



## Case Illustrations

### Davy's abdominal surgery

Davy was a middle aged man with Down's Syndrome who did not use speech much to communicate. He had a recurrence of his abdominal hernia and needed to be re-admitted for surgery. His previous hospital stay had not been a good experience. Because of his limited communication and some autistic features, he had not been told about going into hospital and he had fought the process all the way, once there. Much the same seemed likely to happen on this occasion too as he still did not communicate much and the likelihood of his taking in the necessary information was very low.

Fortunately, Davy had a community nurse who insisted he be told what was happening and made him a booklet to explain everything. She asked the staff at his residential service to go through it with him frequently, and they did, although he showed very little interest.

When I called to see him, Davy was squatting on the floor, scribbling on a piece of paper in green crayon. He looked up when I arrived but went right back to his scribbling – not a promising start! After a few minutes of sitting while Davy scribbled, I got out his booklet and began pointing to the pictures.

Pitch is important: both under and over estimation of someone's ability can jeopardise an interview. I began in the mid-range of where I thought Davy might be:

'Tell me about this book.'

'Tell me about this picture.'

'What is this picture about?'

These drew no response and so I moved down the range a little:

'This says Davy went to see the doctor.'

'It says Davy has a pain.' At this, Davy clutched his abdomen.

'The doctor says Davy needs to go to hospital.' 'NO!' Davy said.

Here was a reasonably clear demonstration not only that Davy understood what was being said, but that he had strong objections. We looked at a drawing of a man in a hospital bed. The man had a drip going into his hand:

'Where's the needle, Davy? Show me the needle.' Davy pointed quickly and accurately to the very small detail of the needle.

We looked at more of the pictures. Each time the matter of staying in hospital came up, Davy said 'NO!' very loudly. But when we reached the final picture and I said 'this is about coming home', he gave a big smile.

I had been unable to draw out any information from Davy beyond his reaction to my description of various scenes in his booklet. Nevertheless, he had shown more



understanding of the situation than his carer, in the room with us, had anticipated. However, while his responses demonstrated a grasp, they did not provide evidence either of big-picture appreciation, or any weighing up of the options. I judged him to lack capacity in this instance and referred back to the surgeon with regard to how essential the procedure was judged to be. The opinion was that Davy would suffer bowel obstruction and abdominal complications that might be life threatening if he did not have the surgery. His clear rejection of treatment could not be regarded as 'informed' and so the service would need to act in his best interests.

Davy's carers pulled out all the stops. Because they had seen how much he already knew and what he felt about going into hospital, they were able to work with him and the ward staff to make that much easier. In the end, he had a successful operation and recovered so well that his staff team, redeployed to other services while he was away, had to be recalled early.

Davy's case shows the value of informing people even when capacity seems unlikely. Being unable to give valid consent should not mean exclusion from information. People seem to do better if they know as much as they can take in and those around them give appropriate support.

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Sandra, who wanted to eat biscuits

Sandra was a young woman with intellectual disabilities, a strong will, and a serious swallowing problem. Sandra's swallow had been assessed as 'unsafe' which meant that she was at risk of choking to death if she tried to eat solid food. She had a [peg](#) inserted to maintain her nutrition, and the speech and language service had left clear guidelines about what she could take orally.

Sandra was not happy about the restrictions and often asked staff to give her biscuits, which were not on the list of safe foods. Some staff refused and pointed to the guidelines, but others acceded, saying she had a right to make her own decision. Sandra's mother was rather on the fence about it, sometimes supporting one faction, sometimes the other, and the service management wanted clarification about whose opinion took precedence.

The first thing we needed to do was to ensure Sandra had all the information she needed to make her choice, but this was complicated by the fact that she communicated using a chameleon – a device containing a custom built vocabulary that the user can trigger as required. It appeared that Sandra's device contained nothing of the necessary information for a conversation about choking, risk, choice, or, death. Those words, and many others were not programmed into the device and so we could make no assumptions about her understanding of those concepts.

The first step then was to role play the information-giving process and also the capacity interview to see what words came up. Then we had those programmed into Sandra's



chameleon. Finally, we supported her private tutor to work with her using the new words in context until she felt Sandra knew what they meant.

Unfortunately, there is no resolution because Sandra was moved to a service outside our jurisdiction before these preparatory stages had been completed. The story stands as an indication of the lengths required to fulfil our legal (and humanitarian) obligation that necessary information should be provided in a way the person can understand and use it.

