PlayDecide: PADMACS

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)**
2 **Discussion**	Players take turns to summarise their cards, then the group identifies and discusses themes related to ADM. **(30 min)** Next, players share their own experiences relevant to the discussed issues. **(20 min)**
3 **Reflection**	Players reflect on the discussions and how they relate to their own experiences, then fill out a perspective sheet. **(20 min)**

Quick game (40 min)

1 **Setup & info**	Players select one story card, find one linked issue card, and select one info card. Next, they read the guidelines and information about the ADMCA on the placemat. **(10 min)**
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playdecide.eu/

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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.
1. Respect other people.
1. Allow them to finish before you speak.
1. 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 Family carers Healthcare professionals Policy makers

What key learnings will I take away from playing this game?

I can apply these key learnings by ...

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PlayDecide: PADMACS

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
3) 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

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Story Card

Place your chosen story card here

Older adults & patients

Carers

Health professionals

Info Card

Place your chosen info 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)	Quick game (40 min)
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2 Discussion	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)**	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)**
3 Reflection	Reflect on the discussions and your own experience, then fill out a perspective sheet. **(20 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

play
decide

UCD School of Nursing, Midwifery and Health Systems
UCD College of Health and Agricultural Sciences

Mater Hospital Dublin

ST. VINCENT'S UNIVERSITY HOSPITAL
Elm Park

Family Carers Ireland
Fairness for Carers

THE ALZHEIMER SOCIETY of IRELAND

ROYAL COLLEGE OF PHYSICIANS OF IRELAND

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Story Card ①

The role of carers in ascertaining a patient's will and preferences

Links to: Issue Cards ⑪ + (42)

Mary is a family carer of a person with a diagnosis of dementia.

My dad went in to the consultant and was told he needed eye surgery. He is currently on a waiting list. He has been told he could be waiting for a number of years. I am worried about what stage his dementia will be in a few years. I wonder will he be in a position to even consent to the surgery? I feel it is very important that the medical team includes family carers in the discussion about all the options. I am in the best place to ensure that the will and preference of my dad are respected when the time comes.

SHARING INFORMATION

play
decide

Story Card ②

Access to the healthcare team

Links to: Issue Cards ⑬ + ㉑

Tomás is an older person.

I was admitted to the ward from the ED with chest pain. I asked a few times to meet my consultant and her team but was told that it was not possible as they would only be ‘flying through’. I finally met her and asked her to write down responses to my questions. She was really lovely and spent some time with me in the ward. I feel that often people are scared to ask for time with their doctor. I really had to insist to be given the information I needed. It should not be like this.

play
decide

Story Card ③

Alzheimer's diagnosis is not on file

Links to: Issue Cards (36) + (47)

Róise is an older person with a diagnosis of Alzheimer’s.

I have a short-term memory problem. I arrived into my local hospital with back pain. My Alzheimer’s diagnosis was not on my file despite having been admitted previously. The team came to me the following day to advance my treatment. They mentioned that they had discussed all my options with me on the previous day. I had no memory of it. They had not spoken to my husband. I feel he should have been consulted so that he could support me to understand my options.

SHARING INFORMATION

play
decide

Story Card ④

Repeating patient history

Links to: Issue Cards ㉟ + (40)

Lisa is a carer of an older person with a diagnosis of dementia.

I went to the emergency department with a family member who had recent multiple admissions to the same hospital. The doctor asked me for a verbal summary of my family member’s case history. I found this stressful as I was afraid that I would forget important details. Why weren’t details of her diagnosis and the medications on the notes from previous admissions? I now carry a list of medicines to hand over, but I find my anxiety increases every time.

SHARING INFORMATION

play
decide

Story Card ⑤

When a patient has no capacity to understand information

Links to: Issue Cards ⑨ + (38)

Ben is a carer.

My wife Susan was receiving treatment for end stage cancer. On her last hospital stay, we knew she was very ill. I knew my wife was not going to live for long. I needed information to inform choices about her care in the final stages. I acknowledge the oncology doctor was very good in terms of the treatment he gave Susan, but his ability to communicate with us was terrible. He avoided talking to us. When asked for information, he refused point blank to give us any.

SHARING INFORMATION

play
decide

Story Card ⑥

Having a plan

Links to: Issue Cards 39 + 47

Enda is a doctor.

We had a man in his eighties admitted who had vascular dementia with multiple prior admissions. During the admission he raised the possibility that he may end up in a nursing home. So we discussed it further and he reviewed his options. He wanted to pick a nursing home that he could transfer to if needed at a later date. We supported his application to fair deal and the application form is on his file and will last for 6 months. It’s a horrible conversation to have but a practical one.

SHARING INFORMATION

play
decide

Story Card 7

Conversations about will and preferences may be difficult in the hospital setting

Links to: Issue Cards 21 + 22

Sarah is a doctor.

We had a patient in the acute hospital setting who had a moderate cognitive impairment. He had experienced a catastrophic event causing him to be admitted. The patient expressed his wish to return home, but his family wanted him to be discharged to a nursing home. Our hospital is a very busy environment and the patient was a private man; he did not feel comfortable having discussions about his will and preferences in that setting. There is a risk that a patient’s will and preferences might not get communicated clearly due to the hospital environment and conflicting opinions. He was discharged home and later re-admitted for a chest infection, before moving to a long-term facility.

SHARING INFORMATION

play
decide

Story Card 8

Finding information about a patient’s case is not always straightforward

Links to: Issue Cards 23 + 31

Paul is a doctor.

We had a seventy-year-old patient in after a fall. She was living independently at home, divorced and estranged from her children. She had been diagnosed with new onset dementia but had been coping okay with a minor care package. She presented with a marked cognitive impairment and active hallucinosis associated with the type of dementia she had. She began to re-orientate herself and wanted to go home. However, she had almost no prior contact with the public service – all her care been private. There were no accessible notes on her care up to now. It took time just to establish the facts and ensure that she was being heard and supported during the decision-making process.

