# UL ENGAGE
## Community Briefing

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# The Assisted Decision-Making (Capacity) Act 2015: Interpretation and Practical Application

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# Acknowledgments

We wish to express our sincere gratitude to Dr. John Lombard and the University of Limerick School of Law for their continued support and encouragement.

We also wish to sincerely thank Milford Care Centre. Completion of this project could not have been accomplished without their support and guidance.

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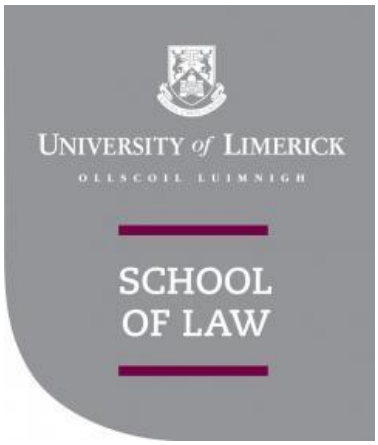
# THE BRIEF

The Assisted Decision-Making (Capacity) Act 2015 enables individuals to make legally binding agreements to be assisted and/or supported regarding decisions about their care. This assistance and/or support may be needed in circumstances where an individual has lost or will soon lose the capacity to make decisions on their own. This project examines the Assisted Decision-Making (Capacity) Act 2015 and outlines the key issues it raises for individuals wishing to make arrangements for assisted decision-making and care. The intention is to outline the implications of the Act in an accessible and clear way for both healthcare professionals and patients. In order to do this, the project examines a number of hypothetical clinical scenarios which may require the application of the ADM(C) 2015 and discusses the legal and ethical challenges in the context of hospice, day care, and nursing home care. In this respect, we are very grateful for the support of Milford Care Centre.




# PROJECT PARTNERS

The project partner for this research is Milford Care Centre. Milford Care Centre is a voluntary, not-for-profit organisation and registered charity. It was first established by the Little Company of Mary Sisters in 1928 and now provides Specialist Palliative Care and Older Person Services in the Mid West.

In addition to providing a Hospice Inpatient Unit, Milford Care Centre provides multiple services to the community. These include Hospice at Home services, a Nursing Home, Day Care for both the Older Person and people with palliative care needs. Milford Care Centre also offers Bereavement Support for families. Milford staff work in conjunction with other health care professionals in the community.

The project organiser is Dr John Lombard, School of Law, University of Limerick. John lectures and researches in the areas of medical law, ethics, and intellectual property law. John has published several articles on the topic of palliative care and the decision-making framework for people lacking capacity. He has also spoken at national and international conferences on issues such as treatment withdrawal, human rights at the end of life, advance healthcare directives, and the doctrine of double effect.

This project was completed by fourth year law students in the School of Law, University of Limerick. Each of the students displayed consistent enthusiasm and dedication to their research.

The students who conducted the research and prepared this report for publication are:

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# PROJECT RATIONALE

The Assisted Decision-Making (Capacity) Act 2015 significantly re-shapes the legal framework for healthcare decision-making in Ireland. The scale of the changes raise substantial practical challenges for healthcare professionals and patients effected by the legislation. This project is a first step in addressing and unpacking what the legislation will mean at the local level. This is an opportunity for students to engage in research which draws on the skills they have acquired over the course of their degree and implement them in a manner which has a real impact and which benefits stakeholders in the local community.

# Key Terms in the Assisted Decision-Making (Capacity) Act 2015

The Assisted Decision-Making (Capacity) Act (**"ADMA"**) provides a statutory framework for an individual to make legally binding agreements to be assisted and supported in making decisions about their welfare, property and affairs.

The purpose of this section is to define the key terms of the ADMA in both legislative and layman's terms. In doing so it is hoped that the key concepts will be easily identifiable for those who use and are affected by the ADMA.

## *1. Relevant Person*

### *1.1. Legislative Definition*

As per S. 2 of the ADMA a relevant person is (a) a person whose capacity is in question or may shortly be in question in respect of one or more than one matter; (b) a person who lacks capacity in respect of one or more than one matter; or (c) a person who falls within (a) and (b) at the same time but in respect of different matters.

### *1.2. Layman's Definition*

A person will be deemed as a relevant person when there capacity is or may shortly be in question. While a person may be found to have full capacity on one matter, they may still be considered as a relevant person where they lack capacity on other matters.

## *2. Capacity (Decision-Making Capacity)*

### *2.1. Legislative Definition*

As per S. 3(1) of the ADMA a person's capacity shall be assessed on the basis of his or her ability to understand, at the time that a decision is to be made, the nature and consequences of the decision to be made by him or her in the context of the available choices at the time (see S. 3(2) for factors to consider in determining lack of capacity).[1]

### *2.2. Layman's Definition*

Whether a person has the capacity to make a decision will be based on their ability to understand information, at the time the decision is to be made, the nature of this decision and what the consequences may be. This information will be provided in line with choices available to the person at that time.

## *3. Functional Test for Capacity*

### *3.1. Legislative Definition*

As per S. 3(2), the Functional Test for Capacity finds that a person will lack capacity to make a decision 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 that information as part of the process of making the decision; or
(d) to communicate his or her decision (whether by talking, writing, using sign language, assistive technology).

[1] S. 3(2) states a person lacks capacity where s/he is unable to (a) understand the information relevant to the decision, (b) retain the information long enough to make a voluntary choice, (c) use or weigh that information as part of the process of making the decision, or (d) to communicate his or her decision (whether by talking, writing, using sign language, assistive technology, or any other means) or, if the implementation of the decision requires that act of a third party, to communicate by any means with that third party.

### *3.2. Layman's Definition*

The functional test for capacity recognises that even though a person may have the capacity to make one decision, they may not have the capacity to make another. The test is set out as such to enable more individuals to be found to have decision-making capacity. It requires that the relevant person be able to understand, retain and weigh up any information as part of the decision-making process and communicate this decision in a manner appropriate to their circumstances. This may include using any assistive measures i.e. talking, writing, using sign language, assistive technology or any other means.

## *4. Decision-Making Assistant (DMA)*

### *4.1. Legislative Definition*

A person who the appointer has, under S. 10(1)[2], appointed to assist the appointer in making decisions on the appointer's personal welfare or property and affairs, or both, in compliance with regulations made under S. 10(4).

### *4.2. Layman's Definition*

Where a person believes they may soon begin to lack capacity, they may appoint a particular person (who has full capacity) to assist them in making certain decisions. This person is known as a Decision-Making Assistant and for example, may be a family member or carer.

[2] S. 10(1) of the ADMCA states: "Subject to section 11, a person who has attained the age of 18 years and who considers that his or her capacity is in question or may shortly be in question may appoint another person who has also attained that age to assist the first-mentioned person in making one or more than one decision on the first-mentioned person's personal welfare or property and affairs, or both, in compliance with regulations made under subsection (4).

## *5. Co-Decision Maker (CDM)*

### *5.1. Legislative Definition*

A person who the appointer has appointed, under S. 17, to jointly make with them decisions on the appointer's welfare or property and affairs, or both, in compliance with this part[3] and regulations made under S. 31.

### *5.2. Layman's Definition*

Where a person believes they may soon begin to lack capacity, they may appoint a particular person (who has full capacity) to jointly make with them, specific decisions. This person is known as a Co-Decision-Maker and for example, may be a family member or carer.

## *6. Decision-Making Representative (DMR)*

### *6.1. Legislative Definition*

In relation to a relevant person, means a person appointed pursuant to a decision-making representation order[4] to make one or more than one decision specified in the order on behalf of the relevant person.

### *6.2. Layman's Definition*

The DMR is a person (who has full capacity) chosen by the court to make specific decisions for another who lacks the capacity to make such decisions.

## *7. Advanced Healthcare Directive (AHD)*

### *7.1. Legislative Definition*

As per S. 82, in relation to a person who has

[3] S. 17 of the ADMCA.

[4] Means an order under section 38(2)(b) as the order is in force from time to time. S. 38(2)(b) states "subject to subsection (7) and section 36, an order appointing a suitable person who has attained the age of 18 years to be a decision-making representative for the relevant person for the purposes of making one or more than one decision specified in the order on behalf of the relevant person in relation to his or her personal welfare or property and affairs, or both."

capacity, an AHD means the advance expressions by this person, in accordance with S. 84[5], of his or her will and preferences concerning healthcare treatment decisions that may arise in respect of him or her if he or she subsequently lacks capacity.

### *7.2. Layman's Definition*

An AHD is a written document in which a person (who has capacity) can express their future will and preferences for any future healthcare treatment decisions. It allows people to make their own healthcare decisions ahead of such a time where they may lack the capacity to do so. This person is known as a directive-maker.[6]

## *8. Designated Healthcare Representative (DHR)*

### *8.1. Legislative Definition*

As per S. 82 a DHR is a named individual designated by the directive maker in their AHD to exercise relevant powers as per S. 88(1) –

(a) the power to advise and interpret what the directive-maker's will and preferences are regarding treatment; and,

(b) the power to consent to or refuse, up to and including life-sustaining treatment, based on the known will and preferences of the directive maker.

All powers must be exercised by reference to the relevant AHD.

### *8.2. Layman's Definition*

In an AHD, the directive-maker may name a person (who has capacity) to be their DHR. The DHR is appointed to make healthcare treatment decisions on behalf of the directive-maker, in a situation where they no longer have capacity to do so. The DHR must make such decisions by correctly referencing and interpreting the terms of the AHD. They must ensure they pay due attention to the directive-maker's expressed will and preferences when discussing any treatments with the attending healthcare professionals.

## *10. Enduring Power of Attorney*

### *9.1. Legislative Definition*

As per S. 59(1) a person who has attained the age of 18 years (in this Act referred to as a "Donor") may appoint another person who has attained that age (in this Act referred to as an "Attorney") on whom he or she confers either or both –

(a) A general authority to act on the donor's behalf in relation to all or a specified part of the donor's property and affairs; or

(b) Authority to do specified things on the donor's behalf in relation to the donor's personal welfare or property and affairs, which may be subject to conditions and restrictions.

As per S. 59(4), an Enduring Power of Attorney shall not enter into force until the Donor lacks capacity on one or more relevant decisions which are the subject of the enduring power of attorney, and the instrument has been registered with the Director of the Decision Support Service (DDSS).[7]

### *9.2. Layman's Definition*

An Enduring Power of Attorney is an agreement

[5] S. 84 a person who has attained the age of 18 and who has capacity may make an advance healthcare directive.

[6] As per S. 82 of the Act 'a directive-maker' in relation to a designated healthcare representative, means the person who made the advance healthcare directive under which the representative was designated as such representative.'

[7] S. 69 of the Act provides that: an application for an Enduring Power of Attorney needs to be made to the Director of the Decision Support Service. Once the Director is satisfied all criteria are met, the instrument creating the enduring power of attorney shall be granted.

between two persons, the Donor and the Attorney. The Donor (the person who may lack capacity in the future) gives a general decision-making power to an Attorney (the person providing assistance). This agreement is made ahead of a time where the Donor may begin to lose the capacity to make such decisions. The Enduring Power of Attorney is not enforceable until the Donor has lost capacity regarding decisions in the agreement and the agreement has been registered with the DDSS.

## *9. An Intervener*

### *10.1. Legislative Definition*

As set out under S. 2 – an intervener is a person who, in relation to an intervention, makes orders or gives directions under this Act, for an action to be taken, in respect of a relevant person. An intervener may be –

(a) the court or High Court;
(b) a DMA, CDM, DMR, DHR or Attorney;
(c) the Director;
(d) a special visitor or general visitor; or
(e) a healthcare professional.

### *10.2. Layman's Definition*

An intervener is a person who can make orders or give directions for any action taken, under this Act, for any relevant person who may now lack capacity. This intervener may be any of the previously stated (a) (b) (c) (d) or (e). An action may include a situation whereby the intervener assists someone who lacks the capacity to make decisions.

# The "Guiding Principles"

The ADMA requires that, in respect of any intervention, the intervener must "give effect" to a set of principles. These are set out under S. 8 of the ADMA and are known as the "Guiding Principles".

*Understanding the Guiding Principles:*

*S. 8 (1)* sets out that the Guiding Principles shall apply for the purposes of an intervention in respect of a relevant person, and the intervener shall give effect to such principles accordingly.

The ADMA sets out the Guiding Principles as a means of protection for personal rights and the dignity of persons with impaired capacity. The person's ability to make relevant decisions in relation to their medical care will remain absolute, unless there is evidence to state otherwise. The Guiding Principles are set out specifically for this reason. They outline regulations for the intervener regarding any intervention, while also, including information regarding who should be involved and informed.

*The guiding principles as set out in the ADMA are as follows:*

- *S. 8(2)* and *S. 8(3)*– provides that all relevant persons are presumed to have decision-making capacity and are considered able to make decisions in relation to the matter concerned (unless it is shown they do not come under the provisions of the ADMA or previous decisions were unsuccessful in helping the relevant person).

- *S. 8(4)* – provides that a relevant person is still presumed as having decision-making capacity even where previous decisions made were unwise or it is likely the decision they make will be unwise.

- *S. 8(5)* – provides that there will be no intervention for the relevant person unless it is necessary taking into account their individual circumstances.

