

Assisted Decision Making (Capacity) Act 2015 Practical Information for Adults with Prader Willi Syndrome and their families.

What is the Assisted Decision Making (Capacity) Act 2015?

The ADMA is a new law and system to support people to make decisions. Old laws and systems are replaced so that everyone has the right to make choices and are presumed to have capacity to make those choices. A new organisation called the Decision Support Service (DSS) has created an Easy Read Guide on the ADMA which explains the differences between the new and old law which can be accessed here: <https://inclusionireland.ie/wp-content/uploads/2023/09/DSS-Easy-Read-26-May-2023.pdf>

Do I have to have to use formal DSS supports?

The Act puts in place new supports but it does not mean you have to use them. It depends on the type of decision you want to make. If you ask your family members, friends, staff, or advocacy groups for informal support already and you are happy with those supports, there is no need to arrange for a formal support arrangement. This document from Family Carers Ireland includes practical information for family members: <https://familycarers.ie/media/3012/a-practical-guide-for-family-carers-on-the-assisted-decision-making-capacity-act-2015.pdf>

When do I use DSS supports?

If you want supports or your capacity is in question, you can access DSS supports. Just because you have an illness, condition or disability does not mean you need formal supports. Page 2 of this “My Choices” document has some questions you can ask yourself if you are not sure about getting supports: <https://decisionsupportservice.ie/sites/default/files/2023-04/10919%20MHC%20DSS%20My%20choices%20-%20screen.pdf>

What types of DSS supports are available?

More information can be found on the DSS website: <https://www.decisionsupportservice.ie/services/decision-support-arrangements>

There are three types of support arrangements for people who currently, or may shortly, face challenges when making certain decisions:

1. Decision-making assistance agreement*
2. Co-decision-making agreement*
3. Decision-making representation order

There are two types of arrangements for people who wish to plan for a time in the future when they might lose capacity:

4. Advance healthcare directive
5. Enduring power of attorney*

Note : you can apply for these on the MyDSS portal at: <https://portal.decisionsupportservice.ie/SignIn>

How do I apply for those supports?

The easiest way to apply for the following is via the myDSS online portal:

- Decision-making assistance agreement
- Co-decision-making agreement
- Enduring power of attorney

Here are videos showing how to register and use the myDSS online portal: <https://decisionsupportservice.ie/resources/mydss-how-videos>

What about the other two arrangements?

The court makes decision-making representation orders following decisions about capacity, more information on these orders can be found here: <https://decisionsupportservice.ie/sites/default/files/2023-04/10916%20MHC%20DSS%20Your%20Guide%20to%20a%20Decision-Making%20Representation%20Order%20-%20screen.pdf>

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. More information can be found here: <https://decisionsupportservice.ie/sites/default/files/2023-04/10922%20MHC%20DSS%20Your%20Guide%20to%20an%20Advance%20Healthcare%20Directive%20-%20screen.pdf>

Planning Ahead:

Safeguarding Ireland, supported by the HSE, and in partnership with organisations across the health, social, financial and justice sectors aims is to raise a greater understanding of adult abuse and safeguarding and the ‘go to’ actions all adults can take to Plan Ahead and reduce their risk of adult abuse. More information can be found here: <https://www.safeguardingireland.org/adult-safeguarding-day-2023/>

Important information about Consent:

The HSE National Policy sets out the rights of people that use health and social care services. All healthcare workers must follow the HSE National Consent Policy. More information can be found here: <https://www2.healthservice.hse.ie/organisation/national-pppgs/hse-national-consent-policy-easy-to-read-version/#:~:text=The%20HSE%20National%20Policy%20sets,the%20HSE%20National%20Consent%20Policy.&text=In%20this%20Policy%2C%20if%20you,a%20medical%20treatment%20or%20test.>

Information about “Next of Kin”:

There is a widespread but incorrect belief that an adult’s closest family member or next-of-kin is entitled to make decisions on their behalf if the adult lacks decision-making capacity. This is the belief that a relation, such as the spouse or partner, an adult child of a parent or the parent of an adult child who lacks capacity has legal authority to:

- access information about them;

- take decisions on their behalf in relation to their property and personal welfare;
- give or withhold consent for their medical treatment.

This is not true outside of a formal legal arrangement. More information can be found here: <https://decisionsupportservice.ie/news-events/myth-next-kin>

Are you worried about your safety?:

One of our most important rights is that you have a Right to Feel Safe. You should have a good quality of life where you feel safe. You should feel safe wherever you are; (in your home, in work, in your centre or out on the street with your friends). Sometimes if you don't feel safe, abuse might be happening to you. Every individual has rights that are protected by our law. More information can be found here <https://www.hse.ie/eng/about/who/socialcare/safeguardingvulnerableadults/safeguardinginformationleaflet.pdf>

Advocacy and Support:

The National Advocacy Service (NAS) is an organisation which helps adults with disabilities. If you have a disability, like a physical or intellectual disability, one of our staff could help you with an issue you are having. NAS provides a free and confidential advocacy service to adults with a disability, aged 18 years and over. NAS has a particular remit to work with people with disabilities who are in vulnerable situations, such as people who are isolated from their community of choice or mainstream society, may communicate differently and who have limited formal or natural supports. More information can be found here: <https://advocacy.ie/>

Gary Brennan, PWSAI National Development Manager:

Gary can offer PWS specific support related to the Assisted Decision Making (Capacity) Act 2015. He provides a confidential advocacy service to adults with

PWS, aged 18 years and over and their families. Gary is also available to deliver ADMA awareness training and advice to parents / carers of adults with PWS.

If you have any questions, contact Gary at: Email: gary.brennan@pwsai.ie or Mob: 087 385 1387