SHARING INFORMATION

play
decide

Story Card 9

Consistent communication is needed to help advance care planning

Links to: Issue Cards 8 + 42

Aoife is a nurse.

This patient was having repeated visits to hospital for what she believed was pneumonia, but the actual problem was recurrent aspiration due to reflux. She would not be well enough to undergo surgery to fix a hernia that was causing the reflux. However, I don’t think this had been well explained to her. It turned out that a conversation with a doctor unfamiliar with the case had given her false hope that she would be well enough for the surgery soon. This caused a lot of confusion. The patient had capacity, but we needed to explain and repeat advice often. In the end she was discharged to a nursing home with the palliative care team’s support. I think clear communication about the reality of her situation could have reduced confusion and delays in care planning.

SHARING INFORMATION

play
decide

Story Card 10

Preparing families around end-of-life care

Links to: Issue Cards 20 + 46

Sean is a dietitian.

We were taking care of a patient with several medical complications and severe cognitive impairment. She was underweight and was refusing food. When she was first admitted, her family told us she had been eating well and had no cognitive issues, but this wasn’t actually the case and in reality, she was reaching the end of her life. I requested involvement of the palliative care team, but the patient’s family resisted. The rest of the team was busy dealing with her other medical issues and couldn’t meet the family to help persuade them that it would be best to make her as comfortable as possible. I was the only one available to meet them and felt unsupported when trying to make the case. The patient passed away during her stay and we continued trying to feed her via nasogastric tube right up until the end.

SHARING INFORMATION

play
decide

Story Card ⑪

Taking time to find out a patient’s preferences

Links to: Issue Cards ㉖ + ㊳

Jane is a dietitian.

We have a patient who doesn’t always follow advice from our team, and often argues with us about his care. He wasn’t coping well at home and was refusing entry to meal delivery services. He was supposed to be following a diet to support his renal function. He told us he was doing well, eating plenty, and keeping active but based on our observations I suspected this wasn’t true. After contacting his sister, we found out that he rarely ate, and seldom left the house. Nutritional support and supplementation was needed, but we needed to get the patient on-board with that idea. I engaged with him and his sister to get a better idea of his food preferences, and tried to accommodate these as much as possible so that he would feel comfortable and eat more. I also worked with him to find a nutritional supplement that he found acceptable.

SHARING INFORMATION

play
decide

Story Card 12

Access to services - who decides?

Links to: Issue Cards 13 + 18

Julia is a family carer of an older person with an intellectual disability.

My sister was ill a few years ago with back pain and the physio said she needed a scan. She has a learning disability and I accompanied her to the doctor. The doctor didn't recommend a scan and seemed dismissive of the pain. I had to really push the doctor to refer her for a scan. After a few months wait my sister was eventually referred to an orthopaedic surgeon where it was discovered that she required a knee replacement. She was without pain in the end, but it took a lot of convincing.

CONTROL & POWER

play
decide

Story Card 13

Will and preference

Links to: Issue Cards 14 + 42

Margaret was the partner and carer of an older person with a diagnosis of Parkinson's.

She was admitted to hospital and the staff wanted to treat her. We had talked it over at home and she wasn't afraid to die. She wanted a do-not-resuscitate (DNR) order. She expressed to me that she no longer wanted to continue treatment. It wasn't a major decision for us – it felt right for us at that stage. So I told the consultant. He sat beside her and I left them to discuss options. The consultant came to me afterwards and agreed that she did not want resuscitation. But what about other treatments? I asked the consultant would she still get antibiotics for a UTI. The consultant said antibiotics would make her comfortable but not prolong her life. I didn't entirely agree with it but maybe it did give her comfort.

CONTROL & POWER

play
decide

Story Card 14

I did not want to take the tablet

Links to: Issue Cards 41 + 43

Terry is an older person with a diagnosis of Alzheimer’s.

I was in a hospital ward and I could not sleep. This one particular night I had very bad anxiety. A ward staff member offered me a sleeping tablet. I did not want to take it because I knew it would impact me the following day, resulting in increased memory loss and disorientation. Once I refused the tablet, nothing else was offered to help address my anxiety or my sleeping. I felt that once I turned down the sleeping tablet there wasn’t a whole lot of sympathy for me in a hospital setting. I felt sad and let down by the staff. They did not seem to understand dementia. All I wanted was comfort and reassurance.

CONTROL & POWER

play
decide

Story Card ⑮

Making the right decision for me

Links to: Issue Cards ⑮ + ⑰

Lisa is an older person.

I am almost 80 years of age and have been receiving treatment for recurrent melanomas. Following completion of recent treatment I was referred to an oncology specialist. After spending time explaining the options to me, he recommended a course of preventive chemotherapy. I responded that I was not interested. The doctor was surprised and asked a nurse to come in and talk to me to see if I would change my mind. I have spoken to my family and my local pharmacist who all recommended the treatment. I have decided I have made the right decision for me at this time to not proceed with the treatment.

play
decide

Story Card 16

Building trust

Links to: Issue Cards 9 + 35

Sharon is an older person with a diagnosis of Lewy Body Dementia.

I was in an acute ward and the consultant psychiatrist came in. I was on a lot of different tablets including morphine for pain. The consultant reviewed my notes and ordered me off them all except my blood pressure tables. I said that I was not coming off my morphine patch as my GP had introduced that patch in increments of five millilitres. I said that I would prefer to come off in increments. After listening to me, the consultant agreed with my proposal. After that, I felt I could trust her as she listened to me and was willing to change her mind.

CONTROL & POWER

play
decide

Story Card 17

Engaging too much with the family?

