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How do we know?
The assessment of capacity.

Until very recently I was working as a consultant in liaison psychiatry in England. I was the psychiatrist who would assess and treat people in the general, physical health hospital. Prior to that I worked as a general psychiatrist in a different hospital. For several years I have taught other doctors about mental capacity. My patient examples are in the public domain, have all been anonymised, or I have the individual's specific permission to share the story widely.

Throughout this talk I shall refer to "the law", by which I mean 'the law as it currently stands in England and Wales'. In England and Wales, as in Scotland and many other commonwealth countries, the law is 'judge made'. That is every time a judge makes a judgement in a particular case the law changes, usually just a little. The judge's opinion is now the law, until it is challenged and changed by further cases. When I first started in practice, in the late 1980's, decisions about mental capacity were dealt with under common law. This means that there had not been a specific piece of legislation voted on by parliament, but rather the law was based on historical practice and what a reasonable doctor would do in that particular situation. We just did what seemed to the medical team to be in the patient's best interest, taking into account what we knew of the patients and families view.

As advances in medical technology meant that people with more severe disabilities survived, and with an aging population and increase in prevalence of dementia, and the move away from hospitals to care in the community the question of how to protect the needs of individuals who lack capacity to make their own decisions became more pressing. This area of law gradually became more and more complex and contested. Parliament drafted a new law to pull together all the previous legislation and subsequent case law, to clarify things. This became the Mental Capacity Act 2005 (MCA). The MCA covers capacity to make decisions in all areas of life, not just in medical situations.

Case law changes medical practice.

A man was very distressed to find that a Do Not Attempt Resuscitation (DNAR) order had been placed on his wife when she went into hospital, and he didn't know about it. She had a cardiac arrest whilst there, and died. He took the hospital trust to court saying this was unlawful, had caused him substantial emotional distress and that the hospital staff should have attempted to resuscitate his wife. The eventual judgment affirmed that the DNAR decision was ultimately a clinical matter for the doctors, but that this should have been discussed with the family or main carer, and in any case, they should have been informed about the DNAR decision immediately, even if the decision was made at 03.00. From the moment that judgment was handed down that became the law. Doctors making a DNAR decision in England and Wales, are now forced to ring families even if it is in the early hours of the morning. This case has been useful in making doctors consider and discuss if someone should be resuscitated, prior to any crisis occurring.

You may feel that phoning the family in the middle of the night is unnecessary, I can recall a surgeon colleague getting very angry with me when I explained this. That is currently the English law, no matter how much you disagree with it. If you don't comply with the law you and/or your employers could be taken to court and fined or even imprisoned.

The next case went to the appeal court and a judgment was made and reported widely.

As you listen to this case imagine the situation arose in your hospital, what would have happened.

Mrs C., 60-year-old divorced woman who had never worked, had taken a large overdose resulting in damage to her kidneys. She was now refusing kidney dialysis. Her reasoning was that she had lost her joy for life, her 'sparkle' and wanted to be allowed to die.

Mrs C. had lived an unconventional life, enjoying parties, youth and beauty, she had always been glamorous, and self-centred. She had had several husbands. Mrs C had children who supported her decision to die, she had always told her family that she would hate to grow old and lose her zest for life.

The renal physicians thought there was an 85% chance that her kidneys would recover fully with dialysis. She was assessed by two psychiatrists and no trace of a depressive disorder was found. The psychiatrists felt she lacked capacity to refuse treatment, the independent expert felt she did have such capacity. The court was asked to judge whether she had the capacity to refuse to have dialysis, which would likely lead to her death.

What would have happened in your hospital?

The appeal court judge determined that to refuse treatment was in keeping with Mrs C's previous personality and choices and that, even though it was not the decision he personally would have made, she had capacity to make that decision and it was her decision. Mrs C was allowed to die, and in fact she had already died shortly before the court decision was taken.

What do we mean by 'capacity'?

