Promoting Assisted Decision Making in Acute Care Settings

Up to 6 players can take part in a game. The facilitator will guide players through the stages of the game, shown below.

Full game (90 min)

1 Setup & info Each player selects one story card, finds the linked issue cards, and then selects two info cards. Next, they read the guidelines and information about the ADMCA on the placemat. (20 min)

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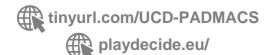
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PlayDecide: PADMACS

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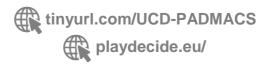
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Promoting Assisted Decision Making in Acute Care Settings

Guidelines

- 1. You have a right to a voice: speak your truth ...
- 1. But not the whole truth: don't go on and on.
- 1. Value your life learning.
- Respect other people.
- 1. Allow them to finish before you speak.
- Delight in diversity.
- 1. Welcome surprise or confusion as a sign that you've let in new thoughts or feelings.
- 1. Look for common ground.
- 1. 'But' emphasises difference; 'and' emphasises similarity.

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Promoting Assisted Decision Making in Acute Care Settings



My position on assisted decision-making









Older adults

Healthcare professionals Policy makers

What key	learnings will	l I take away f	from p	laying th	is game?
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I can apply these key learnings by ...





PlayDecide: PADMACS

Promoting Assisted Decision Making in Acute Care Settings



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Family carers

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Promoting Assisted Decision Making in Acute Care Settings



ABOUT THE ASSISTED DECISION-MAKING ACT

The Assisted Decision-Making (Capacity) Act 2015 provides new arrangements, procedures, guiding principles and structures for maximising the decision-making capacity of all. There is a statutory presumption that all individuals have decision-making capacity and shall not be deemed to lack that capacity unless all reasonable steps have been taken, without success, to help them.

IMPLICATIONS FOR PRACTICE

Under the Act, capacity is context and time-bound. This means that functional capacity is assessed on the basis of the person's ability to understand, at the time that a decision is to be made, the nature and consequences of that decision, in the context of the available choices at that time.

The Act provides a statutory framework of tiered decision supports appropriate to the level of decision-making capacity of the individual:

- 1) At the lowest level, a person may appoint a decision-making assistant to help him/her to obtain and assimilate information and communicate the decision
- 2) At the middle level, a person may appoint a co-decision maker with whom he/she may make decisions jointly
- At the upper level, the courts may intervene to make a declaration of incapacity in relation to certain matters and appoint a representative to act as a substitute decision-maker

The guiding principles of the Act place the will and preferences, beliefs, and values of the person at the centre of the decision-making process. Therefore, in making any intervention, an intervener must give effect to the past and present will and preferences of the individual. Where tiered decision support is in place for a person, an intervener must consider the views of any decision-making assistant, co-decision maker or decision-making representative. This pertains to healthcare interventions made by healthcare professionals.

The Act also provides for the establishment of the Office of the Decision Support Services which has regulatory and information functions.

(See https://www.mhcirl.ie/DSS/)

PlayDecide: PADMACS

Promoting Assisted Decision Making in Acute Care Settings



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Setup & info

Discussion

Story Card Info Card Place your chosen story card here



Info Card

Place your chosen info card here



Issue Card

Place your chosen issue card here

Issue Card

Place your chosen issue card here





Key themes

SHARING INFO Story cards 1 - 11

CONTROL & POWER Story cards 12 - 29

RESOURCES Story cards 30 - 41

ENVIRONMENT Story cards 41 - 54

COMMUNICATION Story cards 55 - 69

Three stages of PlayDecide: PADMACS

Full game (90 min)

Select a story card, find the linked issue cards, then select two info cards at random. Next, read the guidelines and information about the ADMCA on the placemat. (20 min)

Summarise your cards for the group, and identify and discuss themes and issues related to ADM, focusing on the perspectives and issues raised by the cards. (30 min) Next, share your own perspective and experiences relevant to the discussion. (20 min)

Reflect on the discussions and your own experience, then fill out a perspective sheet. (20 min) Reflection

Quick game (40 min)

Select a story card, find one linked issue card, then select two info cards at random. Next, read the guidelines and information about the ADMCA on the placemat. (10 min)

Briefly summarise your cards, and identify and discuss themes and issues related to ADM, focusing on the perspectives and issues raised by the cards. (10 min) Next, share your own perspective and experiences relevant to the discussion. (10 min)

Reflect on the discussions and your own experience, then fill out a perspective sheet. (10 min)

Next steps

Action

Think about how you can implement ADM in your working practice to fully incorporate the will and preferences of patients.