Links to: Issue Cards 20 + 23

Pete is a nurse.

I had an older person in the ward following a stroke. He had a history of alcohol abuse and he was living alone in a council flat. He did not have much contact with his siblings. Initially he was very aggressive but improved. After 3 months we started to discuss discharge. He wanted to go home but his siblings said he could not look after himself and needed to go to a nursing home. The council agreed to move him to a more accessible home, and we arranged lots of additional supports. His family were still not happy but refused to attend the meetings we had arranged. In the end after 10 months in hospital he got his wish and went home. I wish I had engaged less within his family as he would have been discharged much earlier.

CONTROL & POWER

play
decide

Story Card 18

The right to make an unwise decision

Links to: Issue Cards 11 + 19

Liam is a social worker.

A patient, aged 82, was admitted with delirium and had septic leg ulcers. She was living alone in poor conditions with no access to a toilet or running water. Her neighbours said she would wander the streets and would often be agitated. She clearly expressed that she wanted to go home. Both her family and the team felt that she would be better placed in a nursing home. She refused an offer of a commode or any home help but was willing to engage with a public health nurse to look after her dressings. She ended up being discharged home.

CONTROL & POWER

play
decide

Story Card 19

Easier if he didn't have capacity?

Links to: Issue Cards 6 + 46

Saoirse is a social worker.

A patient was admitted with a safeguarding issue. There was a history of family conflicts as well as alcohol and drug addiction. A daughter suggested that he didn't have capacity and a nursing home was his best option. When in her presence he agreed with her. However, when I approached him, he wanted to go home. Myself and an OT undertook an assessment of capacity and he understood the implications of his decision. This caused a massive family argument which played out on the ward. This was very distressing for the patient. The daughter made a complaint about us and our case management was investigated. We continued to support the patient and worked with colleagues in the community to get him home. He is still at home and managing very well there.

CONTROL & POWER

play
decide

Story Card 20

There should have been a plan

Links to: Issue Cards 10 + 27

Inger is a doctor.

We had a patient in his eighties. He had severe cognitive impairment with advanced dementia. He had end-stage kidney disease and was getting dialysis three times a week. He had no English and he arrived to us with a hip fracture following a fall. His family consented to hip replacement surgery. He was transferred to the high dependency unit following the surgery. He had a lot of complications, was in a lot of pain and was very distressed. No translator was available, so I was dependent on his family for information and communication. He remained in full active management of his condition and continued to get dialysis. I think his family were not able to accept he was dying. It should not have been that way. Some efforts should have been made to support him and to ascertain what his care preferences were.

CONTROL & POWER

play
decide

Story Card 21

Balancing supported decision-making with patient’s best interest

Links to: Issue Cards 2 + 45

Leah is a doctor.

A 92-year-old woman was admitted with chest pain. She had a mild cognitive impairment upon admission. Tests found that she needed a heart valve replacement, and she expressed a wish for that to be done. She was referred to a cardiologist who advised her that she was not the best candidate for this procedure and was at high risk for complications. The patient was adamant that she wanted to go ahead. The cardiologist undertook a continuous process of consent and provided information over a period of time. There was tension between the cardiologist and patient. The procedure went ahead, despite the cardiologist’s reservations. The patient has had a lot of complications post surgery and is still in hospital. I wonder now if maybe I should not have referred her to cardiology at all?

CONTROL & POWER

play
decide

Story Card 22

Shared decision making?

Links to: Issue Cards 9 + 12

Jane is an older person.

I was confirmed to have Lewy Body Dementia. My last outpatient visit was with a junior doctor from my consultant's team. He said, "you seem to be a lot better than you were a couple of months ago". I said, "I am". He said "what has changed?" I said, "I have started to take CBD oil regularly". With that, he started shaking his head and flung his pen across the desk. He said, "how do I know what you are taking is working, how do I know it's not the medication?" He said, "we cannot agree with what you are taking. We do not want you back here again." I said, "with the greatest respect for you doctor, you know absolutely nothing about CBD oil. You should be asking me about it rather than dismissing it." He said, "how dare you speak to me like that?", so I left, and they would not give me another appointment.

CONTROL & POWER

play
decide

Story Card 23

I don’t want to be a burden

Links to: Issue Cards 16 + 29

Dawn is a doctor.

A woman in her eighties was admitted and was very deconditioned. Cognitively she was good. She was lacking confidence, but she rehabbed very well. Following assessment she would need 14 hours of home care supports and wanted to go home. Her daughter came to the ward and announced her mother was going to a nursing home. We explained at the family meeting that she did not need to, but the patient was resigned to the nursing home. She said she did not want to be a burden on her daughter. She did change her mind a few times, but her daughter would come in and she would revert back to the nursing home and was eventually transferred there.

CONTROL & POWER

play
decide

Story Card 24

Negotiating palliative care

Links to: Issue Cards 15 + 30

Fernando was caring for his partner.

My partner was in a lot of pain with a bad UTI and there was something wrong with his bone marrow. He was very clear with me that he did not want any further treatment. I had to coax him to go to hospital. He asked me to stop the doctors from doing any further interventions. I spoke to his consultant who was insistent he should continue his treatment. Whilst the consultant was away on leave I asked the nurses very nicely to get the palliative care team in. The locum consultant was in agreement that palliative care was the best option. The staff don’t like being told what to do but I had to ensure that my partner’s wishes were carried out and that he got appropriate end of life care.

CONTROL & POWER


play
decide

Story Card 25

It was challenging because the staff want to keep people safe

Links to: Issue Cards 40 + 44

Caitriona is a doctor.