Capacity is a complex cluster of cognitive functions including memory, judgment, rationality, and imagination. Capacity is always time and decision specific. The individual has, or lacks capacity to make this particular decision at this particular time, it is very rare that there can be a global statement of capacity.
When the MCA first came out a particular private mental hospital had a certificate added to some patient's notes which read "Mrs Smith lacks capacity, signed Prof Jones, Consultant Psychiatrist." This is complete nonsense because Capacity is always time and decision specific.
You could however reasonably write, after recording a full capacity assessment: "For the above reasons Mrs Smith does not currently have capacity to manage her financial affairs and in my opinion, she is unlikely to regain such capacity."
A blanket statement of capacity is rarely appropriate, unless the patient is unconscious, for example even in advanced dementia people can still have capacity to choose which cake to eat.

The MCA gives us clear guidelines for assessing capacity and starts with 5 principles.

1. **Adults, from age 16 years are assumed to have capacity** unless proven otherwise
2. Individuals must be **supported to make their own decisions**. For big decisions, e.g. where someone was going to live you might ensure they had a family member with them, visit them several times to discuss the issue, show them photos, take them to the different possible accommodation. This also covers advance decision making and Lasting Power of Attorney, ways in which people can prepare for their wishes to be followed, as and when they lose capacity.

3. **Unwise Decisions.** Just because we view a decision as unwise, and not the choice which we would make does NOT automatically mean the person lacks capacity. Individuals with capacity have the right to make what we view as bad choices and unwise decisions.
4. **Best interests.** Anything done to or for a patient who lacks capacity must be in their personal individual best interest.
5. **Less Restrictive option.** If someone lacks capacity to choose then the less restrictive thing should be done; the minimal operation necessary to save their life, the nursing home rather than selling off their own home. A lady was admitted to our psychiatric unit, frail with a severe depression. She recovered over several months and was fit to return home to live on her own. Then we found her family had sold her home. That was not the less restrictive option, and so was illegal. She ended up in a nursing home, and decided not to take her family to court.

The legal test in capacity cases is 'on the balance of probability'.
So, if the clinician is more than half convinced that the person lacks capacity then their judgment must be that they do lack capacity; you don't have to be absolutely and utterly certain about your judgment just 51%.

What precisely is the issue the person needs to decide about?

The capacity to decide to refuse life-saving treatment is at a much higher level than the capacity to decide which clothes to wear. What precisely is the question the patient has to decide about?

In law a person over 16 years is assumed to have capacity to make their own decisions, so the next question is: **Is there any reason to doubt this person's capacity?**

We all judge capacity instinctively each day.

Imagine: you are about to get into a taxi, the driver is slurring his words, he looks sweaty and is shaking. You would probably judge that he lacked capacity to drive safely and not get in that car. Most of the time our medical capacity judgments are on that level. You approach a patient to take blood, explain what you are doing, they hold out their arm showing their consent, you take their blood. You have made an implicit decision that this person understands what you are doing and why and has the capacity to consent to that intervention.

I was asked to see a 72 years old lady who was refusing treatment on the ward.

She had type 1 Insulin dependent diabetes, and a small degree of dementia. She had been admitted to hospital in a diabetic coma. She was resuscitated in the Emergency Department (ED), but now was becoming increasingly confused. When confused she was aggressive and refusing treatment. I established the cause for this was that her blood sugars were very unstable, sometime very high, other-times very low because she was not consistent in accepting her insulin.

No one had recorded in the medical notes that they had considered her capacity to refuse treatment, or that we might have to force treatment on to her in her best interest. She had a clear delirium, secondary to hypo- and hyperglycaemia, after several days of enforcing treatment, including gentle restraint at times, her blood sugars were stable and most of her confusion lifted.

What is going on which might cause the patient to lack capacity?

In the case above hypo- and hyperglycinaemia are both clear causes of delirium and hence can cause lack of capacity. Capacity can be impaired by metabolic imbalance or sepsis. Intoxication with alcohol, street drugs or several classes of prescribed drugs, particularly opiates, can all cause temporary loss of capacity. Learning difficulties, head injury or a dementia illness can cause more permanent loss of capacity.