- *S. 8(6)* – provides that an intervention for the relevant person must be made in a way that:

(a) minimises the restrictions of the relevant person's rights and freedom of action;
(b) pays due respect to the relevant person's rights to dignity, bodily integrity, privacy, independence, and control of his or her financial affairs and property.
(c) is proportionate to the urgency and significance of the subject of the intervention; and,
(d) when possible does not prolong the intervention, taking into account the particular circumstances.

- *S. 8(7)* – provides that the intervener, in making an intervention in relation to the relevant person, may –

(a) permit, encourage, and facilitate the relevant persons participation in the decision-making process;
(b) & (c) take into account past and present decisions of the relevant person, their reasonably determinable beliefs and values (especially those expressed in writing and any other factors which the relevant person may consider;
(d) Unless the intervener considers it inappropriate, takes into account the views of any named person (DHR, Attorney) by the relevant person, and any DMA, CDM or DMR for the relevant person; and,
(e) the intervener must ensure they act in good faith and for the benefit of the relevant person.

- *S. 8(8)* – provides that the intervener, when arranging an intervention in

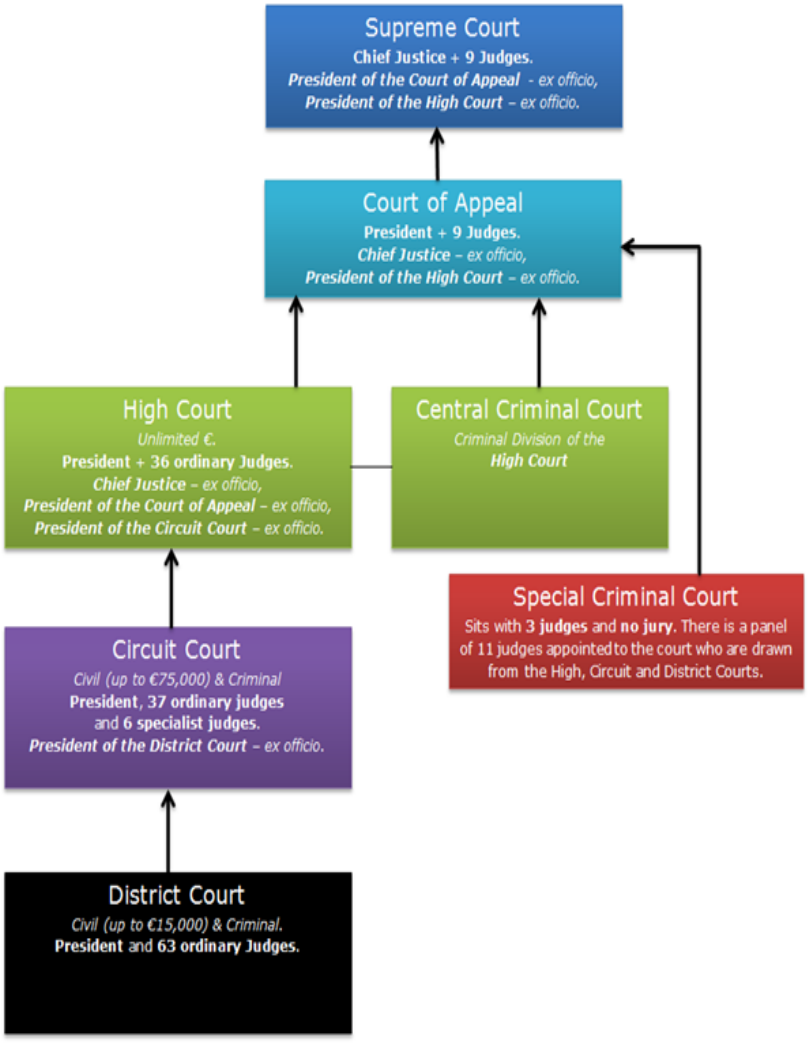
relation to the relevant person, may consider the views of any person involved in caring for the relevant person, any person who has a genuine interest in the welfare of the relevant person, or healthcare professionals.

- *S. 8(9)* – provides that in a situation which involves an intervention in relation to a person who lacks capacity, the intervener shall pay regard to the possibility of recovery of the relevant persons capacity in relation to the matter at hand and the urgency of making the intervention before the recovery.

- *S. 8(10)* – provides that the intervener, when arranging the intervention, must not seek any information that is not required for the decision to be made, or use any information obtained for any other reason than required for the decision. They must also take steps to ensure that such information be kept safe from unauthorised access and ensure it is properly disposed of when it is no longer needed.

# Additional Information

## Hierarchy of the Courts




### THE COURTS

The Assisted Decision-Making (Capacity) Act 2015 explicitly states that the Circuit Court has exclusive jurisdiction to deal with cases relating to the ADMA.

The High Court hold jurisdiction over cases concerning organ donation and the withdrawal of life-sustaining treatment for people who lack capacity.

The High Court will also hear appeals.

All applications under the ADMA go to the Circuit Court.

# Practical Application of the Assisted Decision-Making (Capacity) Act 2015

As previously discussed, the purpose of this report is to provide a detailed analysis of the interpretation and application of the ADMA. The following section will explore a number of clinical scenarios which have been provided by Milford Care Centre. Each of the clinical scenarios will demonstrate how the ADMA could be applied in a clinical setting. In addition to this application, the scenarios will also highlight any legal and ethical concerns which will need to be considered.

## Clinical Scenario A – Expressing Sexuality

***By***
***Darren Quinn & Amy Henry***

*Annie & Joseph are both residents in the same nursing home. Joseph has a diagnosis of dementia. Both residents have enjoyed each other's company for a number of months, often sitting beside each other in the large day room, and in the dining room.*

*One evening, a staff member went to check on Annie and found both residents in her room, lying on her bed together. Joseph was asked to leave the room, and the matter was reported to the Nursing Home Manager. A few days later Annie & Joseph were seen holding hands and regularly embracing one another, and when Annie was found in Joseph's bedroom one afternoon, she asked the carer to close the door and give them some privacy.*

*A team meeting was held and acting in the best interests of both residents, a decision was made to move Joseph upstairs to the first floor of the building, and in an effort to curb inappropriate behaviour that might cause offence to other residents or to visitors.*

*Each of these incidents were documented in the daily nursing notes, but although there was a section in the Nursing Care Plan for "Expressing Sexuality", all that was documented was what clothes the residents liked to wear.*

***Key Issues to be Discussed:***

The purpose of this report is to assist Milford Care Centre (**"Nursing Home"**) in identifying and addressing the key issues in the above scenario. The key issues relate to Annie and Joseph, residents of the Nursing Home, and will be discussed as follows:

1. ***Capacity*** – the report will focus on both Joseph and Annie's mental capacity to consent to an intimate and sexual relationship. In doing so, the authors will draw on two aspects; the assumption of capacity and the applicable tests for capacity.

2. ***Next Steps*** – the report will address the relationship that exists between Annie and Joseph and consider the most suitable action in going forward.

## *1. Capacity*

### *1.1. Assumption of Capacity*

The general principle is that all adults are assumed to have decision-making capacity.[8] In the case of *Fitzpatrick & Anor v K & Anor*[9], Laffoy J. affirmed this by stating that *'there is a presumption that an adult has the capacity, that is to say, the cognitive ability, to make a decision.'*[10]

The ADMA provides that everyone is considered as having the requisite decision-making capacity.[11] S. 8(3) of the ADMA enshrines the concept that no person is considered to lack decision-making capacity until all practicable steps in assisting with such decision-making have been exhausted. Moreover, the HSE National Consent Policy notes that the need to assess capacity formally, should only be considered, if having been given all appropriate help and support, the person is unable to communicate a clear and consistent choice or is unable to understand and use the information and choices available to him.[12]

- Annie: In this scenario, there is no issue of Annie suffering from a mental impairment. Therefore, she is assumed to have full decision-making capacity to consent to an intimate and/or any sexual relationship that may arise.[13]

- Joseph: In this scenario, it has been stated that Joseph was diagnosed with Dementia. Although it has not been explicitly stated what stage and type of dementia it is, it must be highlighted that this diagnosis raises questions surrounding Joseph's decision-making capacity to consent to expressions of sexuality. However, Joseph is still assumed to have capacity[14] until all practicable steps to assist his decision-making ability have been exhausted. If it can no longer be assumed Joseph has the capacity, it is advisable that the Nursing Home carry out an assessment on such.

### *1.2. Assessment of Capacity*

#### *1.2.1. ADMA Functional Test for Capacity*

The ADMA now gives statutory effect to the functional test for an individual's decision-making capacity concerning their healthcare or personal welfare. The test is issue and time specific, dependent upon the ability of an individual to comprehend, reason with and express a choice with regard to information about specific decisions. The functional approach encourages the view that incapacity in one area does not always lead to a finding of incapacity in other areas.[15] S. 3(2) of the ADMA sets out the test stating:

*'a person lacks capacity to make a decision 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 that information as part of the process of making the decision; or*
*(d) to communicate his or her decision (whether by talking, writing, using sign language or assistive technology).'*

[8] As per Thorpe J. in *Re C (Adult: Refusal of Treatment)* [1994] 1 AII ER 819.
[9] *Fitzpatrick & Anor v K & Anor* [2008] IEHC 104.
[10] As per Laffoy J. in *Fitzpatrick & Anor v K & Anor* [2008] IEHC 104.
[11] S. 8(2) of the ADMA.
[12] National Consent Policy. (Dublin: Health Service Executive, 2014).
[13] S. 8(2) of the ADMA.
[14] S. 8(2) of the ADMA.
[15] Deirdre Madden, *Medicine, Ethics and the Law* (4th ed., Bloomsbury 2016) p. 417.

Donnelly notes it is striking that the ADMA makes no reference to the 'best interest' principle and instead introduces the following 'guiding principles' with the intended purpose of assisting interpretation of the Act and reducing the possibility of a person being found to lack capacity.[16] The Nursing Home should be aware that:

- Under S. 3(3) and S. 3(4) an individual is entitled to an explanation appropriate to their circumstances and will be regarded as having capacity if they understand this. In addition, they are only required to retain this information for a short period of time;
- S. 8(4) provides that whether or not the decision being made is unwise does not affect that individual's decision-making capacity.

For this scenario, the ADMA functional test for capacity is limited in its application. This scenario shows there is an intimate relationship between Annie and Joseph and raises concerns that if a sexual act were to be committed, there may be a risk of abuse to Joseph. For this reason, it would be more suitable for the Nursing Home to assess Joseph's decision-making capacity to consent to a sexual relationship from a criminal law perspective.

### *1.2.2. Nature of the Relationship*

Although it is clear Annie and Joseph have an intimate relationship, there is no evidence that they have engaged in a sexual relationship/sexual acts. The following legislative guidance should be viewed in light of such a relationship developing between the two.

### *1.2.3. Criminal Law (Sexual Offences) Act 1993 ("1993 Act")*

In Ireland, capacity to consent to sexual acts is currently regulated by the 1993 Act.

*S. 5(1) 'sets out that a person who –*

*a) has or attempts to have sexual intercourse; or*
*b) commits or attempts to commit an act of buggery;*

*with a person who is mentally impaired (unless they are married or reasonably believe s/he is married) shall be guilty of an offence.'*[17]

S. 5(5) of the 1993 Act refers to a 'mentally impaired' individual as one *'suffering from a disorder of the mind, whether through mental handicap or mental illness, which is of such nature or degree as to render a person incapable of living an independent life or safeguarding against serious exploitation.'*[18] In other words, Joseph would be considered as incapable of giving consent if it can be shown that he cannot live an independent life or adequately protect himself from exploitation.

O' Malley has criticised the application of the 1993 Act stating its paternalistic approach is hugely restrictive and fails to sufficiently recognise the rights of persons to have fully-expressed consensual intimate and sexual relations.[19] For this reason, the National Disability Authority (NDA) encouraged the amendment and

[16] Mary Donnelly, "The Assisted Decision-Making (Capacity) Act 2015: Implications for Healthcare Decision-Making" (2016) *Medico-Legal Journal of Ireland* 22(2) 65-74.
[17] Under the 1993 Act, this person shall be guilty of a term of imprisonment for 3-10 years depending on the offence.
[18] S. 5(5) Criminal Law (Sexual Offences) Act 1993.
[19] Thomas O' Malley, *Sexual Offences in Ireland* (2nd ed., Roundhall, 2013).

redefinition of capacity in respect to sexual relations for vulnerable people.[20]

Recently, there has been a major shift in assessing an individual's capacity to consent to sexual acts. The recently commenced Criminal Law (Sexual Offences) Act 2017 ("2017 Act"), will introduce a functional assessment of capacity, similar to that introduced by the ADMA.[21]

### *1.2.4. Criminal Law (Sexual Offences) Act 2017*

The 2017 Act sets out the functional test for capacity under S. 21(7) and states a 'protected person' is a person who lacks the capacity to consent to a *sexual act*[22] if he or she is, '*by reason of a mental or intellectual disability or mental illness, incapable of:*

*(a) understanding the nature, or the reasonably foreseeable consequences of that act;*
*(b) evaluating relevant information for the purposes of deciding whether or not to engage in that act; or,*
(c) *communicating his or her consent to that act by speech, sign language or otherwise.'*

It is hoped that a functional test such as this will *'achieve a satisfactory balance between protecting mentally impaired persons from sexual abuse and exploitation, and ensuring their right to engage in loving and/or sexual relations'* is protected.[23]

In terms of going forward, it is advisable that the Nursing Home consider all possible scenarios and put in place protective measures to ensure both Annie and Joseph are protected. This report will provide a number of 'Next Steps' that the Nursing Home could consider when implementing the necessary measures.