A patient presented after a fall with marked cognitive impairment and active hallucinosis associated with the type of dementia she had. However, she was able to re-orientate herself and wished to go home. Her family wanted her to be admitted so that she could be supervised continuously. She did not want this. Even though she had problems with memory she did have fleeting capacity. There were times she could recall the plan and understand some of the risks. The OT and I did functional testing and, because of the hallucinations, psychiatry also saw her. Together we supported her decision to go home. It was difficult with the family but also with staff from the emergency department – they can be quite paternalistic as they want to mind people and keep them safe. Even the carer who accompanied her home really struggled with the idea of leaving her in the house.

CONTROL & POWER


play
decide

Story Card 26

The team gave us time to do a full assessment

Links to: Issue Cards 7 + 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 life-threatening 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.

CONTROL & POWER

play
decide

Story Card 27

Sometimes family will make the decisions on capacity

Links to: Issue Card 24

Andy is an occupational therapist.

We saw a man who presented, following a stroke, with severe cognitive impairment. He was dependent living at home with his wife. I was working with him for about 4-5 weeks and I noticed a change in his cognitive profile – he was participating in self-care and functional tasks. I think perhaps the decision was made too early regarding his capacity. He had topographical disorientation which can present as worse than it actually is. The team were reluctant to accept his improvements and it turned out his relationship with his wife was not positive. Under pressure from his wife he was deemed not to have capacity and he went to a nursing home. He absolutely had capacity and it came down to a care issue. There can be a lot of pressure on teams from families. To this day, I'll never forget him. It should never have happened.

CONTROL & POWER

play
decide

Story Card 28

We side-stepped enacting the Enduring Power of Attorney

Links to: Issue Cards 34 + 46

Conor is a doctor.

A man came into the hospital after repeated falls. He had no children but five nieces and nephews. He was keen to go home but was at risk of falling. One of his nieces wanted him to go home because that was his wish, but another wanted him to go into long term care. The patient had an inactivated EPA and that niece wanted it activated. We were concerned because the niece who wanted him in a nursing home would have the financial power, and to an extent the care needs power. We did a risk assessment and noted that he could afford 24-hour care which we felt was the best use of his money, to fulfil his wishes to return home. Two separate solicitors wrote looking for a capacity assessment, but we kept him here long enough to regain capacity and we could sidestep the EPA. He’s now happily living at home, although needs hospital care every so often.

CONTROL & POWER

play
decide

Story Card 29

Working together to make a plan

Links to: Issue Cards 13 + 39

Anthony is an older person.

I had started to have difficulty swallowing, and was seen by the team at my local hospital. Although I have mild cognitive impairment, I don't have much trouble communicating but I still don't feel like they really listened to me. They just gave me a sheet of paper with a plan for a diet of soft foods and sent me home. Many of the things listed in there were new to me and I wouldn't even know how to make them. I had been coping reasonably well on my own, but I wasn't able to manage with this new diet. It was so frustrating, and it wasn't until I had to go into hospital again that I was able to get another team member to sit down with me and listen to my concerns. He helped me to find ways to add more of the foods that I'm used to into my diet plan.

CONTROL & POWER

play
decide

Story Card 30

How many conversations is enough?

Links to: Issue Cards 4 + 9

Tommy is a nurse.

We had an 85-year-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 quite 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.

play
decide

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.


play
decide

Story Card 32

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 overwhelmed.

play
decide

Story Card 33

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.

RESOURCES

play
decide

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.

RESOURCES

play
decide

Story Card 35

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.

play
decide

Story Card 36

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.

RESOURCES

play
decide

Story Card 37

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.

play
decide

Story Card 38

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 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.

RESOURCES

play
decide

Story Card 39

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 thing?

RESOURCES

play
decide

Story Card 40

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 life-threatening 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

play
decide

Story Card 41

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

play
decide

Story Card 42

A hospital environment driven by service needs rather than patient needs

Links to: Issue Cards 32 + 43

Mary is 59 years and has early onset dementia.

I have dementia, so it takes me a while to adjust to new circumstances and places. The last time I was in the hospital for a chest infection was a traumatising experience because I was moved five times in eleven days. Each move made me disoriented and left me feeling frightened. I suffered massive anxiety. I was not involved in the decision about any of the moves. I felt like I was always responding to bed management needs rather than having my care needs met.

ENVIRONMENT

play
decide

Story Card 43

What is a dementia friendly environment?

Links to: Issue Cards 3 + 26

Tom has dementia.

I was admitted to hospital with chest pain. I was very worried as I thought I had heart disease like my cousin. I could not sleep at night, so I would go and sit in the dayroom. The thing that upset me most was the fact that nobody really asked me much about myself. I remember a healthcare assistant ask me if I was ok, but I would like to have talked to the nurses about the chest pain. Did healthcare staff ‘assume’ because I had dementia that I could not participate in a conversation about my care?

play
decide

Story Card 44

Nurturing a caring culture

Links to: Issue Card 14

Slaine is an older person.

My dementia is hardest to manage at night because I develop anxiety and find it hard to sleep. At home, my wife puts on my favourite music, which really helps. My recent experience in hospital was distressing. I was prescribed sleeping tablets. I told the staff that I did not want them. I believe that when you don't take a sleeping tablet there is not a whole lot of sympathy for you when in hospital. I did not get any comfort from the staff about my nighttime anxiety. I felt sad and angry about my experience. Surely patients should be able to decide about taking sleeping tablets or any tablets for that matter?

play
decide

Story Card 45

Dementia hostile environments

Links to: Issue Cards 22 + 23

Jack is an older person with a diagnosis of Alzheimer’s Disease.

The ED is such a hostile environment for someone like me who is living with Alzheimer's. My experience was a place with people all around me and lots of noise. I cannot focus and I cannot think in that environment. Staff do not acknowledge the deeper challenges for people with dementia negotiating their care in those environments. Can hospitals be more imaginative and find quieter places for people like myself who have dementia?

ENVIRONMENT

play
decide

Story Card 46

Emergency departments

Links to: Issue Cards 21 + 41

John has Lewy Body Dementia.