The cause does not have to be a clinical diagnosis. Severe emotional stress, for example having just been in a car crash, would probably cause a temporary loss of capacity to make significant decisions.

When you make a formal capacity assessment you need to record the underlying condition or situation which is leading to the doubt about capacity.

Having established and recorded that there is a reason to doubt the individual's capacity to make a decision about (whatever it is) we ask:

Can the patient Understand, Retain, Weigh up the salient information, and Communicate their decision?

1. **Understand.** The patient needs to be able to understand what you are discussing, using language at an appropriate level for them, with all the appropriate aids for example interpreters, photos or significant objects.
2. **Retain.** The person only needs to hold onto the information for the length of your conversation, so someone with quite severe dementia could have capacity for significant decisions. You have to be convinced that they were holding on to the information, which you test by asking them to summarise your conversation. If they cannot remember the conversation at all the next day you might well, for a significant decision, repeat the process and hopefully get the same answer, which would mean that was a decision made with capacity and should be followed.
3. **Weigh-Up.** The patient needs to understand what their choices are, what the likely outcomes are for each choice. For example, what would happen if they had this operation, or this other operation and what would happen if they had no operation at all? They need to be able to hold all this in mind and then make a balanced decision. Remember that they have the right to make an unwise decision, one that you would not agree with.
4. **Communicate.** They need to be able to let you know what their decision is in words or other clear and consistent way. Someone with a communication disability and no spoken language may use sign language, squeeze your hand, or always point to the picture of one potential home, in a repeated and consistent manner. That would be good enough communication, if they had met the other three tests.

You only have to fail on one of the four tests to lack capacity for that decision at that time.

What do you do when someone lacks capacity to make a significant decision?

If their life is threatened you get on and treat them. You resuscitate the unconscious bleeding patient, and record the details afterwards.

If there is a potential for the person to recover capacity, or if their capacity is fluctuating you come back another time. Perhaps they have just had some strong painkillers, but will be fully lucid four hours later, or like the lady with severe depression whose family sold the house, there is the potential for full recovery in the future, you only make decisions on their behalf that must be made right now.

Best Interest decisions.

If the lack of capacity is likely to be ongoing and the decision is urgent then the question becomes: What is in this patients Best Interest? Which is fundamentally: What would this person choose if they could choose for themselves?

This may seem obvious, life is almost always assumed to be in someone's best interest, so giving life-saving treatment to someone is the default option, but it must depend on the individual's values and preferences not that of the family, the staff or the wider community.

If the question is less clear you would get together those who care for the person; family member, medic, nursing staff, long term carer and others involved, and have a best interest meeting to discuss what the person would have wanted. This does not have to be a big formal meeting; it can simply be a series of phone calls, taking a few minutes.

Advance planning.

Best Interest decisions are made much simpler if the person has laid out their wishes in an advance treatment plan. If someone has a recurrent illness, such as a severe psychotic illness, they can be supported when well to make a plan for what they would like to happen when and if they become ill again. This can be very detailed, down to who has the keys to their flat and what should happen to their pets, and include their preferences for medication and what has worked in the past. This sort of plan is advisory and **NOT** legally binding.

Anyone who currently has capacity can also make an advance directive which is a statement of which treatment they refuse to have. Properly drawn up an advance directive (similar to a living will in other jurisdictions) is legally binding. If you gave the treatment which they have rejected that would be an assault. In England the most common situation for an advance directive is Jehovah's witnesses stating they refuse blood transfusions, even if that will potentially lead to their death. An advance directive stops being legal if the situation of the person's care changes- for example if a new wonderful treatment has been invented, or if the person has acted against their advance directive. If the Jehovah's witness has willingly accepted blood products last week then their advance directive refusing them is now in the rubbish bin. An advance directive states which treatment the patient refuses to have, it can request but cannot force the treating team to give any particular treatment

