

## Case Studies – Italians with Dementia

*Interview with Anita Bonnano, Team Leader, Home Care Services, Co.As.It., held 4/5/2015*

### Lewy Bodies Dementia

Female deceased in 2013 whilst living permanent care, two months after entering facility, would be 78 now.

Diagnosed with Lewy Bodies Dementia, after initially being diagnosed with and treated for Parkinson's Disease.

Lived with husband who was well aged – in 2013 he was 82 years old. He had a history of cardiac problems but remained fit enough through gardening work.

He looked after his wife and did everything apart from the service provided by Co.As.It. which commenced as Level 2 in 2008 and on 27/1/2010 rose to EACH (Level 4)

Wife could feed herself and was verbal.

He was a controlling person who was very fussy about hygiene and cleanliness around the home.

She had been a stay at home mother of 5 children of Southern Italian origin like her husband. She did everything as a home keeper.

The husband expressed feelings of having become like a female because he was doing all the work around the home, that was traditionally seen as being that done by females. He would say that he "had become a woman".

Husband didn't let his wife do anything (when she had become greatly affected by the dementia symptoms) because it wasn't up to the standard that he expected, eg., folding clothes, shelling peas etc. Wife was still capable of feeding herself.

In the presence of her husband the woman was non verbal, but when the workers from the community care service arrived she was talkative- the workers assumed that the woman was fearful of her husband.

Husband was obsessed with making sure that the workers had washed his wife thoroughly. He would also change her incontinence pads every hour and so would consume a much more than an average amount in a year. He would also say that her memory was a lot worse than it actually was. Wife was then referred to a psychologist at Co.As.It. by the team leader of the service because she suspected that the lady was being abused in some way by her husband.

It turned out that it was the wife who was asking her husband for sexual intercourse and this is what helped her to think of herself as a normal person. This was revealed during the counselling sessions. The husband had become obsessed with the cleanliness of his wife because he had to be intimate with her. This soon stopped though as the wife became more affected by the symptoms of dementia.

Activities were devised for the wife via an engagement plan, but the husband blocked all of these plans – he actually didn't allow her to do anything. If the wife ever helped with any chores around the house he would yell at her. Wife then appeared to stop saying anything.

Husband had to be supported to accept and implement a task plan for the wife – for him to supervise her activities. When she started to talk to her dolls, he was mortified by the embarrassment that he would feel if the neighbours and friends found out.

The couple's children agreed with the service in thinking that doll therapy was a good thing for her. But the children could not express this to their father, they didn't want to challenge his view that this was inappropriate and embarrassing. He had always been the patriarch of the family who had always been obeyed.

The wife's descent into dementia related behavior and physical symptoms was rapid and the service provider attributed this to the fact that she was not being allowed to take risks. She retreated into her non verbal world, withheld emotional responses and opinions. Her husband had a fear that she was at risk of harming herself if she was allowed to do whatever she liked.

When finally she entered a RACF she exhibited some so called problem behaviours such as spitting out her tablets when they were offered to her, never displayed any enthusiasm for eating meals, would play with her food. She developed other resistive behaviours as perhaps this was the only way that she was able to command attention.

Whatever skills the wife had left, she wasn't allowed to use them whilst living with her husband.

This family preferred the medical model of care for their mother, and this was a model that did not have enablement at its core. Instead it rendered this woman more helpless than she actually was.

Activity support plans needed to be developed for this woman with the acceptance of the husband. When the woman still lived at home she needed a two person transfer- husband didn't want special equipment, a commode, a wheelchair in the house nor out of the house as he thought that the wheelchair outside of the house would bring dirt inside on the wheels. He didn't want the neighbours to see his wife in a wheel chair.

This husband and wife had lived ½ the time in Italy and the other half in Australia throughout a year.

He was bitter about having had to spend the rest of his life in Australia as now his wife was so unwell that she was not able to fly.

When communicating facts about her to others he would speak about her in a belittling manner. But this was probably due to carer stress and him not realizing that this was not the time to talk about his wife.

Whatever the workers from the service did around the home – it was never good enough, eg., he would always mop up after the workers had just done this. He could never accept that in order to receive assistance – his expectations of the level of cleanliness should be lowered.

Cultural factors played heavily in this man's ability to deal with his wife's dementia in a more appropriate manner– I am like a woman; my home is my castle = my identity; have a dutiful wife who did everything in the home.

Knowledge of dementia in the Italian community is low.

Older Italians and even some of their younger family members like to treat with pharmaceuticals – and sometimes wish to receive treatment with pharmaceuticals that are only available in Italy.

Not into managing with activities.

In this case there existed conflict with kids ; the hands on ones wanted mother to go to RAFC ;3 other children didn't- these children were not very involved in their mother's care anyway.

Home safety was a problem, children had guardianship papers drawn up that father didn't know about. The father was really upset about this.

Husband developed plans for home modifications after wife went to hospital – he didn't get to implement them because it was recommended that his wife go to an RACF.

Having nothing to do was frightening for husband, might have used wife's situation to maintain a purpose for himself; maintaining the thought that "She is my wife – I am her husband"

It's possible that the children got the papers signed without the father's knowledge but, the father got the papers reversed. He cancelled the power of attorney.

The wife died a couple of months after entering a RACF and the husband then flew back to Italy to live in Italy.