PADMACS:

Promoting Assisted
Decision Making in
Acute Care Settings







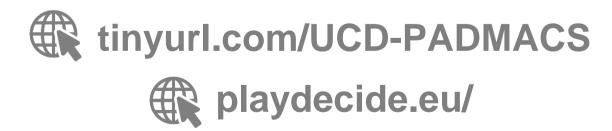












How many conversations is enough?

Links to: Issue Cards 4 + 9



Tommy is a nurse.

We had an 85-vear-old attending frequently at our day hospital. She was living alone with a history of self neglect in relation to medication compliance and self care. When presenting to us she was guite well and was able to hold a conversation. The primary care team felt that she needed a home care package. They had been working with her for a few months and she was refusing to have carers come into her home. We had a long conversation with her about her decision making. She was clear that she did not want anyone helping her with her personal care. I spent some time talking through her options and she did eventually agree on a trial basis. I don't know what the difference was as the primary care team had been working with her for months. How many conversations do you need to have? There are no rules for it

RESOURCES



Story Card (31)



Dementia training for all staff

Links to: Issue Cards (28) + (32)



Leigh is an older person with early onset dementia

I get disoriented in hospitals. I cannot stress how very frightening that is. It takes people with dementia a while to adjust to circumstances and places. During my recent stay in hospital I was moved five times over the eleven days. Every time I moved my anxiety increased. I found it traumatizing. No staff had any understanding of the association between dementia and anxiety. There seems to be a need for ongoing training for all staff including the bed manager to support vulnerable people like me.



Quieter spaces

Links to: Issue Cards (30) + (43)



Daithí is an older person with Alzheimer's.

I was sent to the emergency department by my GP. It was so overwhelming there with so many people and lots of noise. I can't focus when things are so noisy. I found it very difficult to remember any of the information I was given by the staff. I wish hospitals were more thoughtful of the needs of people with Alzheimer's. I looked and sounded like I could say what was wrong with me, but actually I was very





Resources to enable involvement

Links to: Issue Cards (18) + (26)



Fiachra is a Social Worker.

We had a patient in ICU needing 24-hour ventilation. Her son wanted to get her home and he had sourced costings to transfer her home with ventilation. I offered my support. The patient was happy for her son to advocate for her. I submitted a request to the HSE for homecare. They responded that a case conference was needed involving 16 health and social care professionals from the acute and the community care setting. I wanted the patient to attend the meeting, this required two nurses to facilitate her involvement. She made it clear at the meeting that she wanted to go home. I felt that enabling her involvement in the meeting resulted in a positive discussion focused on her will and preferences.



Story Card (34)



We waited and waited

Links to: Issue Cards (21) + (41)



Louie is a family carer.

My wife was in hospital receiving chemotherapy for cancer. One day I brought her in for chemo and after the treatment the nurse discovered that her blood sugars had elevated. At 12pm the nurse said she needed to refer my wife to the diabetic team. So we sat and waited. By 6pm no one had come. The nurse had to stay back, and we watched the cleaning staff clean all around us. We got no offer of any tea or food all day. The nurse wanted to keep my wife in overnight, but because no beds were available she would have to be admitted via the emergency department. I did not want my wife on a trolley for the night. You would not treat a dog like this. We left and went home.





We need extra time

Links to: Issue Cards (24) + (29)



Lisa is a social worker.

I had a patient with moderate dementia in her seventies. She had frequent admissions with mental health issues. Her previous admissions were in other hospitals. so I had no clear case history. The medical team and her family wanted to look at long term care options. The patient was clear in communicating that she wanted to go home. There was a delay in getting the additional home care resources. During this time, the woman's wishes kept fluctuating with her mood and medications. She has now been moved to a post acute ward and needs the time. It's been five months and her discharge plan is still pending.



Nurturing a caring culture

Links to: Issue Cards (9)+(15)



Shane is a carer.