## ***2. Next Steps***

As discussed by the Health Information and Quality Authority ("HIQA") in their report: *A Guidance Note for Designated Centres on Intimacy and Sexual Relationships*[24], inclusive of individuals suffering from dementia, the need for intimate emotional, physical and sexual closeness is a basic human need. All older people including those with disabilities have the right to experience a complete range of relationships, including personal relationships.[25] O'Malley highlights the need for the clearest possible rules and standards relating to capacity and the scope of sexual freedom that should be allowed to persons with different levels of mental ability.[26]

In their report on the *National Standards for Residential Care Settings for Older People in Ireland*, HIQA have set out a wide range of standards to be applied to ensure a person-centred approach to healthcare in these circumstances.[27] This report will now discuss the applicable standards:

***Standard 1.2.2.*** states *"each resident has an opportunity to be alone, with due regard to their safety,*

[20] Submission on Capacity and Sexual Relations in the Context of the Mental Capacity Scheme Bill (Dublin: National Disability Authority, April 2009).
[21] Although the 2017 Act has been commenced, details of which specific sections that have been officially commenced were not finalised at the time of writing this report.
[22] S. 20 of the 2017 Act defines a 'sexual act' as (a) consisting of (i) sexual intercourse, or (ii) buggery; (b) an act described in S. 3(1) or 4(1) of the Criminal Law (Rape) Amendment Act 1990, or (c) an act which if done without consent would constitute a sexual assault.
[23] Department of Justice, Equality and Law Reform Discussion Paper 1988 (Dublin: Stationary Office, 1988) p.73.
[24] Guidance Note for Designated Centres: Intimacy and Sexual Relationships (Dublin: HIQA, 2014).
[25] *Ibid* p. 3.
[26] Thomas O' Malley, *Sexual Offences In Ireland* (2nd ed., Roundhall 2013) p. 150.
[27] National Standards for Residential Care Settings for Older People in Ireland (Dublin: HIQA, 2016) at p. 12.

*ensuring that privacy and dignity are respected at all times."* This expressly refers to their expressions of intimacy and sexuality.[28]

***Standard 1.3.2.*** notes a balanced approach should be taken when managing risk-taking and promoting independence, taking the resident's preferences into account. In addition, ***1.3.12.*** provides that where residents have difficulty communicating these preferences, every effort must be made to support them in communicating their views, or to provide further support, by getting the best understanding of such from other sources. This may be useful where the individual suffers a mental impairment i.e. dementia.

***Standard 1.6.*** states *"each resident, where appropriate, is facilitated to make informed decisions, has access to an advocate and their consent is obtained in accordance with legislation and current evidence-based guidelines."*[29]

Under ***1.6.7.*** it is presumed each resident has the legal capacity to make their own decisions. It is only in the case where all other supports have been exhausted that a decision is to be taken on someone's behalf.[30] Here, the Nursing Home must seek independent support and advocacy for the service user. Standard ***2.3.5.*** sets out the necessity for such supports particularly where the resident has a cognitive impairment.

### *2.2. Where there is Risk of Abuse*

***Standard 3.1.*** sets out the necessity to safeguard each resident from abuse and neglect. ***3.5.1.*** provides for the effective investigation of allegations of abuse. The Nursing Home should have a policy on intimacy and sexual relationships, which includes procedures to be followed for reporting abuse.[31]

HIQA state nursing staff should carry out individual risk assessments to clearly identify where a service user is vulnerable to sexual exploitation, or may pose as a risk to others. They also note that any such assessment or intervention should be clearly identified within the service user's personal care plan.[32]

In accordance with these standards, the Nursing Home should ensure they carry out proper assessments where they believe there may be a risk of abuse to Joseph. It would also be advisable to record all such assessments and interventions in both Joseph and Annie's nursing care plans.

### *2.3. Where Abuse has Occurred*

According to the HSE National Guidelines, set out in their report: *Safeguarding Vulnerable Persons at Risk,*[33] where it is determined that abuse of a vulnerable person may have occurred all relevant people must be contacted. These may include:

- The vulnerable person;[34]
- The family of the vulnerable person;
- Other vulnerable persons, where appropriate;

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[28] *Ibid* p. 20.
[29] At the time of preparing these standards by HIQA, the ADMA Bill 2013 was before the House of the Oireachtas. The legislation was subsequently signed into law in 2015.
[30] This standard is in line with S. 8(2) of the ADMA.
[31] Guidance Note for Designated Centres: Intimacy and Sexual Relationships (Dublin: HIQA, 2014) p. 8.
[32] *Ibid* p. 7.
[33] As set out in the Health Service Executive's Report, Safeguarding Vulnerable Persons at Risk of Abuse: National Policies and Procedure. Social Care Division (Dublin: HSE, 2014).
[34] The HSE refer to a vulnerable person as on which, in the context of their policy, is an adult who may be restricted in capacity to guard himself/ herself against harm or exploitation or to report such harm or exploitation. The restriction of capacity may arise as a result of physical or intellectual impairment.

- The perpetrator, particularly if a service user; and
- Staff.[35]
- An Garda Síochána must be informed if it is suspected that the concern or complaint of abuse may be criminal.[36]
- There is also a requirement that the person in charge of the designated centre report (in writing) to the Chief Inspector (HIQA) within 3 working days of any adverse incident when the injury is deemed to be a consequence of an alleged, suspected or confirmed incident of abuse.[37]

Where it can be concluded that there was a sexual act committed, and Joseph had no decision-making capacity to consent to it, Milford should take the above steps and contact all the necessary authorities.

[35] Safeguarding Vulnerable Persons at Risk of Abuse: National Policies and Procedure. Social Care Division (Dublin: HSE, 2014) p. 10.
[36] Safeguarding Vulnerable Persons at Risk - National Policy and Procedures; Incorporating Services for Elder Abuse and for persons with a Disability. Social Care Division (Dublin: HSE, December 2014) p. 8.
[37] Safeguarding Vulnerable Persons at Risk - National policy and Procedures; Incorporating Services for Elder Abuse and for persons with a Disability. Social Care Division (Dublin: HSE, December 2014) p. 8.

# Clinical Scenario B – Diminished Capacity in a Community Setting

***By***

***Anna Duggan & Elise O' Neill***

*John is a 58 year old man who is a father with three adult children. He has been a widower for the last four years. John has a complex relationship with alcohol dependency for over twenty years. He has prolonged periods of sobriety but relapses into active addiction resulting in mental health issues and erratic behaviour. The local Gardai are familiar with John and are often called to intervene at his home and pubs when he is drinking.*

*His children have learnt to adapt to the uncertainty this brings, consequently they try not to 'annoy daddy' and are careful to avoid any contentious issue that may 'upset him'*

*John is presently sober, re-engaged with his local church and community activities. At a recent event in the village hall John attended a 'Café-Conversation'. This was a Compassionate Community initiative for a bereavement group John had joined. John took and filled in an IHF Think Ahead Form.*

*Two weeks after he completed the form John had a seizure and blurred vision. He was diagnosed with a stage 4 Glioblastoma with intermittent cognitive impairment exacerbated by lifestyle choices. His prognosis is short months. John lives alone in the family home. His children (who are married) live close by.*

*John has made it clear to his family that he wishes to go to Switzerland to avail of an assisted suicide programme and is refusing all other treatment options offered. He has also written this in the TAF along with other details of his funeral wishes and financial circumstances. John's two eldest sons want to honour their father's wishes whist his youngest daughter is contesting her father's capacity under the Act. John has refused to name any one person as his next of kin.*

## ***Key Issues to be Discussed***

The key issues relating to John will be discussed as follows:

1. ***Assumed Capacity***
2. ***Assessing Capacity***
3. ***Future Care***
4. ***Duty of Care***

## 1. *Assumed Capacity*

The determination of capacity is fundamental to the exercise of self-determination.[38] Cognisant of the consequences outlined and in keeping with its respect for autonomy, the law presumes that all adults have decision-making capacity to make decisions about their own healthcare.[39] Enshrined in S. 8(2)[40] of the ADMA, John is not required to 'prove' his capacity and the presumption may be only rebutted if certain conditions are met. The HSE National Consent Policy[41] advises that *'an implication of the presumption of*

[38] Deirdre Madden, *Medicine, Ethics & The Law* (2nd edn, Tottel Publishing, 2008) p.393.
[39] Deirdre Madden, *Medicine, Ethics & The Law* (3rd edn, Bloomsbury Professional, 2016) p.414.
[40] "*It shall be presumed that a relevant person … has capacity in respect of the matter concerned unless the contrary is shown in accordance with the provisions of this Act*".
[41] National Consent Advisory Group, 'National Consent Policy' (Dublin: Health Service Executive, 2013).

*capacity is that this presumption should not be challenged unless an adequate 'trigger' exists*.'[42]

### *1.1. Issues to consider in assuming capacity:*

#### *1.1.1.Mental Health:*

Although John's addiction often results in mental health issues, which may 'trigger' erratic behaviour; it would still be presumed that he has capacity. The Irish Supreme Court has definitively stated that one does not lose the right to autonomy and dignity with the loss of mental capacity.[43] Healthcare professionals would generally assume that if John is able to manage his daily life, John is competent to make healthcare decisions. Those who provide health and social care services must work on the presumption that every adult service user has the capacity to make decisions about their care, and to decide whether to agree to, or refuse, an examination, investigation or treatment.[44] It must not be assumed that John lacks capacity to make a decision solely because of his behaviour, a medical condition, or mental illness.

#### *1.1.2. Alcohol:*

Although John is presently sober, he has had a complex relationship with alcohol dependency for over twenty years. The fact that John may have been found to lack capacity to make a decision on a particular occasion previously, due to intoxication, does not mean that he lacks capacity to make any decisions at all, or that he will not be able to make similar or other decisions in the future.[45] S .3(5) of the ADMA[46] provides that where there has been a instance where a person lacks capacity to make decisions at a particular time, this does not mean that the person will not have the capacity to make decisions on the same matter another time.[47] The presumption of capacity is that John is capable of decision making and that the burden of establishing incapacity lies on the party asserting this.[48]

#### *1.1.3. Glioblastoma & Cognitive Impairment:*

John's diagnosis of stage 4 Glioblastoma with intermittent cognitive impairment exacerbated by lifestyle choices may hinder his capacity, depending on the severity of the impairment. The severity of the cognitive impairment is something to be analysed and considered. However, John will be presumed to have capacity unless there is sufficient reason to carry out assessment of capacity, otherwise he is entitled to have his decision respected.[49]

### ***1.2. Discussion:***

Shelford described the presumption and its provenance as follows:

"*Reason, being the common gift to man, raises the general presumption that every man is in a state of sanity, and that insanity ought to be proved; and in favour of liberty and of that dominion which, by the law*

[42]Deirdre Madden, *Medicine, Ethics & The Law* (3rd edn, Bloomsbury Professional, 2016) p.415.
[43]Deirdre Madden, *Medicine, Ethics & The Law* (2nd edn, Tottel Publishing 2008) p.393.
[44]National Consent Advisory Group, 'National Consent Policy' (Dublin: Health Service Executive 2013).
[45]National Consent Advisory Group, 'National Consent Policy' (Dublin: Health Service Executive 2013).
[46]S. 3(5) of the ADMA.
[47]Deirdre Madden, *Medicine, Ethics & The Law* (3rd edn, Bloomsbury Professional, 2016) p.427.
[48]Mary Keys, '"Capacity –Whose Decision Is It Anyway?"' <http://www.inclusionireland.ie/sites/default/files/attach/.../capacitypaperbymarykeys.doc> accessed 14 March 2017.
[49]Deirdre Madden, *Medicine, Ethics & The Law* (3rd edn, Bloomsbury Professional, 2016) p.427.

*of nature, men are entitled to exercise over their own persons and properties, it is a presumption of the law, that every person, who has attained the age of discretion, is of sound mind until the contrary is proven: and this holds as well in civil as in criminal cases."*[50]

The approach to the presumption of capacity was affirmed in case law in Ireland in *Fitzpatrick and Another v K and Another*[51]in which Laffoy J. held that:

'*there is a presumption that an adult patient has the capacity , that is to say, the cognitive ability, to make a decision to refuse medical treatment, but the presumption can be rebutted*.'

In relation to John's capacity, the presumption of capacity will still hold in a definite manner unless the presumption can be rebutted with evidence of his incapacity due to his deteriorating health.