I was in the emergency department (ED). I have never been in a war situation, but it felt like a war zone. There were people running, there were people crying, there was a breeze coming in. Once you are lying there and you don’t seem distressed or like you need urgent care, you are left for hours. You are not a priority. Eventually, I was taken to the acute stroke ward and the care I got there was outstanding. It’s absolutely not the doctors’ and nurses’ fault. I have no idea how they work in ED. It is scandalous what they have to do.

ENVIRONMENT

play
decide

Story Card 47

Organisations need to put the patient at the centre of all they do by improving organisational systems

Links to: Issue Cards 37 + 39

Barbara is a carer.

My dad is 80 years old and was recently admitted to hospital with delirium and an infection from a leg ulcer. During his hospital stay, he was in the emergency department, acute assessment unit followed by eight days on the short stay unit. He was just settled there and getting to know staff and trust them when he was moved to another medical unit. All the steps in the process were stressful for him. It impacted on his ability to recover and the consistency of care. Could they not have fast- tracked him to the medical unit? Negotiating clinical pathways in hospitals felt very hospital-led and not person-centred.

ENVIRONMENT

play
decide

Story Card 48

A challenging discharge

Links to: Issue Cards 25 + 42

Liam is a doctor.

We had an older man admitted for rehabilitation with cognitive impairment. He was single and living alone. His two nephews were his carers and were worried about him returning home. They wanted him to go to a nursing home. The patient demonstrated capacity in relation to his decision to go home. His nephews were very attentive to him. We were trying to source funding for homecare. The application is ongoing. He may need to be readmitted again but at least he will have gone home.

ENVIRONMENT

play
decide

Story Card 49

Conversations about will and preferences may be difficult in the hospital setting

Links to: Issue Cards 10 + 22

Jessie is a doctor.

A patient in the acute hospital setting had a moderate cognitive impairment. He expressed his wish to go home, but his family wanted him to be discharged to a nursing home. The busy hospital environment made this decision even more complicated. The lights are on most of the day, other patients are disruptive, and mixed genders may be present in the ward. The patient was a private man and he did not feel comfortable having discussions about his will and preference in that environment. He was eventually discharged home and coped for a period before being readmitted for a chest infection, and then moving to a long-term care facility. I think it’s important to be aware of the difficulty some patients have in communicating openly and honestly in the hospital setting.

ENVIRONMENT

play
decide

Story Card 50

They did not agree with my assessment

Links to: Issue Cards 33 + 46

Chris is an occupational therapist.

A woman in her 80s came in with a fall from home. She had a prolonged admission. Once she regained some physical independence, I assessed her cognition with a functional assessment. She did quite well despite having poor MoCA scores. There were some concerns from a safety point view – she was disoriented. But she expressed that she wanted to go home, and I felt she did have capacity to make that decision. I relayed that to the medical team, and they disagreed – the consultant felt she did not have capacity. I felt uncomfortable, questioning myself and wondering if I made the right assessment. Luckily the reg did the assessment again two weeks later and agreed that she did have capacity. She returned home with no repeat presentation.

ENVIRONMENT

play
decide

Story Card 51

Sometimes family will make the decisions on capacity

Links to: Issue Cards 6 + 20

Andy is an occupational therapist.

There was a man who presented following a stroke with severe cognitive impairment and was dependent, living at home with his wife. I was working with him about 4-5 weeks and I noticed a change in his cognitive profile – he was participating in self-care and functional tasks. I think from perhaps too early a decision was made regarding his capacity. He had topographical disorientation which can present as worse than what it actually is. The team were reluctant to accept his improvements and it turned out his relationship with his wife was not positive. Under pressure from his wife he was deemed not to have capacity and he went to a nursing home. The man had capacity and it came down to a care issue. To this day, I'll never forget him. It should never have happened.

ENVIRONMENT

play
decide

Story Card 52

It was challenging because the staff want to keep people safe

Links to: Issue Cards 40 + 44

Caitriona is a doctor.

A seventy-year-old lady presented after a fall with marked cognitive impairment and active hallucinosis associated with the type of dementia she had. However, she was able to re-orientate herself and wanted to go home. Her family wanted her to be admitted so that she could be supervised continuously. She did not want this. Despite memory problems, she did have fleeting capacity. There were times she could recall the plan and understand some of the risks. The OT and I did functional testing and because of the hallucinations psychiatry also saw her. Together we supported her decision to go home, although the family, the ED staff, and home carers pushed back on this. There was a lot of debriefing with the team afterwards about supporting decisions for as long as people have the capacity to make them.

ENVIRONMENT

play
decide

Story Card 53

What if I missed them?

Links to: Issue Cards 26 + 9

Janice is an older person.

I was in a ward with stomach pain. I was anxious to find out what was wrong with me and asked a few times if I could speak to the team who were looking after me. Each time I asked a staff nurse they could not tell me what time the team would come. I became worried and anxious. What if I fell asleep? Would anyone wake me up? I was afraid I would miss the opportunity to speak with my doctor. Eventually the doctor came, and I asked if I could speak to him privately that evening. He seemed annoyed by the request and said, “for what”?

ENVIRONMENT

play
decide

Story Card 54

You are not a priority

Links to: Issue Cards 43 + 41

Josh is an older person a diagnosis of dementia.

I have a diagnosis of Lewy Body Dementia and had not slept for 11 days. I went to the out-patient clinic and my neurologist said I should be admitted but promised I would be fast-tracked in the emergency department (ED). I arrived at the ED and was placed on a trolley on a corridor with a cold wind blowing on me. I waited for hours it was like a war zone; the staff were so rushed. Once you are lying there and don’t seem distressed no one will approach you to see if you are ok. I will not go to the ED again. It is such a distressing place.

