however it has not yet been registered. If I do register this EPA will it come under the new Capacity Act?

If you have made an EPA under the Power of Attorney Act 1996, this will remain valid and will only be registered if you lose capacity. Attorneys under the 1996 Act will be subject to the complaints and investigation function of the DSS on commencement of the 2015 Act.

What rights, if any, does a family carer have while awaiting the commencement of Part 3, 4 and 5 where a medical or other professional refuse to engage with them regarding the relevant person, but where the relevant person has diminished capacity?

There is no provision for a 'next of kin' to assume an automatic decision-making role or to supply or withhold consent on behalf of another adult. It is true that when a child turns 18, they are an adult in law with the presumption of capacity, and the parent may find they are excluded from information-sharing and decision-making. Equally, however, it should be open to the adult child to say that it is their preference to have their parent present and involved and that they consent to the sharing of information.

What is an Advanced Healthcare Directive?

If you are planning ahead, you can make an advance healthcare directive. This arrangement lets you write down your wishes about healthcare and medical treatment decisions in case you are unable to make these decisions at some time in the future. You can include requests for specific treatments, but these are not legally binding. However, by including them you can make sure they are considered during any related decision-making process. You can appoint someone you know and trust as your **designated healthcare representative** to ensure your advance healthcare directive is followed. They will act on your behalf regarding the decisions in your advance healthcare directive. A designated healthcare representative has the power to advise on and interpret your wishes. They can agree to, or refuse treatment on your behalf, based on your advance healthcare directive. Doctors and other healthcare professionals must consult your advance healthcare directive if you lose the ability to make a treatment decision. You can also appoint an alternate designated healthcare representative who can act should the designated healthcare representative be unable to do so.

How should I record and store my Advance Healthcare Directive?

An advance healthcare directive must be made in writing and signed by you, two witnesses, and by your designated healthcare representative, if you decide to have one. You can write down any treatments you wish to refuse and the circumstances in which this should apply. It is a good idea to give a copy of your Advance Healthcare Directive to your GP or treating hospital doctor, and to let your family know that you have made one.

Where can I obtain an Advanced Healthcare Directive form?

When the Act commences the DSS will have template AHDs on its website. Currently the IHF's "Think Ahead" form is useful for recording your future wishes in relation to medical treatment.

Will resources be made available to help Decision Supporters understand and fulfil their responsibilities? If so what type of supports and by whom will they be provided?

Yes, the DSS will provide information, videos, and how-to guides on its website to help decision supporters understand and fulfil their responsibilities. In addition, it will be possible to contact the DSS Information Service and obtain information over the phone.

I've heard reference to a 'vulnerability form' - what does this refer to and under what circumstances is it used?

At present, some banks and utilities have arrangements in place for 'vulnerable' account holders to ensure that it is in order for another adult to support them. If you need to, it may be useful to contact your bank or utility to find out more.

Where can I learn more about the Assisted Decision-Making (Capacity) Act 2015?

You can learn more about the Capacity Act 2015 by visiting the Decision Support Service at www.decisionsupportservice.ie or send a query to dss@mhcirl.ie

For carer specific queries please see www.familycarers.ie, telephone the free phone Careline at 1800 240724 or contact your nearest [FCI Carer Support Centre](#).