- *Mental Health:*

  Although the presence of a mental illness may influence an assessment of capacity, it does not determine incapacity. The fact that John is suffering from a mental health problem does not of itself preclude a person from having legally effective capacity.[52] Whether a person has the capacity for decision making depends on whether that person can understand and come to a decision upon what is involved. It has been generally assumed that

  "*Most patients in mental hospital are capable of giving a legally effective consent including many who are compulsorily detained*."[53]

  Therefore it is no longer ethically or legally sound to presume that because someone has a mental disorder, they are automatically incapable of making decisions.[54]

- *Alcohol:*

  As intoxication is a temporary condition, the service user must present evidence making it apparent that the patient was so far under the influence of alcohol at the time of decision that he lacked the fundamental elements of capacity. Evidence of excessive or chronic alcohol use generally is admissible on the issue of capacity.[55] Evidence of this is seen in *An NHS Foundation v Ms X*[56] , Cobb J., affirmed Ms X's capacity although alcohol dependent.[57] A decision executed by even a chronic alcoholic may be found valid if the proponent can present sufficient evidence of execution during a lucid interval.[58] Although courts rarely invalidate a decision on the basis of the testator's alcohol-induced testamentary incapacity, a medical practitioner who is aware of the alcohol tendencies should be careful to ensure the alert mental state of John, who drinks excessively or is an

[50]Leonard Shelford, *Practical Treatise on the Law Concerning Lunatics, Idiots, And Persons Of Unsound Mind* (1st edn, S Sweet, 1833) <https://archive.org/details/apracticaltreat02shelgoog> accessed 15 March 2017 23.
[51]*Fitzpatrick & Another v K & Another* [2008] IEHC 104.
[52]See Thorpe J. judgement in *Re C (Adult: refusal of treatment)* [1994] 1 All ER 819.
[53]Mary Keys, '"Capacity –Whose Decision Is It Anyway?"' <http://www.inclusionireland.ie/sites/default/files/attach/.../capacitypaperbymarykeys.doc> accessed 14 March 2017.
[54]Mary Keys, '"Capacity –Whose Decision Is It Anyway?"' <http://www.inclusionireland.ie/sites/default/files/attach/.../capacitypaperbymarykeys.doc> accessed 14 March 2017.
[55]Sharon Glisson Bradley, 'Testamentary Capacity: Is The Alcoholic Incapacitated?' (1985) 46 Montana Law Review <http://scholarship.law.umt.edu/cgi/viewcontent.cgi?article=1666&context=mlr> accessed 13 March 2017.
[56][2014] EWCOP 35.
[57]John Coggon, 'Alcohol Dependence and anorexia Nervosa: Individual Autonomy and the Jurisdiction of the Court of Protection '(2015) 23 Medical Law Review.
[58]*Akers v. Morton*, 499 F.2d 44, 46 (9th Cir. 1974).

alcoholic,[59] is present when making healthcare decisions.

## ***2. Assessing Capacity***

If a question is raised on John's capacity, in order to have his wishes respected, an assessment of capacity must be carried out under the ADMA. The issues in assessing capacity are as follows:

### *2.1. Capacity for Creation of IHF Think Ahead Form:*

The creation and presence of an IHF Think Ahead Form, is an important aspect when assessing John's capacity and also when respecting his wishes. The creation of the form occurred when John was presently sober. As previously discussed, when assessing his capacity during this time period, John would be automatically presumed to have capacity in its creation.[60] However, it is unknown how long John was suffering from symptoms of intermittent cognitive impairment. Therefore, John may have lacked capacity at the time he completed the form. Under S. 3(2) of the ADMA,[61] if it can be shown that John did not understand the process which he undertook then the presumption of capacity may be rebutted.

### *2.2. Capacity to Refuse Treatment:*

The right to refuse treatment is contained within the respect for autonomy enshrined in art 40.3.1 of the Irish Constitution 1937 which has been recognised in a number of cases[62] before the Supreme Court. S. 83 (2) of the ADMA[63] states that an adult with capacity is entitled to refuse treatment for any reason notwithstanding that the refusal appears to be unwise, not based on sound medical principles, or may result in his/her death.[64] In some circumstances people may wish to make a refusal of treatment in advance of losing capacity.[65] These statements are referred to as 'advance directives', provided for under Part 8 of the ADMA[66], which may be oral or written statements. In this case John has completed an IHF Think Ahead Form which provides for an Advance Healthcare Directive.[67]

### *2.3. Assessing Capacity to Travel:*

Regardless of whether John is found to have capacity at the time he wishes to travel to Switzerland to avail of assisted suicide, it is an illegal act in Ireland.[68] The Criminal Law (Suicide) Act 1993, S. 2(2) states:

"*A person who aids, abets, counsels or procures the suicide of another, or an attempt by another to commit suicide, shall be guilty of an offence and shall be liable on conviction on indictment to imprisonment for a term not exceeding fourteen years*."

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[59] Sharon Glisson Bradley, 'Testamentary Capacity: Is The Alcoholic Incapacitated?' (1985) 46 Montana Law Review.
[60] See *An NHS Foundation v Ms X* [2014] EWCOP 35.
[61] S. 3 of the ADMA.
[62] *Re a Ward of Court* [1996] 2 IR 78; *Fitzpatrick & Another v K & Another* [2008] IEHC 104.
[63] S. 83(2) of the ADMA.
[64] Deirdre Madden, *Medicine, Ethics & The Law* (3rd edn, Bloomsbury Professional 2016) p. 470.
[65] Raanan Gillon, 'Why I Wrote My Advance Decision To Refuse Life-Prolonging Treatment: And Why The Law On Sanctity Of Life Remains Problematic' [2016] Journal of Medical Ethics.
[66] Part 8 of the ADMA.
[67] 'Are We Ready To "Think Ahead"? Acceptability Study Using An Innovative End Of Life Planning Tool'.' (Irish Hospice Foundation 2017) <http://hospicefoundation.ie/are-we-ready-to-think-ahead/> accessed 14 March 2017.
[68] 'Questions And Answers On Advance Health Directives - Think Ahead' (*Hospicefoundation.ie*, 2017) <http://hospicefoundation.ie/programmes/advance-care/questions-and-answers-on-advance-healthcare-directives/> accessed 14 March 2017.

Although John's sons want to honour his wishes they are unable to deliberately facilitate or encourage these wishes as assisted suicide is illegal in Ireland.[69]

### ***2.4. Discussion***

As there are different levels of capacity, the challenge for the service provider is to choose the right level to set a gateway for assessing decision making and in order to respect for persons autonomy.[70] A functional or decision-specific approach should be taken when assessing John's decision-making capacity.[71] This approach should be issue specific and time specific and assess John's ability to make the relevant choice depending on both his level of understanding and ability to retain the information he has been given, and his ability to apply the information to his own personal circumstances and come to a decision. The "functional" approach recognises that there is a hierarchy of complexity in decisions and also that cognitive deficits are only relevant if they actually impact on decision making.[72]

S. 8 of the ADMA[73] sets out the Guiding Principles that apply for the purpose of an intervention in respect of a relevant person, which is defined in S. 2(1).[74]

S. 8(4) of the ADMA[75] states that John *'shall not be considered as unable to make a decision in respect of the matter concerned merely by reason of making, having made, or being likely to make, an unwise decision*.'[76] If John is regarded as lacking the capacity to give consent to the proposed investigation or treatment a decision should be made in accordance with the Guiding Principles.[77] S. 8(4) of the ADMA[78] is consistent with Laffoy J.'s judgement in *Fitzpatrick & Another v K & Another*[79] in which she stated that a person who makes an unwise or seemingly irrational decision, is nonetheless entitled to the presumption of capacity.[80]

S. 3 of the ADMA[81] further provides that if John is unable to understand, retain, use or weigh up the information he has been given to make the relevant decision, or if he is unable to communicate his decision, he may be regarded as lacking the capacity to give consent to the proposed investigation or treatment.[82] Even in the presence of incapacity, John's expressed view carries great weight. Many

[69] *Fleming v Ireland & Ors* [2013] IEHC 2.
[70] Michael Gunn "The Meaning of Incapacity" (1994) 2 Medical Law Review 8.
[71] S. 3 of the ADMA.
[72] Deirdre Madden, *Medicine, Ethics And The Law* (3rd edn, Bloomsbury Professional 2016) p.416.
[73] S. 8 of the ADMA.
[74] S. 2(1) of the ADMA.
[75] S. 8(4) of the ADMA
[76] Medical Council, 'Guide To Professional Conduct And Ethics For Registered Medical Practitioners' (The Medical Council, 2009). <https://www.medicalcouncil.ie/News-and-Publications/Publications/Professional-Conduct-Ethics/Guide-to-Professional-Conduct-and-Behaviour-for-Registered-Medical-Practitioners-pdf.pdf> accessed 8 March 2017.
[77] S. 8 of the ADMA.
[78] S. 8(4) of the ADMA
[79] *Fitzpatrick & Another v K & Another* [2008] IEHC 104.
[80] Deirdre Madden, *Medicine, Ethics & The Law* (3rd edn, Bloomsbury Professional 2016) p.427.
[81] S. 3 of the ADMA.
[82] Medical Council, 'Guide To Professional Conduct And Ethics For Registered Medical Practitioners' (The Medical Council 2009). <https://www.medicalcouncil.ie/News-and-Publications/Publications/Professional-Conduct-Ethics/Guide-to-Professional-Conduct-and-Behaviour-for-Registered-Medical-Practitioners-pdf.pdf> accessed 8 March 2017. See also – in keeping with the common law tests outlined in the English *Re C (Adult: refusal of treatment)* [1994] 1 All ER 819and Laffoy J.'s decision in *Fitzpatrick & Another v K & Another* [2008] IEHC 104.

individuals who lack capacity to make a decision will nevertheless be able to express a preference to receive or forgo an intervention. Such preferences should in general be respected. Most health and social care decisions regarding those who lack capacity arise in the community, as can be seen in John's case, and it may often be impractical or undesirable to try to impose care, treatment or investigation on someone who refuses it.[83]

## ***3. Future Care***

In John's case, care will be planned in accordance with his wishes if his presumption of capacity is not rebutted. However if John is deemed to lack capacity in relation to the refusal of treatment an intervention may be made under S. 8 (5) of the ADMA[84].

### ***3.1. Discussion:***

#### *3.1.1. Guiding Principles for Interventions:*

S. 8 (5) of the ADMA[85] provides that 'there shall be no intervention in respect of a relevant person unless it is necessary to do so having regard to the individual circumstances of the relevant person'. S. 8(6)[86] of the ADMA provides that an intervention must be made in a manner that minimises the restriction of the person's rights and freedom of action and have due regard to the need to respect the person's right to dignity, bodily integrity, privacy and autonomy. Therefore there shall be no intervention in relation to John's medical treatment unless it is necessary regarding his circumstances. These provisions provide that if an intervention is deemed as necessary the option chosen should be the least restrictive one.[87]

#### *3.1.2. Refusal of Treatment:*

Even prior to the ADMA, it was beyond doubt that an adult with capacity has the right to refuse medical treatment in Ireland. The Irish courts have expressly stated this principle in a number of cases such as in *Re a Ward of Court*.[88] In this case the court recognised that competent adults had the right to refuse medical treatment, even though such refusal may lead to death. Denham J pointed out that medical treatment may be refused for a variety of reasons, some of which many not be regarded as 'good' or rational decisions, but they must be respected nonetheless.[89] In relation to the right to privacy under art 40.3.1, the Supreme Court held that this right includes a right to refuse medical treatment even where this would lead to death.

S. 8(7) of the ADMA[90] provides that an intervener shall: permit, encourage and facilitate as far as practicable the person to participate as fully as possible in the intervention. This provision therefore refers to the need to 'give effect' to John's will and preferences, to 'take into account' John's beliefs and values, and to 'consider' the views of those who have been appointed to act as decision-making supports for John.

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[83]Medical Council, 'Guide To Professional Conduct And Ethics For Registered Medical Practitioners' (The Medical Council 2009). <https://www.medicalcouncil.ie/News-and-Publications/Publications/Professional-Conduct-Ethics/Guide-to-Professional-Conduct-and-Behaviour-for-Registered-Medical-Practitioners-pdf.pdf> accessed 8 March 2017.
[84]S. 8(5) of the ADMA.
[85]S. 8(5) of the ADMA.
[86]S. 8(6) of the ADMA.
[87]Deirdre Madden, *Medicine, Ethics & The Law* (3rd edn., Bloomsbury Professional, 2016) p. 428.
[88]*Re a Ward of Court* [1996] 2 IR 79.
[89]Deirdre Madden, *Medicine, Ethics & The Law* (3rd edn., Bloomsbury Professional, 2016) p.481.
[90]S. 8(7) of the ADMA.

In this case an intervener could have to look at John's wishes to refuse treatment within the IHF Think Ahead Form.

However John's wish to travel to Switzerland and avail of an assisted suicide programme would not be encouraged or facilitated by an intervener as assisted suicide is illegal in Ireland.[91] If John has expressed an opinion which might enable the intervener to assess his will and preference, beliefs and values it may not be possible to ascertain his views.[92] Therefore if John is considered to have capacity in relation to his medical treatment he has the right to refuse treatment even if this leads to death. If John is said to lack capacity in relation to his medical treatment a decision must be made in accordance the Guiding Principles set out.