My mother was in the advanced stages of cancer. She ended up in hospital after becoming acutely ill and we were told she was dying. She could no longer speak and was hallucinating. I knew she wanted to die at home. My son has Down syndrome and had care needs so getting her home required some extra planning. The doctor gave me the time I needed and did not rush me at all. He looked me in the eye and said she will go home when you are ready and reassured me. He made me feel valued as a carer. He listened and gave me time and reassurance.





Getting my diagnosis

Links to: Issue Cards (4)+(38)





Ben is an older person.

My psychiatric consultant provided such a supportive environment when giving me my diagnosis of dementia. He took me to a private room and spent nearly two hours with me. He spent an hour with my wife and me the following day. He kept asking if there were any questions. He really respected the two of us - there was no question left unanswered. He made me feel like I was the only patient in the hospital. I left hospital happy because although I was told I have an incurable disease. I came out for the first time in five years with a clear head. Now I feel I have time to engage in planning my care and organising formal assisted decision making.



I support her decision-making

Links to: Issue Cards (8) + (22)



Elena is a nurse working in an older person's ward.

I had a patient who was in after a number of falls. She had mild dementia and some cognitive impairment. Her family were looking at increasing home care supports for her. The patient did not want additional strangers coming to her home. Her family started to look at nursing homes, but they never spoke to their mother about the options. One quiet evening I spoke to her and she got upset. She felt everyone was making decisions and that she wanted to look at her options. So I sat with her by a computer, and we looked at a number of nursing homes. She visited a few, and picked one, I helped her weigh up her options to make a decision.





Whose decision do I prioritise?

Links to: Issue Cards (25) + (31)



Steve is a nurse working in a day hospital.

The woman was in her eighties with moderate dementia. She was attending the day hospital frequently. Her son was her primary carer and was struggling to manage. He had a young family. I referred the patient to a social worker to assess if she had an understanding of her care needs. An increased home care allowance was provided with some respite. A few months passed and the patient was back to me. Her dementia had advanced and she had no clear understanding of her needs. Her son was still struggling and was full of guilt. He had promised his mother that she would never go to a nursing home. Those were her wishes. I was trying to get the right balance for everyone. She ended up in a nursing home and I wonder did I do the right thina?





Taking the time to assess capacity

Links to: Issue Cards (6)+(33)



Maria is a speech and language therapist.

We had a patient who had aphasia associated with a stroke. She was with us for about 6-8 weeks before going to a rehab facility, and then had to come back to us due to a lifethreatening illness unrelated to the stroke. She survived that but her cognition deteriorated. No single assessment could reveal her ability to function in everyday life, so myself and the OT took a very functional approach to see how she was coping. We used the "communication aid to capacity evaluation" tool which gave us insight into how much the patient understood and her insight into her deficits. This revealed that she knew where she was and what had happened, and that she wanted to go home. We decided she had the capacity to make this decision and the team listened to us. She ended up going home and living independently.

RESOURCES





A communication difficulty does not mean that a patient does not have capacity

Links to: Issue Cards (19) + (20)



Diarmuid is a speech and language therapist.

A patient was referred to me for a swallowing disorder. She presented with a hip fracture and was in post-op recovery and acutely delirious. While I was assessing her communication. I realised that this wasn't typical of a dementia patient. I consulted with my colleagues and with the OT. We completed a language modified cognitive assessment and her cognition was relatively strong. The diagnosis then shifted to progressive aphasia. Through an augmentative and alternative communication approach, she expressed strongly that she wanted to go home. The issue was her husband did not want to take her home - their marriage had broken down. It took a long time to work through it all with family meetings and the MDT members. In the end her husband agreed to take her home with an increased home care package.

RESOURCES

Issue Card



ADM is not a one size fits all approach

Throughout a hospital stay, people may require different levels of support to communicate their decisions. How can this be accommodated in the acute care setting?



Issue Card (6)

Cognitive function assessments versus capacity assessment

Healthcare professionals use screening tests for assessing cognitive function. These tests should never be conflated with capacity, which is decision-specific, functional, and time-bound.



Issue Card 8

A communication plan

A formal approach to communication between the patient, decision-supporter, and healthcare professionals should be agreed at the outset of the care journey.