ENVIRONMENT

play
decide

Story Card ㊺

Communication is critical in the decision-making pathway

Links to: Issue Cards ② + ㊳

Farhad is a carer.

I always knew my dad wanted to die at home. But he was worried when he ended up in hospital because he relied on the healthcare staff for information which would allow him to plan his care at home. Dad could no longer express his preferences because he had lost the ability to speak. The doctor’s interaction with us was sympathetic but honest, that no more could be done. It was not just what they said but how they said it. They sat down and spoke to us. The frank communication was necessary because it informed our plans to get dad home, where he died peacefully.

play
decide

Story Card 56

Communicating with people with a learning disability

Links to: Issue Cards 3 + 9

Elaine is a carer.

I hate when people turn to me to talk about her care like she is not in the room. I am particularly nervous in busy hospitals. Recently we had a great experience. The doctor addressed her directly. He asked her how she was feeling. The fact he related to her was really nice. I could see that the interaction with the doctor helped her to trust him and decreased her anxiety about the procedure. I wonder why all healthcare professionals do not communicate with the same degree of skill and sensitivity?

COMMUNICATION

play
decide

Story Card 57

Fluctuating capacity

Links to: Issue Cards 6 + 19

Siofra is a social worker.

A patient aged 54, married with a young family experienced frequent seizures and cognitive impairment following a stroke. Her husband was working full time and due to her young age, the family did not qualify for a home care package. Her care needs were putting enormous strain on the family. After a few weeks in a nursing home, she was readmitted to acute care and was indicating that she wanted to go home. A functional capacity assessment was never undertaken but the medical team assumed capacity and discharged her home against the will of the family.

COMMUNICATION


play
decide

Story Card ⑤⑧

Dementia

Links to: Issue Cards ⑦ + ⑩

Sean is caring for his husband who has dementia.

Some days are better than others in terms of his ability to interact and communicate. But once you make the effort to communicate with him, he will respond either through talking or through non-verbal nods. Junior doctors are not good with communicating with people with dementia. Are they not given these communication skills in their training? Now when they turn to me and say, ‘how are we today’ I respond by saying “well, Hugh is here, so ask him”. It is so undignified and awful.

COMMUNICATION

play
decide

Story Card 59

Shared decision-making

Links to: Issue Cards 13 + 15

Carmel is an older person.

I have a great relationship with my neurologist. I remember our first meeting. He was making decisions that I had to question him on. He ordered that my morphine patch be taken off and discontinued. I had known from my GP the importance of not missing it or stopping it suddenly. So I told this consultant that “under no circumstances” would I come off the patch suddenly because it should be stopped gradually. With that, he said, “you know what, you are right, we will do it that way, we will drop it in fives.” And I just thought, “you are ok.” Right there and then I knew I could trust him. I knew I could talk to him and he wasn’t one of these guys that think they know it all.

COMMUNICATION

play
decide

Story Card 60

What matters to me most

Links to: Issue Card 41

Brad is an older person with dementia.

I hate hospital because I am so embarrassed by my night terrors. They are caused by my dementia. I have had staff react in ways that is condescending. I will always remember the nurse called Susan and the way she interacted with me during a horrible night terror. I had woken up sweating and thinking there was blood on my face. I ran into the corridor feeling very distressed. Susan walked over to me and held my hand. She spoke in a soft caring voice and asked me if I was ok. She told me my name, explained where I was and reassured me that I had a nasty dream. She got a mirror so I could look at my face and know it was not bleeding. She brought me back to my bed. I will never forget her for taking the time to talk to me and find out what matters to me most.

COMMUNICATION

play
decide

Story Card 61

Clarity in the communication process

Links to: Issue Cards 5 + 11

Lisa is an older person.

I was recently admitted to hospital with a kidney infection. The team were asking me lots of questions and discussing my treatment with me. They were saying, “you know we went through this yesterday” but I couldn’t remember what we had talked about. With my vascular dementia, I have short term memory problems. I was annoyed that the doctors and nurses did not understand my predicament. My diagnosis is not on my file. Once I informed them, they involved my husband in the conversations. I told the staff that I wanted him involved and everybody was clear about the process. Of course, he was not making the decision for me, but he was supporting me in the decision that I was making.

COMMUNICATION

play
decide

Story Card 62

A communication difficulty does not mean the patient does not have capacity

Links to: Issue Cards 20 + 27

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 the augmentative and alternative communication approach, she expressed strongly that she wanted to go home. I had no queries about her capacity to make that decision. 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 but in the end the husband agreed to take her home with an increased home care package.

COMMUNICATION

play
decide

Story Card 63

There is a need to be consistent when in discussion with patients about their condition

Links to: Issue Card 29

Sean is a nurse.

This patient was having repeated visits to hospital for what she believed to be pneumonia, but the actual problem was recurrent aspiration due to reflux. The patient would not be well enough to undergo surgery to fix the hernia that was the underlying cause of reflux. I don’t think this had been well explained to her. It turned out that a doctor, unfamiliar with the case, had given false hope that she would be well enough for the surgery soon. This caused a lot of confusion. The patient was capable of understanding and retaining information around advance care planning, but we needed the time to explain and repeat advice frequently. In the end she was discharged from hospital to a nursing home with support from the palliative care team. I think clear communication about the reality of the patient’s situation could have helped avoid delays in care planning.

COMMUNICATION

play
decide

Story Card 64

Family members may be able to help with patients' decision-making

Links to: Issue Cards 4 + 42

Sophie is a doctor.

A patient, in her 70's, was admitted with a kidney injury and was cognitively impaired. The patient believed the team was not helping at all and did not trust them. She requested another consultant's opinion. Even afterwards, the patient did not take on board the advice given. Following a family meeting the patient accepted to follow a family member's advice, who agreed with the care team. The patient returned home and finally agreed to receive some home help. I think patients need to be informed as early as possible about why they are in hospital and what is happening, and their families need to be involved too. Sometimes people can't communicate or agree to care plans without extra support.