#### Caroline's beautiful booklets

Caroline was a woman in her thirties with Down's Syndrome and an abdominal obstruction for which she required surgery. She was articulate and engaging and everyone who knew her was confident about her ability to consent. Caroline arrived for assessment with two large booklets, one made by her residential staff team, the other by her day care team. They were detailed and comprehensive with one full of images and illustrations, the other drawings and [widgits](#). Caroline was very happy to show me these, and without being asked, she began to go through them, naming each item in turn, 'nurse', 'scar', 'doctor' and so on.

It was clear that, whether she was looking at widgits or pictures, Caroline could identify almost every item successfully with only a few that she made up a name for on the spot. But when I asked her to tell me about what they meant or how some of them went together, she could only repeat the individual elements:

'You told me about 'operation' and 'scar' – what does that mean?'

'Operation. Scar.'

'How do 'operation' and 'scar' go together?'

'Operation. Scar.'

Caroline was very pleased with her responses so going through the booklets quite thoroughly was not arduous for her. She was very confident which is probably why those around her had been so convinced of her capacity.

My opinion was that Caroline lacked capacity because, while she could identify all the elements of the required information, she showed no evidence of putting these together towards the bigger picture. I had no sense that she knew even that she was going into hospital, only that she had thoroughly enjoyed learning the contents of the booklets.

Caroline's father and one of her staff were present for the session and so I asked what view they held about her capacity, following the interview. Both said that they were shocked at how little she had really understood. I told them that this was my view too.

Caroline then had a great deal of support towards her essential surgery and came through it well.

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### Ellie's eyelashes

Ellie was a young woman with intellectual disabilities whose eyelashes were growing inwards, causing repeated infections and threatening to damage her eyes. The ophthalmic surgeons had suggested that she have the eyelashes removed, but they warned that her eyelids would need to be stitched closed at least for a while, and possibly permanently.

Ellie's staff team had made a booklet for her about the proposed operation and Ellie had written in it. Her writing was very neat and comprised complete sentences such as 'Ellie is going into hospital to have her eyelashes taken out'. There were limited images but the personal entries were promising evidence of engagement.

I began by asking Ellie to read out what she had written:

'What does this say, this bit here?'

'Ellie is go ..... out.' As Ellie read this, her articulation of the middle part of the sentence was not just indistinct, it was a string of mumbled nonsense syllables. I asked if she minded if I read the sentence too and then I asked what she thought it meant. Ellie seemed unable to say.

This was the case with all the sentences in the booklet which suggested that, while Ellie may well have written them, she had not taken in the content and did not understand it. I put the proposed surgery to her in context:

'Ellie, I can see that your eyes are sore,' Ellie nodded. 'What does the doctor say about that?'

'What does the doctor want to do to make your eyes better?'

'What will happen after the doctor takes your eyelashes out?'

Ellie had no response to any of these questions and her face showed no expression, either of disappointment or embarrassment at not knowing, nor curiosity – a desire to find out.

I concluded that, articulate as she seemed to be, this was relatively superficial in this context and Ellie lacked decisional capacity at that stage. I recommended that her support team bolster her booklet with images and discussion so that she would have a better chance of absorbing enough information in the near future to maximise her potential.

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### Jason's tongue

Jason was an articulate and independent young man diagnosed with Asperger's syndrome. He had a problem with his tongue that required surgery but that carried the risk that he would struggle to communicate in the future. Jason was given the necessary information by his surgeon but refused to have anyone else present to support him with that afterwards. Jason's surgeon felt he had capacity to consent but his support team was not convinced and he was referred for interview in case a 'best interests' plan was necessary.



Jason refused to come for interview but agreed to talk on the phone. At first he was accommodating and responsive – he gave a list of facts about the proposed procedure, told me that was all I needed to know, and was about to hang up. I asked him to give me a minute or so just to ask about what it all meant:

'I've just told you!'

'Yes you did, I wonder though, what they mean by 'anaesthetic'. What do you think?'

'That's obvious, are you stupid? It's an anaesthetic, everybody knows what that is!'

'Oh but aren't there different sorts? What sort will yours be?'

'Ask the doctor if you want to know that.'

The interview progressed in this way for several more minutes, with Jason becoming increasingly angry, loud, and irritated. Not promising material, one would think. But critically, in the course of this dialogue, it was evident that where Jason knew the answer, he would provide it. He liked being right. Where he did not know the answer, he resorted to shouting and deflection. For a procedure as complex and potentially disabling as the one that was proposed, I had no confidence that Jason had capacity to decide for himself. I proposed a 'best interests' approach but also recommend that, as Jason seemed to want the surgery, he should be encouraged to sign any necessary forms as if he had capacity to do so. This would avoid angry confrontations at a time when calm was preferable and would maintain his sense of personal dignity and self-determination.

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