The other mechanism for ensuring your wishes are carried out, as and when you lose capacity, is to complete a Lasting Power of Attorney (LPA) form whilst you still have capacity. These are commonly recommended when people receive a dementia diagnosis. There are two types of LPA, one to deal with finance, and the other to deal with healthcare decisions. You nominate someone to make the decisions on your behalf when you can no longer make decisions yourself, often a family member. Clearly this needs to be someone you trust to make the right decisions, and you need to have had conversations about what you would want to happen in different situations. An LPA is binding on the medical staff, the appointed person speaks as if they were the patient and has the same ability to make decisions and refuse treatment as a patient with capacity.

In the absence of any advance decision making the family, friends and carers are called upon to discuss what is in the patient's best interest. If there are none, then there is a mechanism for an Independent Mental Capacity Advisor to be appointed who will spend extra time with the patient, talk to more distant family or friends, maybe reading old letters and diaries to try to find out their values and what they would have wanted.

The best interest being 'what the patient would have wanted' does not mean that they then get better treatment than other people with similar conditions who do have capacity. Just because they would have always wanted to live in a 5-star hotel doesn't mean they get that rather than a nursing home. The options considered have to be those that would be available to the same patient if they did have capacity.

Capacity can fluctuate.

If someone has capacity, but then loses it, then you do what they decided when they had capacity. If they keep on changing their mind about a procedure or treatment, that may be a sign of fluctuating capacity. People who are under severe stress may temporarily lose capacity.

If you fail to act in the best interest of someone who lacks capacity you could end up in jail. At one time my hospital had a big problem with non-clinical staff moving patients from ward to ward, even sometimes in the middle of the night. If the patients were elderly with vulnerable brains this would commonly result in a delirium and an extended stay in hospital. I managed to get the system to understand this was a bad idea, and moves in the middle of the night were much diminished. However, such inappropriate moves still happened from time to time, and I was furious when they moved one lady who had an early dementia at around midnight. It was clearly against her best interest, and I discovered that the bed manager had actually said "I know it's not in her best interest, but I need a side room.” That staff member had broken the law, by not following the individual’s best interest and moving someone else. I put in another complaint and they went on a capacity training course.

Someone who is acting for the patient under lasting power of attorney must ensure that they are following the patient’s wishes, not their own. If they do not, they can be replaced as the patient’s representative and even risk imprisonment.

I was asked to see Mr J. because his family was refusing to allow him to go home. Mr J. was 78, a retired businessman. He had early signs of dementia and he had had a fall. His family were worried about what might happen to him, but he wanted to go back to his own house. Mr J. had been assessed by the physiotherapists and occupational therapists as being able to manage at home with some minor adjustments, including bringing his bed downstairs. When I saw Mr J. he was perfectly clear in his thinking. He explained that he realised that he might fall again, he could tell me what he would do if he did fall over, how he would get help. Mr J. knew if he fell again it could shorten his life and he still wanted to take the risk and go home. I talked to the family and explained that we could not keep him in hospital, he had the right to go home. The same level of support was put in place as if Mr J had no family involved, and an ambulance took him home. I never heard what happened next.

Capacity to refuse life-saving treatment.

It is a long-established principle of English law that an adult with capacity can choose to refuse treatment and so die.

Mrs K. was at the end of her life. I had been asked to see her urgently for “suicidal ideation”. She was 86 years old and had several chronic life-limiting conditions. She had developed a chest infection, and as it worsened, she agreed with her family not to treat this, and to allow nature to take its course. Unfortunately, her care arrangements broke down and she came into hospital by ambulance, moribund, was resuscitated in the Emergency Department and woke up on a ward. Mrs K. was quietly angry that her wishes had not been followed, and now she was refusing to have any further investigations. This was interpreted as her being suicidal.

The questions I considered were: Did she have a depressive illness which was driving her choices? Did she have the capacity to refuse treatment?

