

Informal Carer: who cares for her mother who is in the early stages of dementia

This carer is from the UK and takes on the responsibility for caring for her elderly mother at home. Her mother is in the early stages of dementia and requires a good deal of supervision due to her memory loss. The carer works 4 days a week at present in her job in the education sector and has to care for her mother for the rest of the time. She originally worked 5 days but had to cut down to 4 days because of her caring responsibilities. She has received no formal training in care and only has the support of her daughter to help with her mother's care. Her daughter works full-time and sometimes works at weekends, so her contribution is minimal. The carer has received very little support from anybody else in the family (she has three other siblings that do not undertake any care for their mother) regarding both care and also financial support. She has responsibilities for making sure that her mother takes her medication, all aspects of cleaning and also ensuring that she is fed properly. Although there are aspects of physical/personal care needed for her mother, the carer also has to have a good understanding of the needs of somebody with memory loss.

This carer has found many aspects of caring for her mother difficult due to lack of knowledge about care and also the time restraints because she also works. Basic personal care such as washing has been difficult due to its personal nature, but in general she is coping with this aspect. Dealing with her mother's dementia has been more problematic. She has received very little support from social services and has had to rely on information mainly taken from the internet concerning dementia and recently she has been in contact with other formal carers, which has been a great help. This information is not the most reliable and she feels that she undertaking work that requires much more competence and training than she has already.

'We are doing a great service to the government because we are unpaid. We really need guidance as carers. I am doing the same job as a nursing home but I get nothing in terms of help or support'.

This lack of empathy and understanding from the government induces anger and frustration from this carer, not just for her own situation but for other informal carers in a similar situation who are often isolated and doing the best they can. Although the carer says that she doesn't receive adequate support and also is not confident with some aspects of her mother's care, she still wants to continue to care for her mother and is still optimistic and feels it as the best option for both of them.

'I love being in her company. We have a great time together. I feel I am doing the right thing, morally. You hear so many bad things in the caring industry and I would hate my mother to be a case number. It is important to be there'.

The carer has had to learn a lot and consider many things through the experience of looking after her mother. She considers that certain attributes need to be inherent as carers. Some essential character traits that carers need (particularly with people with memory loss) is patience and understanding. She says that is very valuable when dealing with her mother. She has also realised that not everybody can be a carer and that she has discovered that she is suited to caring. For more practical help for informal carers, alongside a basic personal care course and courses on handling medicines and moving people, the carer suggests short training courses providing a background in dementia and how to conduct care with people who have this condition would be very useful. She recognises that her mother's condition will worsen over time and keeping that valuable connection with her mother and meeting her needs will be her biggest challenge.

'At the moment my mum guides me, she tell me what she needs. But as the illness progresses that will not be the case. I need to be prepared for that. And without the proper training how do I know what to do? How do I communicate with her?'

Finally the carer advocates an outlet, point of contact or society that allows informal carers to be recognised and listened to by both the government and the general public. She feels that only with solidarity and a support network, the situation for informal carers will change for the better.

'I'd like to have a voice. We all (informal carers), need help. I do not know who to contact and where to get help. We need proper representation to maintain and improve the quality of care we give'.