### *3.1.3. Absence of next of kin:*

S. 8(8)[93] of the ADMA provides that the intervener may consider the views of (a) any person engaged in caring for the relevant person (b) any person who has a bona fide interest in the welfare of the relevant person (c) healthcare professionals. In this instance where John has not nominated a carer to be consulted in this context, and there is no decision-making support structure in place, the intervener is not obliged to consult carers but may do so at his/her discretion.

The discretionary approach is useful here as the intervener may be aware that family members and carers are in disagreement about what the relevant person would have wanted, or be concerned that family members and carers may exert influence over the relevant person's own views.[94] As John's two eldest sons want to honour their father's wishes but his younger daughter is contesting her father's capacity, the intervener may consider both views at his/her discretion. Care must always be taken by the health care professional in considering representations made by family members about the views of the relevant person. However it is important to remember that even close friends or family members cannot always know the past preferences or the relevant beliefs and values of the person lacking capacity.[95]

## ***4. Duty of Care***

Once the requisite doctor-patient relationship is established, the doctor owes to the patient the duty of care and treatment with that degree of skill, care, and diligence as possessed by or expected of a reasonably competent physician.[96] Therefore, in the case of John it raises questions as to if the doctor owes the duty to follow through with the advance health care directive. Although the wishes that John has made in his IHF Think Ahead Form may be at odds with the views of a patient's loved ones or even the opinion of the doctor, the wishes of a patient who has capacity when making their decisions must be respected.[97]

The Guide to Professional Conduct and Ethics of the Medical Council provides that an advance treatment

[91]Questions And Answers On Advance Health Directives - Think Ahead' (*Hospicefoundation.ie*, 2017) <http://hospicefoundation.ie/programmes/advance-care/questions-and-answers-on-advance-healthcare-directives/> accessed 14 March 2017.
[92]Deirdre Madden, *Medicine, Ethics & The Law* (3rd edn, Bloomsbury Professional 2016) p.428.
[93]S. 8 (8) of the ADMA.
[94]Deirdre Madden, *Medicine, Ethics & The Law* (3rd edn, Bloomsbury Professional 2016) p. 429.
[95]Mary Donnelly, 'Best Interests, Patient Participation and The Mental Capacity Act 2005' (2008) 17 Medical Law Review.
[96]'What Is A Doctor's Duty Of Care? - Findlaw' (*Findlaw*, 2017). <http://injury.findlaw.com/medical-malpractice/what-is-actionable-medical-malpractice.html> accessed 28 March 2017.
[97]Questions And Answers On Advance Health Directives - Think Ahead' (*Hospicefoundation.ie*, 2017) <http://hospicefoundation.ie/programmes/advance-care/questions-and-answers-on-advance-healthcare-directives/> accessed 14 March 2017.

plan has the same ethical status as a decision by a patient at the actual time of an illness and should be respected.[98] An advance healthcare plan or directive has the same status as a decision by a patient at the actual time of an illness and should be followed provided that the request or refusal was an informed choice, the decision covers the situation that has arisen and there is nothing to indicate that the patient has changed their mind.[99]

### ***4.1. Discussion:***

Advance directives are not regarded as legally binding[100] however they should be taken into account by the healthcare provider.[101] The Irish Hospice Foundation's Think Ahead Form allows you to specifically document an Advance Healthcare Directive.[102] The presence of Johns IHF Think Ahead form can be helpful in preventing family disputes during difficult times by removing uncertainty about John's wishes.

S. 84 of the ADMA[103] sets out the requirements for making a valid advance healthcare directive. It provides that a refusal of treatment in such a directive shall be complied with if at the time in question John lacks capacity to give consent to the treatment. The treatment to be refused is clearly identified and the circumstances in which the refusal of treatment is intended to apply are clearly identified in the directive.

S. 85 of the ADMA[104] sets provisions in relation to the validity and applicability of advance healthcare directives. Directives are not valid if the person did not make the directive voluntarily, or while he or she had capacity, had done anything clearly inconsistent with the relevant decisions in the directive. In this case, although John was sober, uncertainty as to whether he had capacity when he filled in the Think Ahead Form may still exist due to his illness.

The directive is only applicable in circumstances where the person lacks capacity to make a contemporaneous decision and will not apply if the treatment is not materially the same as the treatment refused by the terms of the directive or the circumstances set out in the directive as to when the treatment to be refused is absent or not materially the same.[105] S. 84 of the ADMA[106] provides that the directive must be in writing, contain the details set out in subs (5), and be signed and witnessed. Further significant provisions in S. 85[107] of the ADMA state that an advance healthcare directive will not apply to life-sustaining treatment 'unless this is substantiated by a statement in the directive by the directive-maker to the effect that the directive is to apply to that treatment even if his or her life is at risk'.

If there is any ambiguity in the wording or applicability of the directive, S. 85(5)[108] of the ADMA provides that the healthcare professional must consult with the person's designated healthcare representative (if any), or the person's family and friends, and seek the opinion of a second healthcare professional. If

[98] Deirdre Madden, *Medicine, Ethics & The Law* (3rd edn., Bloomsbury Professional, 2016) p. 499.
[99] Medical Council, 'Guide To Professional Conduct And Ethics For Registered Medical Practitioners' (Medical Council 2016). <https://www.medicalcouncil.ie/News-and-Publications/Reports/Guide-to-Professional-Conduct-and-Ethics-8th-Edition-2016-.pdf> accessed 28 March 2017.
[100] *R(Burke) v GMC* [2005] EWCA Civ 1003 at [31-32].
[101] Deirdre Madden, *Medicine, Ethics & The Law* (3rd edn., Bloomsbury Professional, 2016) p. 490.
[102] Questions And Answers On Advance Health Directives - Think Ahead' (*Hospicefoundation.ie*, 2017) <http://hospicefoundation.ie/programmes/advance-care/questions-and-answers-on-advance-healthcare-directives/> accessed 14 March 2017.
[103] S. 84 of the ADMA.
[104] S. 84 of the ADMA.
[105] Deirdre Madden, *Medicine, Ethics & The Law* (3rd edn., Bloomsbury Professional, 2016) p.498.
[106] S. 84 of the ADMA.
[107] S. 85 of the ADMA.
[108] S. 85 of the ADMA.

resolution is not possible and the ambiguity remains, it should be resolved in favour of the preservation of the life of the directive-maker.

If a doctor, acting in good faith, fails to comply with the terms of a valid Advance Healthcare Directive as they didn't know it existed or its contents, they will not incur any civil or criminal liability. The existing common law rule remains in that a healthcare professional can be liable under either criminal or civil law if a healthcare professional deliberately fails to comply with a valid and applicable Advance Healthcare Directive.[109]

## ***5. Conclusion***

As capacity is fundamental to the exercise of self-determination,[110] this gatekeeper function can often be problematic because a determination of decision making capacity is, itself the product of a pre-established balance of moral principles of autonomy and beneficence. However the introduction of the ADMA has provided clarity in the eyes of the law. It establishes the presumption of capacity which places John firmly at the centre of decision making. Medical practitioners owe a duty of care to John to follow his wishes which he has previously requested.

[109] 'Advance Healthcare Directives - What You Need To Know' (hospicefoundation) <http://hospicefoundation.ie/wp-content/uploads/2013/04/Health-Directives-What-you-need-to-know..pdf> accessed 28 March 2017.
[110] Deirdre Madden, *Medicine, Ethics &The Law* (2nd edn., Tottel Publishing, 2008) p.393.

# Clinical Scenario C – Refusal of Treatment

***By***

***Julieanne Cawley & Anna Dwane***

*Mary is a 36-year old woman who has just been admitted to the hospice inpatient unit (IPU) following transfer from the local acute hospital.*

*Mary is married to and lives with David – they have no children. They seem to have frequently moved from place to place in Ireland and when asked could not confirm a current permanent address. Mary was evasive when asked about her own family. She has some contact with her husband's family but she did not want any visitors on this present admission.*

*Since her illness began, Mary has attended multiple different GP practices. In the previous year she has been admitted to, assessed at, and subsequently taken her own discharge from several hospitals in Ireland and abroad.*

## *(a) Diagnosis & Treatment*

- *Mary was given a diagnosis of stage IV metastatic ovarian cancer one year ago. The diagnosis has been repeatedly confirmed to them at each hospital location to which she has been admitted*
- *She and her husband continue to vehemently dispute this diagnosis and on this basis have declined any potential disease-modifying treatment of any kind (surgery, chemotherapy or radiotherapy) recommended to her*
- *The team caring for her at the hospital recognised that she was very unwell and that her likely survival was short and asked the Specialist Palliative Care Team at the hospital to assist with symptom management and probable end of life care*
- *Mary accepted transfer to the IPU for better management of her symptoms but she and David continued to refuse to accept that she might be dying*

## *(b) Mary's Problems on Admission to the IPU*

### *Physical*

- *Pain, but Mary refused to take analgesia*
- *She rarely accepted paracetamol from nursing staff but often hid it rather than took it*
- *She wouldn't take morphine-based medications stating that it would "slow her brain down"*
- *Abdominal ascites causing abdominal swelling contributing to her symptoms of pain, breathlessness, nausea & vomiting - further ascites drainage may have been helpful but Mary refused this*
- *She was bed bound and had little ability to alter her position in bed due to weakness and pain*
- *Nausea and vomiting, but Mary refused all offers of antiemetic medication*
- *Incontinence of both urine and faeces, but Mary refused catheterisation or changes of incontinence wear and sheets - four mattresses had to be destroyed due to contamination as David repeatedly cutting off the protective plastic covering the mattress*
- *Pressure areas at very high risk and extremely difficult to assess as Mary not consenting to having*

*them checked or treated.*

*Psychological*

- *Mary was very suspicious of all healthcare staff*
- *Despite numerous consultations with the medical team and frank discussions around her illness, Mary continued to deny that she had cancer, feeling instead that she "had a bad infection and it had progressed too quickly to be cancer"*
- *Mary was confused and forgetful at times but refused to let us assess her for possible reversible causes*
- *As her condition deteriorated, Mary's levels of consciousness would fluctuate*

*Social*

- *David's behaviour was erratic and occasionally volatile*
- *He refused to accept any suggestion that Mary might have cancer and became angry if this was challenged*
- *When present, David would speak for his wife, rather than letting her answer questions for herself*
- *Though she often demanded to be let home, we were never convinced that she and David could manage*

***(c) Matters of greatest concern***

- *David and particularly Mary's refusal to accept appropriate treatment to ease her physical distress*
- *That David's influence on his wife was such that she could not accept her illness or any form of assistance that the team wished to provide*
- *That Mary's death was imminent and as far as we could establish, neither she nor her husband was remotely prepared for it*
- *David presented us with letter that he had completed and that Mary had signed and dated the previous day. It stated that:*

    1. *Mary wished to have treatment for the infection in her body*
    2. *No-one was to discuss Mary's condition with her if David wasn't present*
    3. *If she ever got really sick she should be moved to an intensive care unit*
    4. *She demanded to have cardiopulmonary resuscitation whatever the circumstances*

***(d) Discharge***

- *Ultimately, and against all medical and nursing advice, Mary and David demanded that she be transferred back to the local acute hospital. This was facilitated*
- *She continued to refuse all medical and nursing care there and died at the hospital ten days later. David was not present.*

***Key Issues to be Discussed***

1. Does Mary have the capacity to participate in decisions regarding her healthcare?

2. If at any time Mary did not have the capacity to be involved in discussions regarding her care, how would one proceed?
   - ❖ Who should be consulted?
   - ❖ What evidence of Mary's wishes can be availed of?

3. What is the status of the letter David handed to the team looking after Mary?

4. Within the ADMA, what are the range of provisions for dealing with differing or conflicting opinions between:
   - ❖ Mary and the healthcare team?
   - ❖ David and the healthcare team?
   - ❖ Different members of the healthcare team

5. Mary demands transfer from the Hospice IPU to a busy hospital location – what is your view on what the hospice team did in response to this request?

***1. Does Mary have the capacity to participate in decisions regarding her healthcare?***

It would seem that Mary does not have the capacity to consent to, or refuse medical treatment as pursuant to S. 3(2) of the ADMA. The functional test for capacity which is applied in Ireland requires a patient to understand and retain the relevant information, believe that information and weigh up the information, balancing the risks and needs. Mary has attended multiple GP practices and has been admitted to multiple different hospitals. At each hospital, it has been confirmed that Mary has stage IV metastatic ovarian cancer, which she refuses to believe. As believing the information given is a key aspect to capacity, Mary can be assumed not to have capacity.

*1.1. Discussion:*

S. 3(2) of the ADMA states that – *'a person lacks capacity to make a decision 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 that information as part of the process of making the decision, or;*
*(d) To communicate his or her decision, or if the implementation of the decision requires the act of a third party, to communicate by any means with that third party.'*

The right to autonomy is protected under Article 40.3.1° of the Irish Constitution. In the case of *Fitzpatrick & Anor v K & Anor,*[111] Laffoy J. held that "*a competent adult is free to reject medical advice or decline medical treatment".* S. 8(2) of the ADMA asserts that it shall be presumed that a relevant person has capacity in respect of the matter concerned, unless the contrary is shown in accordance with the provisions of the ADMA.

[111] *Fitzpatrick & Anor v K & Anor* [2008] IEHC 104.

