Page reference: The issues / Discrimination

Video 3: Assumptions about quality of life

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I think particularly when somebody’s got a very severe or profound disability perhaps, you know, additional physical disabilities, we’ve often been concerned that medical teams can make fairly quick judgements about the kind of meaning and quality of somebody’s life and are having the conversation about resuscitation at a very premature stage because they see the person as having a very poor quality of life and maybe a life they deem as not worth saving.

And so families often tell us that they have that conversation with them with the kind of words like ‘Wouldn’t it be better if we just let him go?’, ‘we’ll just let him slip away’ even in circumstances where the condition, the health condition itself is extremely treatable.

And obviously, one of the things we’ve been trying to get across is that the person’s quality of life may be different to one most other people experience, but it’s their life and they experience it in the way that they do and their families love and support them.

We had a situation recently where a family told us about the decision to remove somebody from an intensive care bed – clearly, you know, all part of prioritising a busy hospital. But their perception of what happened was,
because their daughter had such a profound disability, that she kind of lost her place in intensive care because people didn’t really think her life was worth saving.

They’d explained to the family that they thought that when she had needed resuscitating that she may have experienced further brain damage, although they didn’t really know that that was the case. And the Mum in this situation explained that she’d cared for her daughter all of her life with her profound disability and whatever the case she wanted to go on caring for her daughter and that that wasn’t a consequence to her.

And she explained to me that she didn’t feel like the doctors believed her when she told them that. That somehow they felt that her daughter must be some sort of burden on her and that she just was only saying that because she was her mother and it wasn’t real.

And she’s been left with a feeling that somehow she didn’t explain well enough to them that her daughter was so loved and had a good life, and you know maybe if she’d done that better somehow, they would have worked harder to save her life. Which is a very sad thing to be left feeling.