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Video 1: Capacity to consent

Dr Matt Hoghton I think there is some uncertainty and lack of clarity around some of the decision-making in capacity and I think the more we can provide people with examples about that people may have capacity to make decisions about daily living activities, but they may not have capacity to make a decision about a large operation, such as an operation on their heart, where they may not fully understand what that means, they may not fully understand the benefits, the risks etc.

And I think we should try and maximise the capacity and maximise the way they are able to achieve that.

Geraldine McCluskey Not all people are aware that no one can consent on behalf of a person who is over 18, and that includes people with a learning disability.

Professor Baroness Sheila Hollins We found that some patients were not being offered a choice of treatment because their capacity hadn’t been assessed, and because sometimes their family members or a member of the healthcare team would make an assumption about capacity without actually checking for it.

Geraldine McCluskey Doctors need to be very aware that, yes, there is a role for the carer in the consent process in bringing them on board to help facilitate the decision-making process, but
that they can't ultimately consent on behalf of the individual themselves.

I can think of one example that a colleague of mine gave me recently where an adult with a learning disability, a lady who was taken to her doctor by her mother and her mother wanted her to be sterilised. The lady herself didn't know what being sterilised meant and went willingly with the mother to the doctor. And a really good GP actually took on board what the mother had wanted, but in the same respect broke down the information, explained what the process would entail, and was able to get a very, very clear indication from the person with the learning disability that that's not something that she wanted. She wanted, as an independent lady, to be able to make a choice in the future if she wanted children or not.

So instead of going from a direct conversation with a carer about this lady being sterilised, other areas and other options of contraception were actually explored instead of just listening to a person. And that lady went, and could have been put on a list to be sterilised without actually realising what it is.

So I think it's really important that you have to ensure that the person is given all the information in a way they can understand. And it's also really important that doctor just doesn't assume that because of a learning disability this person doesn't have the capacity, because often when information made clear in an accessible way, that person may well be able to make a decision.

Some research we've done at St George's, around end of life care, we found that that some patients were not being offered a choice of treatment because their capacity hadn't been assessed, and because sometimes their family members or a member of the healthcare team would make an assumption about capacity without actually checking for it.

I'd like to give you an example of a young woman who has a learning disability and who had a diagnosis of cancer - and it was a brain tumour, I don't recall the exact diagnosis. She was told she needed to have
treatment and the treatment was described to her and the treatment sounded horrible, and she didn’t want to have the treatment at all. But the doctor was very straightforward with her because he asked her ‘Do you understand what will happen if you don’t have the treatment’ and she said ‘What will happen if I don’t have the treatment?’ and he said to her ‘You will die. Do you know what that means?’ And her mother had died of cancer and she did know what it meant, and she said ‘I don’t want to die’. So then he explained the treatment to her again and talked to her about how much support she would get while she was having the treatment. And she had the treatment and she’s now able to teach medical students about issues of consent and capacity. So I think she’s a very positive example of how, when the information was presented to her in a way that she could understand in a straightforward kind of way, that she was able to make a decision and people were confident that she did indeed have capacity.

Nahida Hussein

Involve me in discussions.