The case *Re a Ward of Court,*[112] dealt with the termination of artificial nutrition and hydration of a woman in a near persistent vegetative state. Hamilton J. held that the competent adult has the right to refuse medical treatment even though such a refusal may lead to death. O'Flaherty J. agreed that '*there is an absolute right in a competent person to refuse medical treatment even if it leads to death'.* Therefore, if Mary was found to have capacity, she would have a right to refuse medical treatment, even if it leads to death.

The HSE National Consent Policy 2013 provides that consent is the granting of permission for or agreeing to an intervention, receipt or use of a service, or participation in research following a process of communication about the proposed intervention. For consent to be valid, the service user must:

(a) Have received sufficient information in a comprehensive manner about the nature, purpose, benefits and risks of an intervention/service or research project;
(b) Not be acting under duress; and,
(c) Have the capacity to make the particular decision.

Mary has gone to multiple hospitals, all of which have given her the diagnosis of stage IV metastatic ovarian cancer, and have informed her of the available treatment. There is also evidence that Mary has experienced undue influence from her husband, David (this will be discussed later in Question 3). In accordance with the functional test for capacity (S. 3(2)), it would appear Mary is lacking in the requisite decision-making capacity.

## ***2. If at any time Mary did not have the capacity to be involved in discussions regarding her healthcare, how would one proceed?***

### *2.1. Whom might be consulted?*

S. 8 of the ADMA sets out guiding principles for healthcare professionals when there is ambiguity, as well as protecting the autonomy and dignity of a person with impaired capacity. Further, it is worthwhile to look at the HSE National Consent Policy,[113] which sets out the role of the family in medical decisions. It states that the family cannot give or refuse consent on behalf of Mary unless they have specific authority to do so. The healthcare team may however consult with the family to get an insight into Mary's previously expressed views.

#### *2.1.1. Discussion:*

S. 8(5) states that there shall be no intervention in respect of a relevant person unless it is necessary to do so having regard to the individual circumstances of the relevant person. While S. 8(6) minimises the restriction to the person's rights and freedom of action and must have due regard to the need to respect the person's right to dignity, bodily integrity, privacy, autonomy, and control over his/her financial affairs; it must be proportionate to the significance and urgency of the matter and be as limited in duration as practicable.

S. 8(8) sets out guidelines for who the intervener, in making an intervention, may consider the views of:

(a) Any person engaged in caring for the relevant person;

[112] *Re a Ward of Court* [1996] IR 79.
[113] *S. 5.6.2* of the National Consent Policy. (Dublin: HSE).

(b) Any person who has a bona fide interest in the welfare of the relevant person, or;
(c) Healthcare professionals.

On this basis, the healthcare professionals, in making an intervention must consider the views of David, Mary's family, any person who has a real and genuine interest in the welfare of Mary, and other healthcare professionals.

***S. 5.6.2*** of the HSE National Consent Policy sets out the role of the family in consenting. It sets out that no other person such as a family member, friend or carer, and no organisation can give or refuse consent to a health or social care service on behalf of an adult service user who lacks capacity to consent unless they have specific legal authority to do so. Nonetheless, it may be helpful to include those who have a close, ongoing, personal relationship with the service user. Their role in such situations is not to make the final decision, but rather to provide greater insight into his/her previously expressed views and preferences and to outline what they believe the individual would have wanted. [114]

*2.2. What evidence of Mary's wishes can be availed of?*

Mary's wishes have been set out in a letter that has been completed by David and that Mary has signed and dated. This raises the question of whether or not this letter constitutes a legally binding Advance Healthcare Directive (AHD), or simply a letter that can be used as a guideline of Mary's views. This is also largely dealt with in Question 3. Mary has also expressed some of her wishes orally to David and the healthcare team.

S. 84 of the ADMA provides for the formalities that must be complied with when making an AHD. The letter containing Mary's wishes does not comply with the formalities set out in S. 84, thus the letter does not constitute an AHD. Further, the possibility of undue influence from David will render the letter invalid as an AHD.

*2.2.1. Discussion*

- *Basic Care:*

  In its Consultation Paper,[115] the Commission provisionally recommended that an Advanced Healthcare Directive ("AHD") which directs a refusal of basic care, should not for reasons of public policy be enforceable. In the Commission's view, basic care that is designed to make the patient comfortable must always be provided. The Commission recommends that basic care should be defined to include, but not limited to, warmth, shelter, oral nutrition, hydration and hygiene measures. It also recommends that the proposed Code of Practice on Advance Care Directives should contain detailed guidance for healthcare professionals on what constitutes basic care. Mary has refused catheterisation or changes of incontinence wear and sheets, thus refusing basic care. However, it is a doctor's duty to provide basic care. Therefore, the healthcare team must continue to provide basic care for Mary.

- *The Letter Containing Mary's Wishes:*

  An AHD is *'a statement made by a competent adult relating to the type and extent of medical treatments s/he would or would not want to undergo in the future should s/he be unable to express*

[114] Part 10 principle 1 and part 11 principle 1 of the Nursing and Midwifery Board of Ireland Code of Professional Conduct and Ethics also provides for steps to be taken if it has been determined that a patient lacks capacity.
[115] Law Reform Commission. *Consultation Paper Bioethics: Advance Care Directives* (LRC CP 51-2008).

*consent or dissent at that time.'*[116] The Irish Nursing Board sets out that '*you should respect an individual's advance healthcare directive, if you know they have one'.*[117]

Nonetheless, for an AHD to be valid and applicable, there are formalities that must be complied with:

- S. 84(1) of the ADMA provides that a person who has attained the age of 18 years and who has capacity may make an AHD;
- S. 84(3) specifies that a request for specific treatment is not legally binding but shall be taken into consideration. In circumstances where it is not complied with, then the healthcare provider is to record the reasons for not complying with the request;
- S. 84(4) requires that an AHD shall be in writing;
- S. 84(5) sets out that an AHD should contain the name, date of birth and contact details of the directive maker, the date the directive-maker signed the directive and signatures of two witnesses.

While the letter written by David satisfies both S. 84(1) and S. 84(4) of the ADMA, the letter would be held invalid as an AHD, in accordance with S. 84(5) of the ADMA. The validity of an AHD is provided for under S. 85 of the ADMA, which will be discussed further in Question 3.

Finally, S. 90(2) provides that a person who knowingly creates, falsifies, alters, or purports to revoke an AHD on behalf of another person, who has capacity, without their consent commits an offence and shall be liable:

- On summary conviction, to a class A fine or imprisonment for a term not exceeding 12 months, or both, or;
- On conviction on indictment, to a fine not exceeding €50,000 or imprisonment for a term not exceeding 5 years, or both.

### *3. What is the status of the letter that David handed to the team looking after Mary and why?*

As set out in Question 2b, the letter given to the team looking after Mary does not comply with the formalities set out in S. 84 of the ADMA. Further, the letter does not comply with S. 85 of the ADMA which provides for the validity of an AHD. The letter is not valid as an AHD because Mary did not make the letter voluntarily. Furthermore, as shown in Question 1, it would seem that Mary may not have sufficient capacity.

#### *3.1. Discussion:*

S. 83 of the ADMA provides for the formalities of an AHD. S. 84(1) of the ADMA provides that a person who has attained the age of 18 years and who has capacity may make an AHD. Thus, Mary would satisfy the age requirement, but as it has been established in Question 1 that Mary lacks capacity to make an AHD.

Mary requested to have treatment for the infection in her body and demanded CPR whatever the circumstances. However, as underlined in S. 84(3)(a) of the ADMA, a request for specific treatment as set out in an AHD is not legally binding, but shall be taken into consideration during any decision-making process which relates to the treatment of the directive maker. The specific treatment must be relevant to the medical condition for which the directive maker requires treatment.

[116] Irish Council for Bioethics, '*Is it time for Advance Directives?*' (2007).
[117] Irish Nursing Board, '*Code of Professional Conduct and Ethics'* (2014).

S. 84(4) requires that an AHD shall be in writing, which is satisfied in this case. S. 84(5) sets out that an AHD should contain the name, date of birth and contact details of the directive maker, the date the directive-maker signed the directive and signatures of two witnesses. This formality has not been complied with, along with the capacity requirement. Therefore the letter would not constitute an AHD, under this section.

The validity of AHD's is provided for in S. 85 of the ADMA:

- S. 85(1) provides that an AHD is not valid if the directive-maker did not make the directive voluntarily or while s/he had capacity to do so.
- S. 85(2)(b) states that an AHD is not applicable if the treatment in question is not materially the same as the specific treatment set out in the directive that is requested or refused. This alone could quash the letter, as the treatment set out is not materially the same treatment that is required for Mary's illness.
- S. 85(3) affirms that an AHD is not applicable to life-sustaining treatment unless this is substantiated by a statement in the directive by the directive-maker to the effect that the directive is to apply to that treatment even if his or her life is at risk.

S. 87(1) of the ADMA provides that a directive maker may designate, in his or her AHD, a named individual to exercise the relevant powers. Under S. 90(1) and S. 90(2) of the ADMA a person who uses fraud, coercion or undue influence to force another person to make or who knowingly themselves creates, falsifies, alters, or purports to revoke an AHD on behalf of another person, without that other person's consent in writing shall be guilty of an offence. As there is some evidence of the undue influence of David on Mary, this provides for the charges that David may face.

An Enduring Power of Attorney is set out in S. 59 of the ADMA. An Enduring Power of Attorney is where a person gives another person power to make decisions relating to personal welfare or property affairs, or both. An Enduring Power of Attorney is designed to take effect at a future time when the person lacks capacity.[118] S. 59(2) of the ADMA provides that the instrument conferring an Enduring Power of Attorney shall be in writing and comply with regulations set out in S. 79. Under S. 59(1) a person who has attained the age of 18 years old may appoint another person, who has also attained that age on whom he or she confers either or both of the following:

(a) General authority to act on the donor's behalf in relation to all or specified part of the donor's property and affairs; or
(b) Authority to do specified things on the donor's behalf in relation to the donor's personal welfare or property and affairs, or both.

However, the procedure for executing the Enduring Power of Attorney is complex and requires the involvement of a solicitor and a doctor. The Enduring Power of Attorney can only come into effect when certain procedures have been completed and the Courts have a general supervisory role in the implementation of the power. As these procedures have not been followed, the letter does not give David the status of Enduring Power of Attorney.

A Decision-Making Assistant means the person who the appointer has, under S. 10(1), appointed to assist the appointer in making decisions on the appointer's personal welfare or property and affairs, or both, in compliance with regulations made under S. 10(4). Section 11(1) of the ADMA sets out persons who are not eligible to be a Decision-Making Assistant.

[118] www.inclusionireland.ie

Where a person considers that their capacity is in question, or may shortly come into question, that person may appoint someone else to jointly make with them one or more decisions about their welfare and property and affairs. A suitable Co-Decision-Maker is defined in the ADMA as a relative or friend with whom the person has a relationship of trust built up over a period of personal contact and that the Co-Decision-Maker is able to perform the duties of the role.[119] However, David does not qualify as a Co-Decision-Maker as a Co-Decision-Making Agreement must be registered with the Director of the Decision Support Service within five weeks of signing. This requirement has not been complied with.

## ***4. Within the Act, what are the range of provisions for dealing with differing or conflicting opinions between:***

### *4.1. Mary and the Healthcare team?*

If it is established that Mary has capacity to consent to, or refuse medical treatment, then her decision should be respected. However, if it is established that she doesn't not have the capacity to consent to, or refuse medical treatment, then the Healthcare team should follow the guiding principles set out in S. 8 of the ADMA.

### *4.2. David and the healthcare team?*

It has already been established that David has not acquired any legal authority to make a decision on behalf of Mary, as he qualifies as neither having a power of attorney nor as a co-decision maker, provided for in S. 59 and S. 17 of the ADMA respectively. Both the *National Consent Policy* and the *Guide to Professional Conduct and Ethics* set out that the healthcare team are not obliged to follow David's orders, however, may look to him for a greater insight into Mary's previously expressed views.

#### *4.2.1. Discussion:*

It is essential for the healthcare team to maintain good communication with family members. However, this does not mean that family member's views should have precedence over the legal and ethical obligation of the healthcare professional to provide care to the patient.[120]

S. 8(8) of the ADMA provides that the intervener, in making an intervention in respect of a relevant person, may consider the views of –

(a) Any person engaged in caring for the relevant person;
(b) Any person who has a bona fida interest in the welfare of the relevant person, or;
(c) Healthcare professionals.

***S. 22.4*** of the *Irish Medical Council Professional Guidelines*,[114] provides that a medical practitioner should take care to communicate effectively and sensitively with patients and their families so that they can have a clear understanding of what can and what cannot be achieved. A medical practitioner should offer advice on other treatment or palliative care options that may be available to them.

***S. 5.6.1*** of the *National Consent Policy* states that no other person such as a family member, friend or carer and no organisation can give or refuse consent to a health or social service on behalf of an adult service user who lacks capacity to consent unless they have specific legal authority to do so, such as enduring

[119] S. 2(1) of the ADMA.
[120] Healthcare Decision Making and the Role of Rights (www.hospicefoundation.ie, 2013).

power of attorney. It may be helpful to include those close to the patient in the discussion and decision-making process pertaining to health and social care interventions. Their role is not to make the final decision, but rather to give insight into his/her previously expressed views and preferences and to outline what they believe the individual would have wanted.

