

Appendix 2: Communication experiences

“I am not allowed to give my point of view, my concerns are side lined or ignored and quite naturally I now feel useless, frustrated and angry at the lack of help, support and dare I say common sense. Most appear to have a ‘tick-box’ mentality. I belong in the tick-box titled: ‘carer’. My husband however is the “client” so he has to ask for what he wants.”

“One staff nurse told us, ‘He shouldn’t be in here’, and that they were not trained to look after people with his illness.”

“She made me feel part of the team straight away. I really appreciated the fact that she wanted to hear what I had to say. She showed an interest in me as well as in my husband.”

“I was told that I was ‘only a carer’ and was asked to leave.”

“I kept telling them that he couldn’t understand what they were saying. They smiled at me but I knew they weren’t really listening... they just kept asking him all these questions. He was getting upset... I was getting upset... but they didn’t stop.”

“I don’t know if she was supposed to or not but after he died, she asked me if I would like a hug. I did. She gave me a real, proper hug... not one of those half-hearted ones. She had a tear in her eye too. That meant all the world to me.”

“He didn’t actually say anything. I didn’t need or want him to. He listened. That was all I needed. There are no solutions but being listened to really helps.”

“I never felt a nuisance or a bother. Whenever I said that I was sorry to keep on, she said, ‘Without you we couldn’t care for your mum... you are very much part of the team and we appreciate everything you do’. Wasn’t that nice?”