

Supporting families of people living with dementia

Maureen is 57 and the main caregiver of her 75 year old father, Malcolm. Malcolm has had Alzheimer's disease for six years.

Malcolm experiences short-term memory loss and received a cognitive screening score of MMSE 23/30 and MoCA 18/30. Malcolm lives alone in his own home which is 25 minutes away from Maureen. Malcolm no longer drives, is often very anxious, and phones Maureen several times a day. The following community services regularly support Malcolm; Meals on Wheels during the week; a house cleaner comes once a week to change the sheets, vacuum, mop and clean the bathroom; and a gardener mows the lawn once a fortnight. Malcolm also receives some nursing care services to assist with showering on weekdays.

Maureen has a part-time job (3 days per week as a nurse) and still has her youngest child living at home (Stephen, 29) who has learning difficulties. Maureen has been married to Phillip for 35 years and they have two other children, Sarah (32) and Michael (34). Phillip is a carpenter who runs his own business, generally working around 60 hours per week.

Maureen manages most of her father's care. This generally involves cooking food that he enjoys (which Meals on Wheels doesn't provide), gardening, showering him on weekends, cleaning as needed, shopping for personal items and keeping him company. She can spend up to four hours a day on weekends with her father, and she drops in every night after work for at least one hour. On the days she doesn't work, Maureen visits for most of the day leaving little time for her to attend to her own needs. Maureen relies heavily on her husband and son to keep their family home in order, but from time to time she gets very frustrated with the level of cleanliness. If she had more time, her house would be at a much higher standard. Maureen cooks meals for Phillip and Stephen most nights, so she can provide her father with some of his favourite meals.

Malcolm has had incontinence issues for the last six months. They are progressively getting worse, which places more pressure on Maureen as she receives calls from Malcolm to help him. Malcolm's situation is getting to the point where Maureen thinks her father will have to move into a nursing home. However, her older brother Alex (58), and younger sister Anne (52) do not agree that their father should move out of his home.

Maureen feels that no one else helps and that she is trapped. She is extremely tired, not sleeping well and has noticed that lately her mood is very low. At home, she is snappy with her husband and son, and often cries for no apparent reason.

Maureen's concentration at work is slipping, and she is making mistakes. Maureen has gained weight because she used to play tennis on a Monday night but has let this social activity slide due to tiredness.

Phillip and Maureen have always led fairly independent financial lives. Phillip covers the mortgage and bills, but no other expenses. Maureen thinks she could manage her father better if she stopped working or reduced her hours. However, Maureen is not sure whether Phillip will help, and she does not want to lose her financial independence or her friends at work. Anne has offered to help, but unfortunately Malcolm only wants Maureen. When Anne visits Malcolm, Maureen has noticed that her father becomes distressed which causes Maureen more stress.

After many weeks of feeling low and exhausted Maureen decides to make an appointment with her family GP.