As it has already been established that David is not legally a co-decision maker, or Enduring Power of Attorney, he therefore does not have the power to make decisions on behalf of Mary. Instead, he would be able to provide the healthcare team with an insight to Mary's previously expressed views.

***Section 41.3*** of the *Guide to Professional Conduct and Ethics*,[114] sets out that if there is any doubt about the existence of an advance treatment plan, the patient's capacity at the time of the making the treatment plan or whether it still applies in the present circumstances, you should make treatment decisions based on the patient's best interests. In making such a decision, the healthcare team should consult with any person with legal authority to make decisions on behalf of the patient and the patient's family where possible.

Consequently, David has no legal authority to make decisions on behalf of Mary, so the healthcare team are not obliged to follow his wishes. They may, however, take into consideration his views when making a decision that is in Mary's best interests.

### *4.3. Different members of the healthcare team?*

There is nothing in the ADMA that addresses conflicting opinions between different members of the healthcare team. All decisions made by the healthcare team should take into account the patients will and preferences.

## ***5. Mary demands transfer from the Hospice IPU to a busy hospital location – what is your view on what the hospice team did in response to this request?***

It is recognised by the authors that this was a difficult decision which the healthcare team were faced with. However, there is insufficient evidence to comment definitively on what type of approach should be taken under the ADMA in these circumstances.

# Clinical Scenario D – Family Decision-Making

***By***

***Mark O' Sullivan & Leanne Griffin***

*Mrs X is an 80yr old lady, living in the Nursing Home for the past 3 yrs. She has an element of cognitive impairment, although has never been formally diagnosed with dementia. Her health has been deteriorating over recent months, and she has been treated for several chest infections which has necessitated admissions to hospital.*

*One evening, the staff nurse had a discussion with Mrs X's daughters regarding Mrs X's condition and it was decided by her family that treatment was upsetting, disruptive and futile; and she would not be transferred to hospital in the event of future infections. Mrs X's daughters reported that Mrs X hated hospital and would be much happier in the Nursing Home, surrounded by familiar staff in a homely environment. They understood that this decision would mean Mrs X would be for "comfort measures" and not for cardiac resuscitation. The staff nurse carefully documented in the "End of Life" section of the nursing care plan that the resident was not to be transferred to hospital in the event of illness.*

## ***Key Issues to be Discussed:***

The purpose of this report is to assist Milford Care Centre (**"Nursing Home"**) in identifying and addressing the key issues in the above scenario. The key issues relating to Mrs X who resides in the Nursing Home will be discussed as follows:

1. ***Assumed Capacity***
2. ***Assessing Capacity***
3. ***Third Party Consent – Decision-Making Supports***
4. ***Do Not Resuscitate Order (DNAR)***

## ***1. Assumed Capacity***

**From the scenario, it is clear that Mrs. X suffers from an "element of cognitive impairment". However, she has not been formally diagnosed with dementia. As stated in S. 2 of the ADMA, everyone is presumed to have capacity unless otherwise stated. Therefore it is assumed that Mrs. X has decision-making capacity**.

S. 3(1) of the ADMA defines capacity as a person's *'ability to understand, at the time the decision is to be made, the nature and consequences of the decision to be made by him or her in the context of the available choices at the time.'*

It is imperative to note that the ADMA requires the patient to understand the consequences of their decision at the time it is to be made. The Courts have been seen to take a flexible view regarding capacity as *to 'impose too high a test of capacity to decide issues such as residence because to do so would run the risk of discriminating against persons suffering from a mental disability'*.[121] The principle finding of this case is that although someone may suffer from a mental impairment, they may still be considered as having the requisite decision-making capacity.

[121] *PH v A Local Authority & Z Limited* (2011) EWHC 1704.

The Irish Medical Council emphasises that:

'*every adult patient is presumed to have the capacity to make decisions about their own healthcare. As their doctor, you have a duty to help your patients to make decisions for themselves by giving them information in a clear and comprehensible manner and by ensuring that they have appropriate help and support. The patient is also entitled to be accompanied during any such discussion by an advocate of their own choice*'.[122]

When consenting to medical treatment or the refusal of medical treatment, any consent obtained must be informed consent. Informed consent is the process whereby a health care professional discloses all necessary information to a patient prior to obtaining consent to go ahead with a procedure.[123] This consent can be obtained from the patient or their legally recognised representative. The consent obtained must be free from any element of inducement, fraud, deceit, duress or coercion. In the absence of obtaining this consent, where the medical treatment is performed, medical professionals may be held liable for a criminal offence i.e. if touching a person without his permission is unlawful, it follows that the doctor who treats the patient without his consent is on breach of the law.[124] As noted by Cardozo J. *'a surgeon who performs an operation without the patient's consent commits an assault.'*[125] In their report Supporting People's Autonomy,[126] HIQA have placed great emphasis on the person's right to autonomy. The central idea of autonomy is that one's actions and decisions are one's own.[127] From this, it can be concluded that in addition to the capacity to consent, a patient may also be considered as having the capacity to refuse medical treatment.

***2. Assessing Capacity***

**Mrs. X should be assessed by a healthcare professional prior to every decision she makes as she may experience differing periods of incapacity and lucidity. If, on assessment, Mrs. X is found to lack decision-making capacity, and if the matter is not pressing, the decision may be postponed until she returns to a lucid state and recovers the necessary capacity.[128]** S. 3(2) of the ADMA provides that:

*'a person lacks capacity to make a decision if he or she is unable:*

- *(e) to understand the information relevant to the decision;*
- *(f) to retain that information long enough to make a voluntary choice* (people diagnosed with dementia or similar conditions may struggle with this);
- *(g) to use or weigh that information as part of the process of making the decision* (i.e. may not understand the importance of the decision); or
- *(h) to communicate his or her decision (whether by talking, writing, using sign language or assistive technology)* or if the implementation of the decision requires the act of a third party, to communicate by any means with the third party.

Every effort must be made to facilitate the patient's understanding of the relevant information. This may be achieved through the use of clear language, visual aids or by any other means. The language used in assisting a patient's understanding must be appropriate to their circumstances. The person cannot be

[122] Irish Medical Council Guide to Professional Conduct and Ethics (Dublin: Irish Medical Council) p. 34
[123] Deirdre Madden, *Medicine, Ethics and the Law* (1st ed. Tottel Publishing, 2007) p. 410
[124] Simon Mills, *Clinical Practice and the Law* (2nd ed. Tottel Publishing, 2007) p. 77
[125] *Schloendorff v Society of New York Hospital* [1914] 211 NY 125
[126] https://www.hiqa.ie/sites/default/files/2017-01/Supporting-Peoples-Autonomy.pdf.
[127] Dworkin, *The Theory and Practice of Autonomy* (1988) p. 108.
[128] S. 3(5) of the ADMA.

deemed to lack capacity if he or she does not understand complex medical terminology. This strongly represents the principle that the person is assumed to have capacity unless otherwise proven.

The fact that a patient may only retain the relevant information for a short period of time does not prevent them from demonstrating the appropriate decision-making capacity in that period.[129] As it may be difficult to comprehend the entire decision, it is only required that a patient understands the salient factors (those which are most important to the decision).[130] It should also be noted that capacity can fluctuate and when a patient is experiencing a lucid period they are considered as having complete capacity and this cannot be restricted.

The ADMA provides a number of guiding principles. These principles provide guidance as to when an intervener is permitted to take action under the ADMA on behalf of the relevant person. This action is known as an intervention. There will be no intervention in respect of a relevant person unless it is necessary to do so, having regard to the individual circumstances of the relevant person.[131] This essentially means that the person can conduct their own affairs without the assistance of others, unless they are deemed to lack capacity.

The Irish Constitution grants patients a number of personal rights (i.e. a right to dignity, bodily integrity, privacy, autonomy, and control over their own finances) which may only be minimally restricted. In the event of a restriction, it must be proportionate to the significance and urgency of the matter and as limited in duration as practicable.[132] This principle safeguards the idea that a person is always assumed to have capacity.

When partaking in an intervention, the intervener should take into account the views of any person engaged in caring for the relevant person, any person who has a *bona fide* interest in the welfare of the relevant person and any healthcare professional.[133] This ensures the will of preferences of the relevant person will be considered in the decision-making. By allowing for suggested decisions from all relevant parties, i.e. the patient's carers, relatives and any healthcare professionals, the intervener can make a more informed decision on the relevant person's behalf.

If the relevant person is found to lack capacity, the intervener should take into account the likelihood that they may recover the necessary capacity at a later time. If a person is found to lack capacity and it may possibly be recovered, an intervention may be delayed until such a time it is regained. However, this will depend on the urgency of the intervention.

### *3. Third Party Consent – Decision-Making Supports*

**Perhaps putting a Co-Decision-Making Agreement in place would be the best decision for Mrs. X. All the children could be made co-decision makers and as they are children there is already a relationship of trust established. Mrs X may or may not have the capacity to refuse treatment and go to hospital, but to clarify the family's position in their refusal to treat chest infections it would be best if they formally had the capacity to do this; a co-decision-making order.**

A person who is concerned about their future capacity may appoint a Decision-Making Assistant (DMA), a

[129] S. 3(4) of the ADMA.
[130] *CC v KK & STCC* [2012] EWHC 2136.
[131] S. 8(5) of the ADMA.
[132] S. 8(6) of the ADMA.
[133] S. 8(8) of the ADMA.

Co-Decision-Maker (CDM), a Decision-Making Representative (DMR), a Designated Healthcare Representative (DHR) or an Enduring Power of Attorney.

- The DMA is appointed in a Decision-Making Assistant Agreement. The appointer and the individual being appointed must both have attained the age of 18[134]. The formalities of what the Decision-Making Assistant Agreement will entail are yet to be finalised.[135] This agreement may be revoked or varied at any time.[136] The DMA is appointed to assist the relevant person (the appointer) to understand and assist them in the decision-making process but never make the decision for them.[137]
- A CDM is appointed in a Co-Decision-Making Agreement. The individual appointed as a CDM may be a relative or a friend or the appointer, or an individual who has a previously established relationship of trust with the appointer.[138] An appointer may choose to have more than one CDM at a time to act on different decisions for them. The CDM's role differs from that of the DMA as they jointly make decisions with the appointer rather than only assisting them with their decision-making.[139]
- A DMR is appointed by the court when a co-decision maker cannot be identified. The court will only do this if the matter is urgent. It must be made sure that the role will not be inconsistent with any enduring power of attorney present. The court could will look as some factors in determining the appointment of the decision-making representative; if there is any family connection, it will be influential. The court may appoint them for a certain reason such as safeguarding the person's finances. If it is for safeguarding the person finances, then their qualifications will be assessed to determine if they are the best person for the post. The decision-making process is like the other two agreements; where the decision can be made jointly, jointly and severally or either or in certain decisions.

***4. Do Not Attempt Resuscitation Order (DNAR):***

**With regards to Mrs X, a decision to not provide cardiac resuscitation would be imposing a DNAR. Her age should not be a major factor in the making of this decision. This decision should be made on the basis of the likely success of CPR and the risks and benefits of carrying out CPR. A DNAR order must be recorded in the patient's file. If Mrs X is determined to have capacity then she should make this decision for herself, as outlined below and should at least, be informed of the implementation of such an order. If Mrs X is deemed to not have capacity to make a decision for herself, then the Staff Nurse can consult with Mrs X's daughters to find out what her beliefs or preferences may be. The Nurse should not however allow their views to make her final decision. The Nurse's final decision should be made on the basis of what is in the best interests of the patient, as outlined below. It could be lawful for the treatment to be withheld provided it is in the best interests of the patient.**

A DNAR order allows patients to express any future wishes for Cardio-Pulmonary Resuscitation ("CPR") not to be used on them if a situation arises where they may need it. In Ireland, there is a lack of legislation in this area. The ADMA initially intended to legislate for DNAR's, but unfortunately it was not implemented. As

[134] S. 10(1) of the ADMA.
[135] S. 10(5) of the ADMA.
[136] S. 10(2) of the ADMA.
[137] S. 14(1) of the ADMA.
[138] S. 17(2) of the ADMA.
[139] S. 19(1) of the ADMA.

there is also a lack of Irish case law regarding this area, one can turn to similar case law from England. Professional Codes of Conduct, such as the Irish Medical Council Guidelines[140], and the HSE National Consent Policy 2014[141] also provide guidance in relation to the making and enforcement of DNAR orders. It should be noted that both the Irish Medical Council Guidelines and the HSE National Consent Policy are provided as sets of guidelines and hold no legal basis in relation the matter.

The HSE National Consent Policy, Part 4[142] focuses solely on DNAR's. It notes that if a person's wishes regarding CPR are unknown, or if there is an emergency situation and their preferences are unknown, then there is an automatic presumption in favour of providing CPR[143]. It also notes that when deciding whether or not to proceed with CPR, all future consequences[144], risks and the patient's current health must all be taken into consideration. It is also noted that there is a lack of clarity in relation to the making of a DNAR, how to record them and the role that others, such as close family members, can take in the making of one.