Issue Card (9)

Communication training for healthcare professionals

ADM requires practitioners to be highly skilled and proficient in interpersonal communication. How can this be enabled?





Doctor-patient relationship

Historical views of the patient-doctor relationship assumed that the doctor's role was to act in the best interests of the patient and to direct their care. This may lead the decision supporters and patients to leave the decision entirely to the doctor.





Patient advocates

People in the acute care setting may not have family or friends to call on for support. Should they routinely be offered the services of an independent advocate to support them in their decision making?





Ethical dilemma around the discharge process

Healthcare professionals may face ethical dilemmas in supporting the will and preferences of a patient who wants to be discharged home but is deemed at-risk by family members or community services.





Internal family conflicts

Internal family conflicts are a common source of stress for healthcare professionals when trying to support decisions of care. What strategies can they use to manage these conflicts?





The reality of the acute hospital

Some patients with complex needs require significant time in acute care to allow them to weigh up all the information necessary to make a decision about their care. How can we reconcile this within an environment operating key performance indicators that measure the length of hospital stay?





Uninterrupted privacy and time, please!

Private space and time are crucial for healthcare professionals to support the capacity of patients in their decision making. The acute hospital environment often lacks the appropriate spaces and time to facilitate this.





Building the capacity of patients takes time

Some patients may require additional time to build capacity. How can this be resourced-for in an acute care setting?



(25)

How can we better resource the system to facilitate patient choice?

Often healthcare professionals can feel frustrated as they don't have access to adequate home care packages to enable the will and preference of their patients. Do healthcare professionals have a responsibility to promote policy change?





Therapeutic relationships are a key resource for quality ADM

Staff working in acute care services recognise the value of building a therapeutic relationship with the patient. Time pressure and competing workload can mitigate against this.





Are Key Performance Indicators a negative influence on ADM?

Some patients require more time to build capacity to be involved in decisions about their care. Do key performance indicators related to the length of stay in acute medical care create a culture that inhibits this?





When do you know a decision has been made?

Decision making requires time so that information can be processed, questioned and shared with a decision supporter. When the patient is changing their mind, what are the implications for resourcing (e.g. theatre lists)?





Resources for education & training

ADM legislation is new, and there is a need for clear guidance for healthcare professionals. What resources for education and training would support healthcare professionals in ADM implementation?



Can ADM be standardised?

What would a clinical guideline look like to support healthcare professionals to implement ADM into practice?





Mandatory dementia training for all working in healthcare

People with dementia would receive greater quality care if all staff in hospitals had dementia training. Who should have training and how can it be realised?



(33)

Are we using all of the resources available to us within the team?

Occupational therapists and speech and language therapists have discipline-specific expertise in relation to functional assessment of capacity. How can we ensure their involvement in the ADM process?



Issue Card (38)

Amount and quality of information

Patients may have different information needs over their time in the acute setting. What can be done so that patients and their families always have the appropriate level and quality of information about their care and condition?





The hospital environment can make people feel vulnerable.

Patients often feel 'lucky' to have a hospital bed and accept healthcare conditions and services they would not tolerate elsewhere. Because of this, they can be reluctant to speak up. What can be done?





Dementia-friendly environment?

Acute care is often delivered in noisy and chaotic environments. They may be frightening and distressing for people with dementia and may worsen their levels of confusion and or anxiety. How can we reduce the vulnerability of patients with dementia in the acute care setting?



Assisted Decision-Making Act 2015

The ADMCA 2015 maximises the autonomy and dignity of persons who lack decision-making capacity in relation to one or more matters in the here and now, or who may do so in the future, by supporting them to make decisions based on their will and preferences.

Decision-making capacity

"Decision-making capacity" is the ability to understand, at the time that the decision is to be made, the nature and consequences of the decision to be made in the context of available choices at that time.

Provisions of the Assisted Decision-Making Act 2015

The provisions of the ADMCA apply to day-to-day and personal welfare decisions which include decisions about day-to-day living, finances, property, and healthcare treatment such as whether to consent to, or refuse, medical intervention.

Presumption of decision-making capacity

A person is presumed to have decisionmaking capacity in respect of the matter concerned. The burden of proving otherwise rests on the person who is questioning their ability to make a decision.

