



## Challenging Stigma and Staying Engaged

### Stigma

Rising to the challenge of living well with dementia can involve more than just adjusting to the changes brought about by the symptoms of dementia – for some people it also means addressing the stigma that can accompany a diagnosis of dementia. Stigma refers to a set of negative and unfair beliefs which sets a person apart from other people. Some people with dementia have expressed the fear that if people know about their diagnosis then they will be seen as different and less valuable, this is stigma, and its effect can be damaging whether it is actually encountered or internalised. For some people this fear can lead to social withdrawal, a reaction that is likely to only exacerbate a person's decline. A more positive approach is to challenge stigma.

Dementia changes a person's capabilities, as does a wide range of mental and physical health conditions, but the critical thing in living well with dementia is for a person to work towards maintaining their abilities by staying active and engaged in their life and community for as long as possible. In the same way that the disability community have fought hard to change perceptions of disability and have their rights recognized, so too are dementia organisations, people with dementia and their supporters working towards improving awareness and challenging limiting views of what it means to live with dementia. This means understanding the changes that dementia can bring and adjusting to these accordingly so that people with dementia can continue to be involved in their communities in enjoyable and meaningful ways.

### Quotes from people living with dementia and care partners:

*"When I first found out what I had I was a bit embarrassed about it, I wasn't sure exactly what it was. Now I just accept it, as long as I've got a notebook by my side to write things down in it. It started off I wasn't too keen, I thought people would think I was a half-wit but now I've just got on with life best I can".*

*"I just say sometimes I forget about things. I think it's best if you just talk about it. I just laugh about it and say I've forgotten, but people are very understanding, they are".*

*"People should be realistic, not just pretend that everything is alright because obviously it's not, they still need to treat the person as normal but just realise the person might not answer at that time, or appropriately, but just not read into it too much. People have good days and bad days and you just need to roll with it".*

*"We've found a drop off of people who don't visit and things like that, which is a shame really".*

*"Knowledge is power, the public need knowledge to know that it isn't a stereotype, they have a stereotype in their head of what the person is like and this is an area where the public need educations".*

### Staying Engaged

The 'use it or lose it' principle is key to living well with dementia. Whatever is regularly practiced – verbal skills, social skills, physical skills – will be maintained for longer than skills which are only rarely used. Therefore, arguably the best 'treatment' for dementia is to engage in a range of activities both social and where possible practical/physical, that are enjoyable and meaningful to the person with dementia.

Over time the progressive nature of dementia means that a person's abilities change and a person may need more help or different activities to keep them engaged and experiencing success. The interaction or activity needs to be 'just right' so that the person can meet the challenge without being overwhelmed or under stimulated. Remember that the needs of a person with dementia are no different from anybody else's, but as dementia progresses and a person's thinking, language and physical skills decline, a person will need more support to ensure they are able to effectively meet their needs. This can require creative thinking and support.

#### **Quotes from people living with dementia:**

*"Just figuring out what I can't do helps me keep going, I've had to give up driving. What is great is getting the taxi cabs, it's incredible, if it wasn't for that I don't know what we'd be doing. Meeting people is something I love...I can do calligraphy, it's so relaxing and walking...I wrote my memoirs last year. I had no trouble remembering things from my past. I'm reading it again and remembering things again".*

*"I enjoy tramping, trying to see friends and doing things like television. I'm not a member of other clubs. One of the problems I've got is that because I retired earlier than a lot of others, they're still working and I don't want to intrude on them. When they retire then I can socialize a lot better. I'm in a tramping club, we do 15, 17 kilometres. I walk regularly. I garden. I'm more sensitive to things".*

#### **Key Points**

- Stigma can lead to social withdrawal which may cause an increase in the rate of decline that a person with dementia experiences
- Human beings are social animals; keeping socially active keeps the brain active and helps to maintain self-esteem and quality of life
- Incorporating physical activity into daily life promotes independence, physical health and may help with mood
- Engage in activities that are enjoyable to the individual, whether it is gardening, singing, walking or going to cafes, by doing it with others the benefits are multiplied
- Sometimes it is necessary to get support from family, friends or professionals to reengage in activities, getting started can feel scary, but the rewards are worth it.

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