

## Hold on

When a loved one is diagnosed with dementia, it can be hard to know how to cope or where to turn. Here, Caterina Hrysomallis shares her experience and offers advice on how to support your family member when they need it most.

Caterina Hrysomallis

My yiayia (grandmother) Stratigoula was a total inspiration. She was clever and strong, her name aptly translating as 'lead soldier'. Though, when dementia hit there was no stopping it. My family was put on a ride they never anticipated, trying to understand and navigate the trickiness of the disease.

No one or thing can fully prepare anyone for the emotional demands of a loved one being diagnosed with dementia. But it's imperative that those who are caring also remember to care for themselves as well.

447,000 Australians are currently living with dementia; 1.5 million people are involved in their care. Due to an ageing population, this number is expected to exceed 1.1 million by 2058, if there is no major medical breakthrough before then.

Organisations like Dementia Australia provide valuable resources and are conducting important research into the disease. With that in mind the most important thing to remember is that if you are affected directly or indirectly by Dementia, you are not alone and reaching out during difficult moments is wise.

### What to do if you suspect someone you love has dementia

"Getting a diagnosis is very important to ensure that any treatable conditions are addressed and to ensure families have access to the information and support that they need," says Leanne Emerson, Dementia Australia's Executive Director of Business Development. Emerson has been with Dementia Australia for 21 years and has seen the hardship dementia can bring during her time as a psychologist, aged care facility manager and trainer of paid carers.

"It can be very difficult to talk to a loved one about your concerns, but often the person affected shares those concerns – perhaps they're reluctant to bring it up, Emerson says.

"You can contact Dementia Australia, your GP, and then get a referral to a specialist such as a geriatrician, an old age psychiatrist or a neuropsychologist. Some states have memory clinics, or a Cognitive Dementia and Memory Service (CDAMS) that provides a multidisciplinary approach to diagnosis."

Then, there are specialist programs, such as the Royal Melbourne Hospital's BRIGHT-YOD Project, led by consultant psychiatrist and clinical lead Sarah Farrand.

"The project aims to improve access and reduce costs for patients and families involved with specialist care for young onset dementia specifically," says Farrand, referring to the kind of dementia diagnosed prior to 65 years of age.

"We do this by offering initial diagnostic assessments as well as ongoing care for people with young onset dementia, including medical and neuropsychology appointments. If needed we can also engage speech therapy, social work and occupational therapy," she says.

If you need a little more guidance on where to start, there's the National Dementia Helpline (1800 100 500) open Monday to Friday, 9am – 5pm. Support figures provide information about dementia and memory loss, direction to support and services in specific areas, as well as providing emotional support and counselling.

### Elements a carer may experience as dementia progresses

Everyone's dementia journey differs, with many different types of dementia around. As such, the experiences families and friends may experience also differ. Some moments are certainly more difficult to handle than others.

"Feeling overwhelmed, anxious, uncertain, angry, sad are all very normal reactions, and most people will experience all of these along the journey with dementia," says Emerson. "Family members often describe an experience of loss, that their partner or loved one has changed or is unable to do the things their previous have done."

Dementia evolves over time and it's key to note that adaptation is a major part of the process. "People may experience a symptom that they find challenging to handle, it's likely that will last for just a short while before changing again."

"There can be guilt, sadness, exhaustion and frustration," adds Farrand. "However we also see people living with dementia and their families make really lovely memories together, and undertaking meaningful experiences and activities. It is critical to support families and carers, to enable people living with dementia to live well."

### Ways families and friends can assist someone with dementia

The best ways to help someone with dementia is to stay interested, keep in regular contact and be sure to remind them they are important and indeed loved.

As for the practicalities, there are many. "Use touch to keep the person's attention and to communicate feelings of worth and affection. Talk in a gentle, matter-of-fact way, keep sentences short, focusing on one idea at a time. Allow plenty of time for what you have said to be understood. Silence can give time to think and respond," says Emerson.

Farrand echoes the importance of sense of touch – hugs or holding someone's hand both easy ways of displaying affection.

"Reminisce, look through old photos, tell stories. Do something fun together, maybe a walk, or a swim. Simple behavioural interventions can also be really useful, like playing soothing music, or maybe finding a task the person can do."

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#### Things for families and friends to remember

A key thing to remember is that in moments of behavioural difference, it's not a person's true self or feelings – it's the disease. They're not meaning to be difficult on purpose.

“Remember that people with dementia retain their feelings and emotions even though they may not understand what is being said, so it is important to always maintain their dignity and self-esteem,” says Emerson.

Families also ought to know they are not alone in dealing with dementia. “There are people who have and are going through this who can offer support, as well as other professional supports, such as Dementia Australia, Dementia Support Australia, Carer Organisations (such as Carer's Victoria), and the professionals involved in their care,” says Farrand.

#### The carer needs to take care of themselves, too

Being involved in someone's life with dementia can be extremely demanding, physically and emotionally.

#### Emerson's things to try:

- Implementing a consistent schedule can make life a little easier when living with a person who has dementia
- Learning as much as possible about dementia and encouraging friends and relatives to do so as well can be helpful
- It is important to talk things over with family, friends and other people in a similar situation
- Look after yourself by looking after your diet, get regular exercise and maintain your social contacts and lifestyle
- Be realistic about what you can expect of yourself and recognise that taking care of yourself is better for everybody.

As time passes, new forms of care and demands are needed and as such, family members and friends doing a great deal of caring compromise and often forget to look out for themselves.

#### When should you engage professional care?

When it comes to beginning to think about employing care for someone with dementia, whether it's in or out of the home, it's common for people to experience emotions of loss, guilt and even relief.

Such intensity of emotion can be challenging, so a strong support system is important – whether it's sought from family, friends or medical professionals.

“As a rule of thumb, engage home care early, so that family members can get the support and respite that they need to continue in their caring role for as long as possible. Accessing early support will set you up on the right path moving forward,” says Emerson.

“It's never too early to start care, whether it is regular appointments with a physician, having an occupational therapist home assessment, or seeing a GP regularly,” says Farrand.

“Having support in place early helps to reduce carer burden and keep people at home for longer. Having assessments done early – before they are required – to enable respite and residential care means that this can be accessed in a timely way.”

“Don't be afraid to use respite care, and before it is desperately needed. It is often much less scary for people with dementia at an earlier stage of their illness, which can make the transition much smoother later on.”

“It is also important to remember that as people with dementia progress in their illness, they require more care than one person can reasonably provide, which is where residential care comes in.”

“The stages of grief and carer burden may not necessarily dissipate however following placement into residential care, and it is important that carers have a space they can talk about this.”

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