Info Card (5)

Screening

Screening for decision-making capacity involves a functional assessment which focuses on how a person makes a decision, as opposed to the nature or the wisdom of that decision.

Lacks capacity

A person can only be said to lack decision-making capacity if, at the point in time when they are being assessed, they cannot understand and retain the relevant information, do not believe the information, cannot weigh the information in the context of the decision-making process, and communicate their decision using whatever means they use to communicate.

Practicable steps have been taken

A person shall not be considered unable to make a decision for themselves unless all practicable steps have been taken, without success, to maximise his/her capacity and support him/her to make the decision. The nature of the support required will differ from person to person and depends on many factors.

Understand information

A person is not be regarded as unable to understand the information unless the information is provided in a manner that is appropriate to his/her needs.

Steps

Steps that support a person to make their own decision involve creating the right environment based on an understanding of the person, providing him/her with appropriate information tailored to his/her individual personality and needs, and providing tailored communication support.



Unwise decisions

People have the right to make decisions that others may not agree with. Believing a decision to be unwise is not a reason in itself to question someone's decision making capacity and is not evidence of a lack of capacity (although it may be indicative of this). People's values, beliefs and preferences differ.

Info Card (1

Functional assessment

The functional assessment of decision-making capacity is issue-specific and time-specific (the ability to make a specific decision at a particular point in time about a specific issue). Blanket assessments for capacity should not be made.

No intervention unless necessary

Guiding Principle 4 – no intervention unless necessary. In so far as possible, there should not be any intervention by others in decisions made, or to be made, by a person whose capacity may be called into question in relation to a specific issue in the here and now, or at some time in the future.



Scope of the intervention

Guiding Principle 5 – the scope of the intervention should be limited so as to minimise the restriction of the person's rights and freedom of action. Due regard must be had to respect his/her rights to dignity, bodily integrity, privacy, autonomy, and control over his/her financial affairs and property.



Intervention should be proportionate

The intervention should be proportionate to the significance and urgency of the matter, and the subject of the intervention (take into account the individual's circumstances, will and preferences, beliefs and values, and consider whether there is a less intrusive intervention available).



Supporting decision-making

Guiding Principle 6 - Supporting decision-making requires permitting, encouraging, and facilitating, in so far as is practicable, the person to participate/improve his/her ability, as fully as possible, to make the decision, rather than having the decision made by someone else.



Past and present will and preference

Supporting decision-making requires, giving effect to a person's past and present will and preference, taking into account his/her beliefs and values (that may have previously been expressed in writing) and considering the views of anyone named by the person to be consulted.



Enduring Power of Attorney

A person who anticipates a future lack of decision-making capacity may enter into an Enduring Power of Attorney (EPOA), with another person, called their Attorney. The Attorney is authorised to make decisions in accordance with the terms of the EPOA, EPOAs are limited in so far as decisions pertaining to restraint of the person (unless exceptional emergency circumstances and conditions exist); the refusal of life-sustaining treatment and decisions that are expressed in an Advance Healthcare Directive, cannot be created/authorised by the EOPA.

Advance Healthcare Directive

An Enduring Power of Attorney (EPOA) cannot create/authorise a decision that has already been addressed by the person in an Advance Healthcare Directive (AHD) nor can it create/authorise a decision to refuse life-sustaining treatment, irrespective of whether an AHD exists. An EPOA cannot create/authorise a decision to restrain the person unless there are exceptional emergency circumstances and strict conditions apply.



Losing decision-making capacity

A person who anticipates that they may lose decision-making capacity in the future may make an Advance Healthcare Directive (AHD) that expresses their will and preferences regarding medical treatment that may arise in the event of their losing capacity, for example, if they were to become comatose.

Advance Care Directive

The Advance Care Directive (ACD) may be a stand-alone directive or the person may appoint a dedicated healthcare representative (DHR) to exercise the powers conferred in the ACD. Significantly, a person may express their wish to refuse lifesustaining treatment through an ACD.

Screening

Screening for decision-making capacity involves a functional assessment which focuses on how a person makes a decision as opposed to the nature or the wisdom of the decision.

Lacks capacity

A person can only be said to lack decision-making capacity if, at the point in time when they are being assessed, they cannot understand and retain the relevant information, do not believe the information, cannot weigh the information in the context of the decision-making process, and communicate their decision using whatever means they use to communicate.