Part 3 of S. 4[145] of the policy outlines that decisions about CPR must be made by way of individual assessment for each case. It should not be based on the patient's health, age, or on the views of others. It highlights the importance of taking into consideration the patient's own views, values and preferences, as well as the likelihood of CPR being successful and any possible risks or benefits. Part 3[146] notes the need for healthcare professionals to respect a patient's wishes to involve others, i.e. family members or friends, in their decision-making. If they still have decision-making capacity, they must consent to the involvement of such individuals in the decision-making process. If the patient is found to lack capacity, any third party, who maintains a close, on-going personal relationship with the patient, may be able to provide insight in relation to any wishes, preferences or beliefs that they may have previously mentioned. The discussion between a healthcare professional and any relevant third party should allow for weighing up any benefits and/or risks of CPR. The relevant third party is not entitled to come to a conclusive decision regarding CPR. Their provision of information is merely to aid healthcare professionals to make appropriate decisions. If it is decided that they will not proceed with CPR, it is not necessary to acquire the third party's consent, however, it is considered good practise to inform them what is happening.

Part 6[147] notes that if a person with capacity refuses CPR and makes a DNAR, it should be respected, regardless of a healthcare professional's opinion. This applies where the patient previously made a valid DNAR while they had the capacity to do so, but now they are found to lack capacity. Again, it is emphasised that if the person wishes that this decision be discussed with a relevant third party, it should be respected however, they cannot make the final decision. Their input is to assist the healthcare professional to make the most appropriate decision.

The Irish Medical Council Guidelines also provide some guidance in relation to DNAR's. It notes that a patient's right to refuse medical treatment should be respected[148], every adult with capacity can refuse medical treatment and that should be respected[149], a person may want to plan their medical treatment in the future, in case they become incapacitated, this can include refusing treatment[150]. It states this type of

[140] Professional Conduct Ethics: A Guide to Professional Conduct and Behaviour for Registered Medical Practitioners (The Irish Medical Council).
[141] HSE. National Consent Policy: Do not attempt resuscitation (DNAR). (Part 4, Quality and Patient Safety: HSE).
[142] *Ibid.*
[143] Ibid, Part 5.
[144] Ibid, Part 6.
[145] *Ibid.*
[146] *Ibid.*
[147] *Ibid.*
[148] Section B, Part 22.3.
[149] Section D, Part 40.1.
[150] Section D, Part 41.1.

decision-making maintains the same status as a decision made by a patient at the actual time of an illness. Provided it was an informed decision, the patient has not since changed their mind and the decision covers the situation in question, it must be respected. It notes that if there is doubt about the existence of such a decision, doubt about capacity at the time it was made or whether it still applies in the circumstances, then decisions in regards to treatment should be made in the patients best interests and when doing so, a person with legal authority to make decisions on the patient's behalf or their family, should be consulted.[151]

As previously mentioned there is a lack of Irish case law, in the English case of *Re R,*[152] R, a 23 year old man, was born severely disabled, with minimal awareness. In the year prior to the making of the DNAR decision, he was hospitalised 5 times. It was agreed by R's Doctor and parents that if he suffered from a life-threatening condition, CPR was not to be carried out. This was allowed by the Court. They considered factors such as R's quality of life after CPR in making their decision.

In *Tracey v Cambridge University*[153]*,* Mrs. Tracey was made the subject of a DNAR order regarding CPR when she was admitted to the hospital after a car accident. She was also a cancer patient. This DNAR order was lifted after her family objected to it, as neither Mrs. Tracey, nor her family had been consulted about it. Her family brought a claim, claiming it breached her rights, as they failed to consult her or her family about it's being made, they did not notify her about its being enforced, they did not offer her a second opinion, failed to make their DNAR policy available to her and failed to have a clear and unambiguous policy. It was held there was an unlawful failure to involve Mrs. Tracey in the decision to impose the first DNAR as they should have involved the patient in the decision-making process and allow the patient to get a second opinion.

Madden[154] notes that the decision to make a DNAR is influenced by both medical and non-medical factors. If it is possible to talk to the patient, then the refusal must be complied with but this can be disregarded in certain situations. If the patient does not have capacity, then the doctor should consult with the medical and nursing team and the patient's family, and then make a decision in the best interests of the patient.

[151] Section D, Part 41.3.
[152] *Re R (Adult; medical treatment)* [1996] 2 FLR 99.
[153] *Tracey v Cambridge University Hospital NHS Foundation Trust* [2014] EWCA Civ 822.
[154] Deirdre Madden. *Medicine, Ethics and the Law in Ireland, p. 537.*

# Conclusion

*"Healthcare decisions can be among the most important decisions which any of us make in our lives. This is why facilitating people with impaired capacity to make such decisions in line with their values and preferences to the greatest extent possible is a goal worth pursuing."*[155]

The purpose of this project is to provide a detailed report on the interpretation and application of the Assisted Decision-Making (Capacity) Act 2015. The community partner for the project, Milford Care Centre, provided the authors with four clinical scenarios which encompassed both legal and ethical issues. The scenarios analyse these issues and apply the Act accordingly. In doing so, the authors hope to assist in supporting healthcare professionals, patients and families to understand the relatively new legislation.

[155] Mary Donnelly, 'The Assisted Decision-Making (Capacity) Act 2015: Implications for Healthcare Decision-Making (2015) 22(2) *Medico-Legal Journal of Ireland* 65-74.

# Glossary of Terms

***Attorney*** - a person (over 18), called a Donor, may confer certain authorities on another person over the age of 18, referred to as an Attorney (s. 59(1) ADMA 2015). The Donor would give the Attorney a general authority to make decisions for them in relation to all or a specific part of their property or welfare. The Donor also gives the Attorney authority to do specific things on their behalf in relation to their personal welfare, property or affairs.

***Basic Care*** - basic care is essentially the day to day care that a patient should receive. It includes (but is not limited to) warmth, shelter, oral nutrition, oral hydration and hygiene measures but does not include artificial nutrition or artificial hydration.

***Co-Decision Maker Appointer*** - where a patient (over 18) believes their capacity is or may soon be in question, appoints a relative, friend or person with whom they hold a relationship of trust to jointly make with them, specific decisions relating to their personal welfare, i.e. medical decisions, or property or both (s. 17(2) ADMA 2015).

***Co-Decision Making Agreement*** - an agreement in which an appointer formally appoints their chosen CDM. This is a formal written agreement.

***Cohabitant*** - one of two adults (whether of the same sex or the opposite sex) who live together as a couple in an intimate and committed relationship and who are not related to each other (S. 172 of the Civil Partnership and Certain Rights and Obligations of Cohabitants Act 2010).

***Court Friend*** - a person appointed to be a court representative of an individual who lacks capacity. This may include representation at any court connected meeting, consultation or discussion. This Court Friend must consider the will and preferences of the person they are representing at all times (S. 100(2) ADMA 2015).

***Debt Settlement Agreement*** - an agreement entered into by a person who cannot afford to pay their debts (S. 2 of the Personal Insolvency Act 2012).

***Decision-Making Assistance Agreement*** - an agreement entered into by an appointer and their appointed DMA. The minister is still to establish specific regulations governing this agreement. This agreement may be revoked by the appointer any time.

***Decision-Making Representation Order*** - an order of the Circuit Court appointing a person to make one or more specific decisions for an individual who lacks decision-making capacity. These decisions regard the individual's personal welfare or property and affairs, or both.

***Decision Support Service*** - is a supervisory and regulatory body for all decision-making supports. It is headed by the Director (see below) and its primary functions are provided for in S. 95(1) of the ADMA 2015.

***Designated Centre*** - A designated centre refers to a location in which the HSE provides a residential service i.e. care, home-help, etc. The designated centre cannot be the person's own house but part of a government based scheme. The Health Information and Quality Authority provide a concise summary of what constitutes a 'designated centre'.[1]

***Director of the Decision Support Service*** - is a regulatory body whose function is to promote the appropriate use of the Act and ensure that the provisions of the Act are adhered to and implemented correctly. If a person has any issues with a certain provision of the act or suspect any discrepancies, they should contact the Director of the Decision Support Service for a thorough investigation.

***Disqualification Order*** - if a person has been subject to a disqualification order under s. 838 of

the Companies Act 2014, they are disqualified from acting in the following positions:

(a) Decision-Making Assistants;
(b) Co-Decision Makers;
(c) Decision-Making Representatives;
(d) Attorneys acting under an Enduring Power of Attorney; or
(e) Designated Healthcare Professionals

***Donor*** **-** a Donor (being the person who may lack the capacity in the future) gives a general power to an Attorney (the person providing assistance) to act on their behalf in respect of all or some of the person's property and affairs, or to do specified things on the Donor's behalf.

***General Visitor*** **-** appointed by the Director to assist them with any supervisory functions. These may include assistance with: (a) the performance of functions as instructed to the director; (b) the supply of services; and (c) outlining information and guidance by him or her under the act.

***Healthcare Professional*** **-** may be a registered medical practitioner (see below) or another healthcare professional appointed to monitor the health and well-being of the relevant person.

***Immediate Family Member*** **-** as per S. 17(10) an immediate family member may consist of:

a) a spouse, civil partner or cohabitant;
b) a child, son-in-law or daughter in-law;
c) a parent, step-parent, mother-in-law or father in law;
d) a brother, sister, step-brother, step-sister, brother-in-law or sister-in-law;
e) a grandparent or grandchild;
f) an aunt or uncle; or
g) a nephew or niece

***Nullity*** **-** refers to a legal agreement which is held null/void (S. 12 ADMA). The Act sets out a decision-making agreement concerning relevant decisions made concerning the person who lacks capacity, and these will be held null or void when a specified events occurs. These specified events in relation to the relevant decision are as follows:

a) A decision-making order, a decision-making representation order or co-decision-making agreement in relation to the appointer;
b) An advance healthcare directive made by the appointer and the appoint lacks capacity; or
c) An Enduring Power of Attorney or enduring power under the Act of 1996 made by the appointer that has entered into the force.

***Interim Order*** **-** a temporary court order issued by the court, intended to be of limited duration, usually until the court has had an opportunity to hear the full case and make a final order. It protects the relevant persons' interests until a final order from the court.

***Jointly and Severally*** **-** a partnership in which individual decisions are bound to all parties involved, coupled together in interest; shared between two or more persons. It is a combined, undivided effort or undertaking involving two or more individuals. It can act independently, separately, singly, or solely or being severally responsible in respect of the relevant person matters.

***Judicial Separation*** - it is a legal separation where the court grants a decree of judicial separation on a number of grounds including adultery, unreasonable behaviour, desertion, existing separation or where a normal marital relationship has not existed for at least one year prior to the application. A decree of Judicial Separation can be sought in the Circuit Court or the High Court depending on the financial circumstances of the parties.[2]

***Mental Health Commission*** - the Commission is an independent statutory body and its functions are to promote, encourage and foster high standards and good practices in the delivery of

mental health services and to take all reasonable steps to protect the interests of persons detained in approved centres under the Mental Health act 2001 (S.33(1)).

***Revocation*** - The recall of some power, authority, or thing granted, or a destroying or making void of some deed that had existence until the act of revocation made it void. It may be either general, of all acts and things done before; or special, to revoke a particular thing (Black's Law Dictionary).

***Revocation in Part*** **-** revocation whereby the co-decision-maker continues to act as co-decision-maker for the appointer in respect of one or more relevant decisions which are the subject of the co-decision-making agreement.[3]

***Treatment*** **-** an intervention that is or may be done for a therapeutic, preventative, diagnostic, palliative or other purpose related to the physical or mental health of the person, and includes life-sustaining treatment.

***Personal Welfare*** **-** in relation to the relevant person, 'personal welfare' means one or more of the following matters:

a) accommodation, including whether or not the relevant person should live in a designated centre;
b) participation by the relevant person in employment, education or training;
c) participation by the relevant person in social activities;
d) decisions on any social services provided or to be provided to the relevant person;
e) healthcare; or
f) other matters relating to the relevant person's well-being.

***Registered Medical Practitioner*** **-** a medical practitioner whose name is entered in the register (S.2 of the Medical Practitioners Act 2007). Only doctors who are registered with a licence can treat patients by law. Patients can check the register to verify that their doctor is on the register on www.medicalcouncil.ie.

***Relevant Powers*** **-** a designated healthcare representative has the power to ensure that the terms of the advance healthcare directive are complied with. A directive-maker may, in his or her advance healthcare directive, consult with his or her designated healthcare representative on one or both of the following powers:

a) the power to advise and interpret what the directive-maker's will and preferences are regarding treatment, by reference to the relevant advance healthcare directive; and
b) the power to consent or refuse treatment, up to and including life-sustaining treatment, based on the known will and preferences of the directive-maker.

***Special Visitor*** - a person whose medical qualifications have been recognised by the relevant health authorities (HSE) or can also be a non-medical practitioner as long as the director believes the person has an understanding of the patient's capacity.

***Voluntary Choice*** **-** when the patient makes a decision based on their own free will even if it's against the advice of the medical practitioner.

***Wills and Preferences*** **-** the will and preference of the patient is essentially what the patient wishes or does not wish to happen to them. The patient may consent to certain treatments but also may refuse certain procedures. This should be set out in any agreement ordered and constructed under this Act.

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