COMMUNICATION

play
decide

Story Card 65

Lack of consideration

Links to: Issue Cards 39 + 43

Sibeál has early onset dementia.

I was admitted to my local hospital with chest pain. The doctor said I needed to attend another hospital to undertake further tests which was four hours away. I was told that I would have to travel via a bus ambulance. My early onset dementia was not considered. I should have been given other options like being accompanied by my husband. The travel was very tiring, and we got there and back in the day. When I returned to that hospital that evening, I was moved out of the cardiology ward to an orthopaedic ward which was confusing.

COMMUNICATION

play
decide

Story Card 66

What if I missed them?

Links to: Issue Cards 26 + 41

Janice is an older person.

I was in a ward with stomach pain. I was anxious to find out what was wrong with me and asked a few times if I could speak to the team who were looking after me. Each time I asked a staff nurse they could not tell me what time the team would come. I became worried and anxious. What if I fell asleep? Would anyone wake me up? I was afraid I would miss the opportunity to speak with my doctor. Eventually the doctor came, and I asked if I could speak to him privately that evening. He seemed annoyed by the request and said, “for what”?

play
decide

Story Card 67

Working together to make a plan

Links to: Issue Cards 33 + 37

Michael is a speech and language therapist.

We worked with an older gentleman with mild cognitive impairment who was on a special diet of soft foods because he had difficulty swallowing. When I saw him on a repeat visit, he complained that the plan he'd been given didn't have anything he liked to eat, and he didn't know how to prepare many of the meals that were specified. I could tell he was angry, and he said he felt as though the hospital team were just trying to dictate to him and didn't care what he liked or disliked. I was able to take the time to sit down with him and find out what types of foods he was used to preparing and eating. We worked together to find ways of incorporating them into his new diet plan.

COMMUNICATION

play
decide

Story Card 68

Assisting patients to communicate in whatever form is needed

Links to: Issue Cards 1 + 17

Marta is a speech and language therapist.

We had been working with a patient with dysphagia who was repeatedly in and out of hospital with aspiration and chest infections. She had been told to consume thickened fluids but wasn’t doing this when at home. Our team members wondered if she actually had the capacity to understand the risk, as they were having difficulty communicating with her. I tried asking simpler closed-ended questions which she could easily answer with short responses. This helped because her communication issue was actually not due to cognitive impairment, but rather she had dyskinesia which made it difficult to communicate and be understood. In fact, she had only very mild cognitive impairment, and using the new communication strategy she told us that she understood the risks of not using the thickened fluids.

COMMUNICATION

play
decide

Story Card 69

Creating the right conditions for patients to communicate their preferences

Links to: Issue Cards 6 + 33

Andrea is a speech and language therapist.

Our team had advised that one of our patients should go to a nursing home for care, but he was refusing to go. The team thought that he had moderate cognitive impairment and was simply confused and didn't understand the situation. However, we re-assessed him and it turned out that he had only a minor cognitive impairment, and understood everything that was happening. We found that he was capable of going home and living independently. When he was first admitted he didn't have his hearing aid with him, and his quiet speaking voice made it even more difficult for the team to communicate with him. As a result he had been mis-labelled as having cognitive impairment.

COMMUNICATION

play
decide

Issue Card ①

Check your jargon?

Sometimes healthcare professionals need to use discipline-specific or technical language when communicating with patients or with their family.

play
decide

Issue Card ②

ADM is fostered when teamwork is interdisciplinary and guided by a shared vision

Interdisciplinary teams that communicate well together and with the patient can foster quality ADM for patients. What are the characteristics of this type of interdisciplinary team?

play
decide

Issue Card ③

Having dementia does not mean a person cannot communicate

Why do healthcare professionals tend to direct the conversation to a family member rather than to the person with dementia?

play
decide

Issue Card ④

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?

play
decide

Issue Card ⑤

Communication is a two-way process

Do people with dementia have a responsibility to share their diagnosis with healthcare professionals?

play
decide

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.

play
decide

Issue Card ⑦

Communication difficulties can often get perceived as cognitive issues

How can a speech & language therapist improve communication to support a patient’s capacity for decision making?


play
decide

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.

play
decide

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?

play
decide

Issue Card ⑩

Preferred methods of communication

Oral communication should not be assumed as the preferred method of communication. Patients should be consulted about how they wish to be communicated with.

play
decide

Issue Card ⑪

Communicating with nominated decision supporters and others

Sometimes there is tension between family members and healthcare professionals with respect to the patient's wishes. What is the difference between healthcare professionals' responsibilities to communicate with a nominated decision supporter as opposed to other family members, friends, or next of kin?

play
decide

Issue Card ⑫

Still “Best interests” approach

By having a diagnosis of dementia, the will and preference of the person can be overlooked in favour of a ‘best interests’ or ‘professional knows best’ approach. How can we avoid this?


play
decide

Issue Card ⑬

Patients’ assertiveness

Patients can feel frustrated when their experience is not considered or valued in care planning. They may need to be quite assertive to make their voice heard. What could be done to maximise all patients’ participation in the decision-making process?

play
decide

Issue Card ⑭

Speak up

It can be difficult for patients to speak up about their care preferences, in particular when these preferences don’t align with healthcare professionals’ opinions.

play
decide

Issue Card ⑮

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.

play
decide

Issue Card ⑯

Medicalisation & labelling

Medicalisation and the labelling of a person with dementia may impact their self esteem, self efficacy, and self confidence. How can the need for a timely diagnosis be managed by healthcare professionals in such a way as to reduce this impact?

play
decide

Issue Card ⑰

Unwise decisions

Cognitive impairment may be under greater scrutiny from healthcare professionals, especially when they consider an unwise decision to have been made.

play
decide

Issue Card ⑱

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?

play
decide

Issue Card ⑲

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.

play
decide

Issue Card ⑳

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?

play
decide

Issue Card ㉑

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?


play
decide

Issue Card ㉒

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.

play
decide

Issue Card ㉓

Environmental barriers to assisted decision making

What can healthcare professionals do to overcome social and physical environmental barriers in hospitals in order to maximise a patient’s involvement in decision making?

play
decide

Issue Card ㉔

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?

play
decide

Issue Card 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?

play
decide

Issue Card ㉖

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.

play
decide

Issue Card ㉗

Where is a translator when you need one?

