



## Where interviews have mattered

### An avoidable failure of care?

In the very early days of thinking about consent interviews, I met a 56 year old man, let's call him Arthur, with intellectual disabilities who was scheduled for surgery. The staff at the care home had told Arthur what was going to happen and he had agreed. I met him for the first time two days before his operation to talk about something quite different, but I was concerned about his capacity to consent because he was very acquiescent, answering 'yes' to any closed question. When I asked open questions, Arthur did not reply at all and I had not been able to learn anything new from him about his family history.

Staff assured me that he understood but I asked if I could check, just in case. When I said to him, 'Do you know what's happening on Monday?', he answered, 'Yes'. But when I asked, 'What is happening on Monday?', he looked away and did not reply. I tried asking, 'Tell me about what the doctor said,' and 'Tell me about going to the hospital on Monday,' but nothing prompted a free answer. The staff thought this was because Arthur did not know me, and they may have been right. But they also said that he rarely spoke at all except to say 'Yes,' which they took to mean he understood their questions.

When I visited on another matter a week or so later I heard that the operation – a circumcision – had not gone well. Arthur had woken up post operatively and refused then to eat or drink. He had pulled off the dressings, refused medication, acquired an infection, and finally been given intramuscular antipsychotics to calm him down. He had not come back to the care home.

The staff had done their best, but not knowing how to ask Arthur for his opinion in a way that was not leading, or to check his knowledge about the procedure, meant that he underwent a painful procedure that threatened his dignity without giving informed consent or understanding why. No wonder he was uncooperative. Interestingly, it was seen as appropriate to give him antipsychotics by injection without his consent, but not antibiotics.

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### A positive counter balance

This is about 'Denise', a forty something woman with intellectual disabilities who needed a replacement for the heart valve that had saved her life earlier on. She already knew about hospitals and surgery and so there was a vocabulary to build on. Our community nurse worked with the surgeon and specialist cardiac team to make a booklet for Denise, explaining everything that would happen. The risks of surgery were high and these were set out for her, alongside the risks of not going through with it, which were even higher. The odds of surviving the operation were better than those of surviving without it.

Denise added her own comments to the booklet as she, her nurses and carers went through it to be sure she had understood everything, and I saw her a few days before the operation was due to take place. Having the booklet to hand meant the interview was even easier than usual because,



after asking for the free report, I could refer to the booklet to get to the detail. I asked Denise to tell me about what she was being asked to decide about, and she told me clearly in her own words that her heart valve was not working and that it must be replaced. She added that she knew she might die if she had the operation but that she would certainly die if she did not. I asked her what she thought happened when people die and she told me about being buried in a coffin and not being alive any more. She hoped there was a heaven.

We went through the booklet slowly and carefully with Denise's carer sitting alongside for support and also as a back-up and a kind of witness to the process. Every answer Denise gave showed not only that she had learned the contents of the booklet but critically, that she understood it – she could see the big picture. At the end, she told me without being asked that she had decided to go ahead with the operation because her chances of living were better that way.

Very sadly, Denise died suddenly the day she was due to be discharged, which might lead us to think that we had somehow done a terrible thing but I think quite the opposite is true. Denise's chances of surviving surgery were not good but her chances of surviving without it were zero. In her last days, she experienced the dignity of being consulted about her own care, of being taken seriously and supported to make her own decision, and of taking control of her own future to the same extent as anyone else might. She did it with courage and had the respect of everyone involved in her care.

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