



## Answers: De-identification of qualitative data

The mark-up shows how the text was de-identified to reduce the risk to disclose the identity of the interviewee and other individuals mentioned in the text.

Mr Tom Jeavons, aged 63, was suffering from metastatic cancer resulting from a primary site in the bladder. His wife, Sue (58), had been his main carer for many months as he struggled with severe pain, anxiety and other symptoms. Eventually, she received support from the hospice at home team, based at their nearby hospice – St Barbara. 11 days before his death, he was admitted to their inpatient unit, where he died. The case was identified by the staff there as a “critical case”, involving palliative sedation and the difficulties staff experienced in controlling his complex symptoms. Other interviews carried out were with the hospice consultant, Dr Jane O'Connor and three nurses: Elaine McDonald, Claire Smith and Mark Ferguson. Mr and Mrs Jeavons' GP, Dr Paul Hyde, was also interviewed which added a different medical perspective, making this an unusual case.

Central themes in all of the interviews were his intractable and distressing symptoms and the repeated requests from Mr Jeavons for euthanasia. His wife mentions earlier discussions with Mr Jeavons about the possibility of going to a Dignitas clinic, but he was already too ill to travel. She also expresses how concerned she was about what Mr Jeavons's adult children might witness when he was dying in the hospice.

INT: So, really, it's as I said to you: I want you to tell me what you can remember about Mr Jeavons' care in the last week of his life ... or about Mr Jeavons in the last week of his life.

RESP: Yeah, erm, 11 days, Tom was in St Barbara's Hospice for the last 11 days of his life so...

INT: So if you'd like to talk about that period...

RESP: Yeah.

INT: ...that'd be great.

RESP: Prior to him going in, and we was coping with his care at home, but then he was becoming less and less mobile: he couldn't go to the toilet; he had a frame, and everything that you added in that was, it was a step to help him but a downward step to the end of how he could cope. We had a Bariatric bed brought into the other room but he insisted in sleeping in his chair. We had St Barbara's here and, erm, the GP, and, er, we also had him assessed at home as to whether or not we could care for him completely at home. And Tom was about 20-something stone, so he wasn't easy to manoeuvre and, and the one thing that concerned me was the fact that, erm, they needed four people to move him, you know, if he wanted to go to the toilet or if he wanted to go on a bedpan or anything, and we had the bed in there – which he wouldn't sleep in. And, erm, basically the, logistically trying to be able to do everything for him and keep him comfortable, we'd have to wait for an on-call four nurses – could be in the middle of the night – and, and sort of the idea of being able to cope, erm, for his safety and wellbeing was, was really compromised. He didn't want to go into St Barbara's, he didn't want to die in hospital, erm, but I just felt I had to take that decision to say, erm, when the guy came out to assess him, erm, he said, 'We can do it but, you know, you've got to say what you're going to do at three o'clock on Saturday, early hours of

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Saturday morning, and he wants to go on the bedpan or you need to change him or whatever.' And, and it, I had to let logic and let my heart... be ruled by my head.

INT: Mm.

RESP: So we got him into St Barbara's, and he went in on the Friday, 11 days before he died, and, erm... when, when he went in – because he couldn't move – from, from a few days before that he wasn't able to move to get to the toilet or anything and we got commodes and things like that and, you know, with having young, young girls in here, we couldn't find him somewhere that he could be private...

INT: Mm.

RESP: ...and that was a bit of a problem for him, because he was a very private man in that, in that way. Erm, so we went into St Barbara's on the Friday and they decided that what they were going to do was going to fit him with a catheter. Well, unfortunately, it was so traumatic for him because all Tom's waterworks had retracted...

INT: Ah.

RESP: ...so much, but there was a determination on the, on the part of the staff to try and make it easier for him to have this catheter put in. Well, it wasn't, it was counter-productive really because, erm, his son came to see his dad, and I was there, and we went out the room and this nurse had spent about an hour and a half trying to get this catheter in. They tried to do it at home, erm, and failed...

INT: Mm.

RESP: ...and of course he was incredibly sensitive, incredibly tender and everything else, and everything had shrunk and retracted so far back it was nigh impossible to actually, to do it without causing him any distress.

INT: Mm.

RESP: So they left it at home but we tried to get it done, erm, in the hospital, they tried to do it, and this lady, erm, had succeeded in getting a catheter in, but he was traumatised by it – there was no other word, he was traumatised – and when myself and his son went back into the room after about an hour and a half, waiting for this thing to, to be finished, er, he actually said to me and to his son, 'Just go away and leave me alone.' And that, unfortunately, was the last time his son saw him, so, Darren lives way over in Seatown. So unfortunate his son's last memory was that. So he stuck with the catheter but the catheter didn't really feel that comfortable, and every time he passed water he was actually yelling in pain. Er, two or three days later they actually took the catheter out and just put him on a pad and, and let him just wee, because, to be honest, did it matter? You know, and to put him through it, he was traumatised with his catheter fitting, and, you know, obviously they're trying to make life easier and more comfortable, erm, but it was, as I say, it was counter-productive.

Anyway, erm... I came home, had a shower, went back in and he was a little bit calmer. Erm... before he went in, erm, he wasn't eating very much or drinking very much, because his, his requirement for food – he kept asking for, for help to die, because he'd enough – he was, he was really, there was no quality; he was in such a lot of pain; he was on such a lot of drugs, and he, he just really, there was no value to him just languishing as he was. Erm, and so it was basically decided that if, if he wanted a drink... a drink would always be there if he wanted one, but there'd be no encouragement, erm, because as, as St Barbara's said, 'We can't kill him,' you know, quite [?]. 'We can't...' you know, 'There's nothing we can't... we can keep him out of pain; we can keep him calm, erm, but we can't kill him.' Erm, and I remember him saying to Dr O'Connor 'Just put the boot in, Dr O' Connor.' ... 'Just put the boot...' [?], he'd had enough. Anyway ... [ ] I cannot criticise the care that they gave him at St Barbara's because it was, you know, fantastic.

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