

Appendix N Clinician Case Histories

Case A

My 72-year-old patient was diagnosed with Motor Neurone Disease 11 months ago. We had the serious illness conversation the day before she moved to a new house, as she was keen to get her views down, before having to re-register with a new GP.

I was rather anxious as this was my first serious illness conversation but I knew her well. She attended with her daughter and she was totally aware that her life was limited but she didn't want to dwell on this; she wanted to talk about how she can continue to live a fulfilling life. We discussed what was important to her such as being treated and cared for with dignity and respect as she can no longer feed herself, spending time with family and friends and continuing with social activities such as gardening and singing.

I found the conversation quite challenging. She was particularly tearful when talking about how her daughter would cope in the future when she was gone. It helped me understand how simple practical things can make a huge difference to her life, such as the position of her bed in her new flat, getting the room set up for when she becomes bedbound. We did not discuss any of the usual topics such as DNACPR. I left the conversation feeling very positive and upbeat despite the highly emotional subjects covered. **By using the framework provided by the serious illness**

conversations I feel like I have made a real difference to her quality of life by allowing her time to talk and think about it. I am certain, without using the Conversation Guide, I would not have found out about these very practical considerations that are incredibly important to her.

It was one of the most satisfying consultations for some time but I needed a cup of tea afterwards!

Case B

My patient was diagnosed with bile duct cancer [cholangiocarcinoma]. Despite his diagnosis he has remained well in himself with small amounts of weight loss and minimal pain. Palliative chemotherapy had been tolerated very well.

The conversation took place with his wife alongside him. **The patient commented on how useful he felt that this had been as he was able to express some of his desires and wishes about his care.** It became evident whilst we moved through the [conversation] how the patient felt supported by his spirituality. The patient found the ability to distance himself from thoughts about the end of his life but wanted to know about his prognosis. He had a good understanding of what his illness meant and that there was no cure. His wife is a great support to him and her background as an oncology nurse helped him to gain an understanding of his

condition and what the treatments would entail.

The conversation enabled me to gain an understanding of his social circumstance. It gave me the opportunity to get to know him and his partner in more detail and helped us to build a rapport together. In palliative care, trust and relationship building is, for me, one of the most important aspects. In this case the patient got to know me better and felt much more comfortable when attending.

The patient remains positive in himself although his condition continues to progress.

We continue to build on the information that was discussed during our serious illness conversation.

Case C

I happened to know the patient and her husband very well, as she has been under our care for a number of years. Her lymphoma progressed very significantly last year. She was very unwell at the time, but has since responded well to abdominal radiotherapy and a (relatively) novel regimen. She kindly agreed to have a serious illness conversation with me. At that point, things remained a little uncertain although she has made excellent progress since.

It emerged in the conversation that her two major priorities were her family (husband, children, and grandchildren), and maintaining her independence for as long

as possible. We agreed some strategies for the future, but haven't needed to instigate these for now because of her clinical

progress. I found the process relatively easy, though we did ask this lady specifically because she has a very realistic outlook, and had previously been quite satisfied to have open and honest conversations about her illness and treatment. That said, the structure of the questions clearly provide a sound framework for assessing expectations, and I am keen to continue with this.

Case D

I used the conversation with a patient, her husband, and son only weeks before she died.

Her son was concerned that his mother was not aware of how close she was to the end of her life and that she would be shocked and upset by the discussion.

The conversation enabled all of us to be involved in a frank and open discussion about her wishes and the progress of her illness. Her son was surprised how well the conversation went.

This conversation enabled us to plan her end of life care very quickly.

Case E

I met with the patient and his family, including his pregnant daughter and wife. He had always been a man who had a garage and loved to make and mend things.

Since his terminal diagnosis he had got up very early and spent several hours in his garage.

This was upsetting his family who wanted to spend what they saw as precious minutes with him, and they were also scared he would hurt himself as he had experienced periods of confusion. We reviewed his medication as some of his confusion had been due to overuse.

The serious illness conversation enabled us to discuss why his garage time was so important for him and how he wanted to make some things for his new grandchild who he was aware he may not meet.

Through our conversation he agreed to reduce his time a little as he realised what his family wanted from him and they agreed to support his garage time as they realised why he was doing it and why it was important to him ... “when I'm in my garage I'm me – not an old man dying of cancer”.