As we talked, I established that she was a lovely faithful member of her local church, she had no history or current signs of a depressive illness. Mrs K. said that although she would do nothing actively to end her life she simply did not want ‘to be messed about anymore.’ She was declining further tests or treatment and she was ready to die. Mrs K. suggested I should speak to her local minister, with whom she had had many conversations expressing her thoughts and wishes. Surprisingly I was able to get her vicar on the phone and established clearly that Mrs K. had presented a consistent picture for many years, and there were no signs of a depressive illness. I couldn’t at that time get her daughter on the phone, but spoke to her later, confirming my picture.

I was clear in my own mind that she did not have a depressive illness, and that she did have full capacity to choose not to have further investigations and treatment.

I spoke to the consultant physician in charge of her case and explained, against much resistance, that in my opinion she was not depressed nor suicidal, that she had full capacity to make her own decisions and hence her wishes should be respected. The consultant found it very difficult to accept this, and I had to go through the law in some detail to reassure him. K was transferred to a nursing home and died there, peacefully surrounded by family, some three weeks later.

Sometimes the capacity assessment needs to be reviewed.

Mrs J. was a 38-year-old married lady who worked as a carer. She was brought in to the Emergency Department (ED) by ambulance having taken a large overdose of paracetamol. She had no past psychiatric history and no previous overdoses. The trigger was that she had been accused of theft, this threatened her livelihood and her home. She had been greatly distressed and had come downstairs in the middle of the night, written a note saying she did not wish to be resuscitated and taken a lot of tablets. Her husband woke during the night, found she was not in bed and came downstairs to find her asleep but rousable.

The note caused much confusion, the junior doctor treating Mrs J. thought this should be taken as an advance directive, and hence that we could not treat her overdose. However, there are strict legal requirements to setting up an advance directive refusing life-saving treatment, and this note certainly did not meet those requirements.

Thankfully the senior ED doctor overheard a discussion about this and asked my team to get involved. One of the nurses assessed her, found no sign of a depressive illness, but concluded she lacked capacity due to the overwhelming social stress. Mrs J was informed she was going to be treated whether she liked it or not and she accepted this. The next day she thanked the liaison team for ensuring her treatment, she no longer wished to be dead and said “I don’t know what I was thinking, I was so frightened.”

Mrs J. was eventually fully exonerated, returned to her work and continued to support other patients in the community.

To allow a 38-year-old to refuse treatment in that acute situation, likely leading to her death would have been wrong, but this was being argued for by junior staff on the basis of a superficial assessment of capacity and the note she had written. Following this we established a formal policy in the ED that all cases where lifesaving treatment would be withheld must be discussed with a consultant. It was a great surprise to me that junior doctors in their second year of practice would have even considered making such significant decisions on their own. To refuse lifesaving treatment the individual must have a high level of capacity, and this should be discussed amongst the treating team, which could involve the liaison psychiatry team if there is one available.

Some legal questions are simply too difficult for medics to decide. Each UK hospital trust has access to a firm of lawyers, and it is possible for them to get a judge’s interim decision on a case within a few hours, day and night. This decision is then the law, and the treating team must follow it. The decision could later be challenged in a higher court, all the way up to the Supreme Court and the European Court of Human Rights.

In summary.

To make a full accurate capacity assessment for significant choices, requires the healthcare worker to have sufficient time to establish a good rapport, to consider the whole person, and requires a high level of communication skills. On a busy ward, in a busy practice it can be difficult to give the necessary time, and I am sure this was a factor in several of the difficult cases I have shared with you. The intention of the Mental Capacity Act 2005 was to clarify the law in this area and set out the tests to establish if an individual has capacity or not. The act gives extra opportunity for individuals to ensure that their opinions, their views and values are the ones which prevail in decision making. The process of assessing if someone has capacity for a particular decision is straightforward and can be taught to any healthcare professional. Complex cases may need a second medical opinion or a legal opinion.

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