

Case study 2: Margaret

(Person Living with Dementia)

Introduction

Margaret grew up in Townsville, Queensland with her three siblings. Margaret's father died from dementia at the age of 90. Margaret and her husband, Richard, have three sons. At age 85, Margaret was diagnosed with dementia. Margaret's cognitive abilities have rapidly declined, and at age 88 was admitted into an aged care facility. She can be communicative, but exhibits very poor recall. Prior to her admission, she had also been diagnosed with ovarian cancer and was receiving outpatient treatment at a hospital.

Margaret enjoys spending her days watching soap operas, listening to music from her youth, and talking to her children and grandchildren on the phone. Margaret has seven grandchildren and four great grandchildren. Although her memory problems cause her to occasionally forget who they are, Margaret lights up when she is able to speak with her family.

Admission and Pain Identification

Margaret was 88 years old and had diagnoses of dementia and ovarian cancer when she was admitted to the residential aged care facility.

On admission, Margaret's husband, Richard, expressed to the nurse that he was concerned about his wife's behaviour: she was often anxious and restless, and that he thought it may be to do with her dementia.

The nurse observed in the meeting that she was restless, unable to sit for any length of time, and was constantly fidgeting. She seemed tense and irritable in conversation. Although she could converse briefly and respond to questions, the nurse found that she had to keep her questions and comments short and simple otherwise Margaret would lose track of the

conversation.

Richard indicated in conversation that Margaret had been reluctant to complain about experiencing any pain or to seek help over many years during illness.

The nurse asked Margaret a few questions including: 'are you in pain?', 'are you feeling uncomfortable?' and 'do you have any aching or soreness?', but Margaret seemed defensive and irritable.

The nurse reassured Margaret and told her that it was normal to experience pain and that there were many things the team at the facility could do to help. After this, Margaret appeared to settle somewhat but still didn't answer the questions about pain.

The nurse initiated a comprehensive pain assessment for Margaret, in the presence of Richard.

Pain Assessment

The nurse initiated a comprehensive pain assessment, beginning with initial interview to ask Margaret some questions about what she was experiencing. Although Margaret was able to answer some of the questions in a limited way, the nurse decided to interview Richard separately. Richard was able to provide detailed information about his observations of Margaret's behaviours that may be signs of pain.

Richard was asked a series of questions using the Abbey Pain Scale including 'Have you noticed Margaret whimpering, groaning or crying?' (vocalisation) and 'Have you noticed Margaret looking tense, frowning or grimacing?' (facial expression). Richard detailed, to the best of his recollection, moments when he had observed those things. It was determined that Margaret's behaviours were expressions of her pain, rather than BPSD.

Only relying on self-report of pain would be an unreliable measure for Margaret because she was reluctant to report her pain and had some difficulty communicating. In consulting with Richard and conducting a comprehensive pain assessment, the nurse was able to gain a clear picture of the signs of Margaret's pain, and Richard was helped to understand Margaret's behaviour and why she was less likely to talk about the pain and discomfort she had been experiencing.

The assessment revealed that Margaret was experiencing increasingly severe aching pain, mostly in her lower body, while she was moving as well as resting. She was also experiencing fatigue, weakness and some nausea. Margaret had believed that the pain and discomfort were just things she had to 'deal with', but was reassured to learn that the staff could help her alleviate some of these things.

Pain Treatment

After Margaret's assessment at the hospital, the GP read through the documents and consulted with the hospital staff. Margaret would receive treatment for her bone metastasis at the hospital, with the facility GP and other staff implementing a more detailed treatment plan for her pain.

Considering the current severity of Margaret's pain, the GP (with advice from the hospital) recommended initial treatment with an opioid (buprenorphine patch). The GP also recommended a range of non-pharmacological interventions. The nurse, GP, physiotherapist and lifestyle coordinator worked with Margaret and Richard to develop a treatment plan.

The treatment plan involved a stepped approach. A physiotherapist developed an exercise program for Margaret. She would also receive weekly massages. The lifestyle coordinator informed Margaret and Richard about a number of programs in the facility that would help Margaret with relaxation, including

meditation and music therapy sessions (Margaret had always loved listening to music from her past). Margaret seemed enthusiastic to participate.

Richard advised that Margaret loved to watch soap opera TV shows, so an instruction was made in her case notes for care workers to ensure that these were playing regularly for Margaret in her room while at rest.

A nutritional assessment was completed and Margaret's dietary plan was tailored based on her needs and in consideration of the opioid medication that she was about to commence.

Richard was provided with education and information about Margaret's pain, and he felt prepared to support her when visiting. He knew how happy it made Margaret to see her children and grandchildren (although she sometimes struggled to remember them), so he arranged regular visits and phone calls with the family. Care staff helped Margaret and Richard hang family photos in her room.

Monitoring and Evaluation of Pain Management

The Abbey Pain Scale was used every fortnight to monitor Margaret's pain in relation to the treatment. In the first 3 months after admission, Margaret's pain seemed to improve. Margaret was quite distressed and agitated in the first week after admission, but after a few weeks of pain treatment and getting into a routine including relaxation therapies, massage, exercise and activities, Margaret's behavioural symptoms indicating pain appeared to improve greatly. Her scores on the Abbey scale decreased from moderate to mild.

Margaret's response to her pain medication (an opioid) was monitored continuously. Care staff were especially vigilant for side effects including constipation, loss of appetite and dizziness. When a care worker noticed during personal care that Margaret was experiencing constipation, a nurse conducted a bowel assessment and made

changes to her dietary plan and implemented laxative therapy with guidance from the GP. Care workers made sure that Margaret was always drinking enough fluid.

End of Life

Margaret continued to receive treatment for her cancer and bone metastasis at the hospital. Although her condition was maintained for about a year, eventually it was apparent that she was reaching end of life and required palliative care. Margaret began rapidly deteriorating: she became incontinent, was less able to eat or drink, and was increasingly weak and confused. Correspondence from the hospital indicated that her cancer was at an advanced stage.

The care team at the facility, along with Margaret and her family, had completed an Advance Care Plan on admission to the facility. To Margaret and her family, it was important that if she had deteriorated to a point where she completely lost independence, required high-level care and was no longer communicative, that any restorative treatments should be discontinued and that her comfort should be maximised. Margaret had been a practicing Catholic all of her life, and it was her belief that if life support was ultimately futile, then it should be stopped.

Analgesic and other palliative medications were pre-emptively prescribed and administered as Margaret reached her final days. Facility staff provided support and communicated with Margaret's family on a regular and ongoing basis.