In your opinion is there timely access to resources (i.e. translators, assistive technology, visual aids, etc) which would support a patient in the communication of their decision?


play
decide

Issue Card ㉘

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?

play
decide

Issue Card ㉙

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)?

play
decide

Issue Card ㉚

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?

play
decide

Issue Card ㉛

Can ADM be standardised?

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

play
decide

Issue Card ㉜

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?

play
decide

Issue Card 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?

play
decide

Issue Card ㉞

Private health insurance or wealth

Having private health insurance or wealth offers more options for healthcare decision making.

play
decide

Issue Card ㉟

Difficulties in sharing health-related information

Often patients have to repeat their story many times and to many different professionals. This can be very frustrating and a cause of concern to them because details may be forgotten when they are asked to repeat them constantly. What could be done to improve the sharing of health-related information in the care planning process?

play
decide

Issue Card ㊱

The importance of making time to build and harness existing relationships with GPs

There are many demands and time pressures on healthcare staff in acute care settings. They may have little time to build positive and supportive relationships with patients and families. What can be done to involve GPs more in critical clinical and care decisions?

play
decide

Issue Card ㊲

Knowing your healthcare staff

Navigating the emergency department can be difficult for patients. For example, different healthcare professions wear different clothes, colours and uniforms, which signify their professional roles. Patients may not understand how the professional groups differ and who is caring for them. What can be done to further patients understanding regarding an acute care setting and their care team?

play
decide

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?

play
decide

Issue Card ㊴

What matters to me

Admission to acute care settings can be a very stressful, disorientating, and frightening experience for any patient, especially for patients presenting with fluctuating capacity. Could knowing about likes and dislikes of that patient help reduce anxiety and discomfort?


play
decide

Issue Card ㊵

Interprofessional collaboration

How can we enable good interprofessional collaboration which promotes the sharing of information required for assisted decision making?

play
decide

Issue Card ④①

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?

play
decide

Issue Card ㊷

Readiness to engage in care planning for the future

Receiving a formal diagnosis of dementia can be a very vulnerable time for the person. They may not be ready to engage in conversations about assisted decision making and care planning straight away. Is there a best time? What are your views on how this can be approached?

play
decide

Issue Card ㊸

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?

play
decide

Issue Card ㊹

Fluctuating capacity

Patients may experience fluctuating capacity and anxiety on acute admission. This may be exacerbated by frequent changes in their context of care (i.e. staff changes and moving them to a new bed space). What can be done about this?


play
decide

Issue Card ㊺

Fitness to practise

Some healthcare professionals are afraid of liability issues and fear that their professional practice could be called into question as they attempt to navigate the new ADM legal framework. What supports could help healthcare professionals with this transition?

play
decide

Issue Card ㊻

Healthcare professionals can feel vulnerable

Some healthcare professionals recognise that there is a disparity between a patient’s preferences to be cared for at home and the home care services available within the health system. Healthcare professionals may feel a sense of stress and helplessness.

play
decide

Issue Card ㊼

Patients’ will and preference

Early elicitation of patients’ preferences and values is crucial for informing advance care planning. How can healthcare professionals encourage patients to share this information early on in their care pathway?

play
decide

Info Card ①

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.

play
decide

Info Card ②

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.


play
decide

Info Card ③

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.

play
decide

Info Card ④

Presumption of decision-making capacity

A person is presumed to have decision-making 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.

play
decide

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.

play
decide

Info Card ⑥

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.

play
decide

Info Card ⑦

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.

play
decide

Info Card ⑧

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.

play
decide

Info Card ⑨

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.

play
decide

Info Card ⑩

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.


play
decide

Info Card ⑪

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.


play
decide

Info Card ⑫

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.

play
decide

Info Card ⑬

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.

play
decide

Info Card ⑭

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).


play
decide

Info Card ⑮

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.


play
decide

Info Card ⑯

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.

play
decide

Info Card ⑰

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.

play
decide

Info Card ⑱

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.

play
decide

Info Card ⑲

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.

play
decide

Info Card ⑳

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 life-sustaining treatment through an ACD.

play
decide

Info Card ㉑

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.

play
decide

Info Card ㉒

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.


play
decide

Info Card ㉓

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.

play
decide

Info Card ㉔

Three types of decision-making supports

The ADMCA provides for three types of decision-making supports: 1) Assisted decision-making, 2) Co-decision 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.

play
decide

Info Card ㉕

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.


play
decide

Info Card ㉖

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.

play
decide

Info Card ㉗

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.

play
decide

Info Card ㉘

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.

play
decide

Info Card ㉙

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.


play
decide

Info Card ㉚

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.


play
decide

Info Card ㉛

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.

play
decide

Info Card ㉜

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 multi-disciplinary meeting/case conference to discuss the issue. It may be necessary to refer the question to the Circuit or High Court.

play
decide

Info Card ㉝

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.

play
decide

Info Card ㉞

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.

play
decide

Info Card ㉟

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.

play
decide

Info Card ㊱

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.

play
decide

Info Card ㊲

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.

play
decide

Info Card ㊳

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.

play
decide