Practicable steps have been taken

A person shall not be considered unable to make a decision for themselves unless all practicable steps have been taken, without success, to maximise his/her capacity and support him/her to make the decision. The nature of the support required will differ from person to person and depends on many factors.



Three types of decision-making supports

The ADMCA provides for three types of decision-making supports: 1) Assisted decision-making, 2) Codecision making with individuals appointed by the person whose capacity is called into question, and 3) Where a person lacks capacity to make a decision with either of these supports, the court may appoint a decision-making representative or may make the decision on the person's behalf.

Decision-making based on the interpretation of the known past

If the present will and preferences of the person cannot be ascertained after all practicable efforts have been tried, the ADMCA 2015 supports decision-making based on the interpretation of the known past will and preferences, taking into account the values and beliefs of the person as opposed to a third party deciding what is in the person's best interest.

Urgency around a decision

If there is urgency around a decision to be made, there may be less time to ascertain the person's will and preferences, values, and beliefs, but wherever possible, efforts should be made to do so. This could mean talking to the individual nominated by that person or their closest relation, partner or friend, who could help the person with communication or interpret signs that show his/her present will or preferences, or inform you about the person's last known will and preferences.

Role of close family

The role of close family members and next of kin is to guide healthcare and other professionals as to the will and preferences of the relevant person where that person lacks capacity to make the decision in question.

Role of Next of Kin

Generally, family members and next of kin of the relevant person do not have authority to make a decision on the part of that person unless they have been given authority to do so through the provisions of the ADMCA.

Override a person's will and preference

It is a very serious step to seek to override a person's will and preferences by trying to impose an unwanted intervention. Such a person should be facilitated and enabled to challenge an unwanted decision, possibly by the appointment of an advocate.

Act in good faith

Anyone making an intervention on behalf of a person whose decision-making capacity is called into question must act in good faith (in accordance with professional codes of conduct or other applicable guidance) and for the benefit of the person which should be construed with references to their known will and preferences. What is/isn't of overall benefit to the person is unique to that person and should be understood in that way.

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Judgement on a particular intervention

If it is not possible for the person to make a decision, even with support, and their will and preferences, beliefs and values, cannot be established, then a judgement is required on whether to proceed with a particular intervention. This should be informed by clinical/professional skill/experience and it is good practice to discuss the matter with other members of the multi-disciplinary team.

Third opinion

If there is disagreement as to whether a person has decision-making capacity in respect of a particular decision, it is good practice to seek a third opinion or convene a multidisciplinary meeting/case conference to discuss the issue. It may be necessary to refer the question to the Circuit or High Court.

Making an intervention

The person, e.g. a healthcare professional, who proposes making an intervention (an action or direction in respect of an individual whose decision-making capacity has been called into question) must be able to satisfy him or herself as to whether that individual has the capacity to make the decision. The healthcare professional may call upon colleagues to assist in assessing capacity.

Life-saving treatment

In situations involving life-saving treatment, where a person is found to lack decision-making capacity and it is not possible to defer treatment (to a time when they regain decision-making capacity or for their will and preferences to be ascertained), treatment may proceed.

Fluctuating decision-making capacity

In circumstances where a person has fluctuating decision-making capacity, non-urgent decisions should always be deferred to a time when their decision-making capacity is optimal.

Assessment

The assessment of decision-making capacity must be made by a registered medical practitioner and another healthcare professional in two circumstances: (a) the creation, variation, or revocation of an enduring power of attorney instrument, by applying a functional test at the time the instrument was created/varied/revoked, and (b) where the person wishes to create a co-decision-making agreement to appoint someone to jointly make decisions with them.

Called into question

A person whose decision-making capacity is called into question must consent to having their decision-making capacity functionally assessed. If the person is unwilling or refuses to consent to the assessment, steps may be taken to assist them, such as explaining the nature/purpose of the assessment, involving a trusted family member; listening to his/her concerns; providing time, support and reassurance.

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Reasons for refusal

A person whose decision-making capacity is called into question may refuse to have their decision-making capacity functionally assessed and this, of itself, is not indicative of a lack of capacity. Their reasons for refusal should be documented and, if necessary, an application may be made to the Circuit or High Court for relevant orders.