

Worksheet 13:

Madeline and Robbie's story

Madeline is ninety-four years old. She was diagnosed with a mixed dementia fifteen years ago. As the dementia has progressed, Madeline has become increasingly disabled and is no longer able to live independently.

Three years ago Madeline's grandson, Robbie, moved into her home to care for her. Robbie and Madeline have always been very close. Robbie lived with Madeline for five years when he was young and struggling with the divorce of his parents.

If anyone should ask why Robbie cares for Madeline he replies *"I love her... and I owe her"*.

Two weeks ago, Madeline became unwell and was admitted to hospital with pneumonia. Due to Covid restrictions in place, Robbie has not been able to visit Madeline. He calls the ward everyday and is told that Madeline is 'doing well' but 'not really eating and drinking much' and 'not really communicating'. Robbie is told this is because of 'her dementia'.

One day Robbie receives a call from the Consultant in charge of Madeline's care. The Consultant tells Robbie that he is concerned about Madeline, and the fact that she will not eat or drink is worsening her prognosis. The Consultant says that he has called Robbie to ask his views about inserting a feeding tube directly into Madeline's stomach.

Robbie is completely shocked. He was not aware that Madeline was so unwell. He informs the Consultant that prior to admission Madeline was eating and drinking well... as long as he was with her. Robbie says that Madeline has always preferred Robbie to be present before she engages in any activities of daily living. Robbie tells the Consultant that if he could visit Madeline, he is sure that he could get her to eat and drink.

The Consultant agrees to discuss this with the Nurse in Charge, as he is aware that under certain circumstances family carers are allowed to come into the Hospital.

He calls Robbie back a short while later and says that permission has been given for him to come into the Hospital the next day at 12.30 to assist Madeline with her lunch.

Having taken all Covid precautions required of him, Robbie enters the ward at the designated time. As soon as she sees him, Madeline stretches out her arms and says 'my darling... where have you been?'. The ward staff are stunned. Many of them did not know that Madeline could speak.

Robbie asks what Madeline has for lunch and is told 'roast chicken and vegetables.' Robbie replies; *"Oh. Gran is vegetarian... she won't eat that, not even the veg if it has touched the meat."*

The ward staff offer to get something different for Madeline, but Robbie has brought in her favourite lunch – strawberry jam and banana sandwiches. Madeline's eyes light up when he sees them, and she begins to eat. Robbie has brought some sandwiches too, telling the staff *"She won't eat if I don't... she thinks it's really rude to eat in front of people who are not eating too... she's a very polite lady"*. The ward staff are stunned again.

One of the care assistants asks if they would both like a cup of tea. Madeline nods her head. Robbie says "*Yes please. Gran has her tea black... just dip the tea bag three times into the hot water... that's how she likes it*". Robbie has noticed a cup of cold, milky tea on Madeline's table.

The Consultant arrives and introduces himself to Robbie. He is amazed to find Madeline more alert and engaged and eating. The Consultant ask Robbie if he would be able to spend a little time with the ward care team to devise a care plan for Madeline. Robbie is given permission to extend his visit, and the Nurse looking after Madeline sits with them.

Firstly, the Nurse asks if they would feel happy to complete a 'This is Me', which they all do together. From this, the Nurse creates a simple document listing all of Madeline's food and drink preferences which is placed at the head of her bed so that all staff can read it and help her with choosing what she would like to eat and drink.

Robbie also shares with the Nurse some hints and tips for engaging Madeline in a meaningful and motivating way in activities of daily living such as washing and dressing. Robbie has brought Madeline's toiletries and make up and her favourite cardigan and trousers. "*She won't get out of bed without putting her face on or without her cosiest clothes,*" says Robbie.

Robbie also says that Madeline loves music, particularly songs from musicals and the Bee Gees. The Nurse immediately fetches an iPad and finds a Bee Gees song to play. Madeline smiles and moves her body in time to the music.

The Nurse in Charge agrees that Robbie can visit Madeline everyday for one hour and that this can either be at breakfast, lunch or dinner time to assist Madeline. Robbie understands concerns about preventing Covid transmission and is happy to be offered this opportunity.

Four days later Madeline is fit to be discharged home into Robbie's care.

What might have happened if Robbie had not been invited to contribute to Madeline's care?

Why was completion of the 'This is Me' so crucial for Madeline's care?

Why do you think that the ward did not ask Robbie for this information earlier?

Why might Robbie not have provided this information earlier?

What will you do to try to work in partnership with family carers of people with dementia?