

What this information sheet provides

Dementia is a scary diagnosis. It is so easy to become overwhelmed with situations, while underwhelmed with the information and help provided while we try to find a semblance of normality in our new roles. While each family whose loved ones are diagnosed with Dementia goes through their own individual struggles and trials, this information sheet was put together to inform, and to try and find some consistency in an otherwise chaotic time.

Support Phone Numbers

Alzheimer's WA Customer Service – 1300 66 77 88

Dementia Behaviour Management Advice – 1800 699 799

Lifeline – 13 11 14

Crisis Care – 1800 199 008

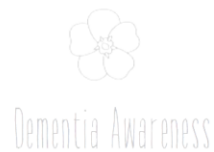
The Samaritans – 1800 198 313

Family Helpline – 1800 643 000

Carer's Counselling Line – 1800 007 332

Emergency Respite and Carelink Centre – 1800 052 222

National Dementia Helpline – 1800 100 500



Forget-me-not café

Email: fmncafe@outlook.com

Phone: 0468 549 143

Website: www.forgetmenotmemorycafe.com

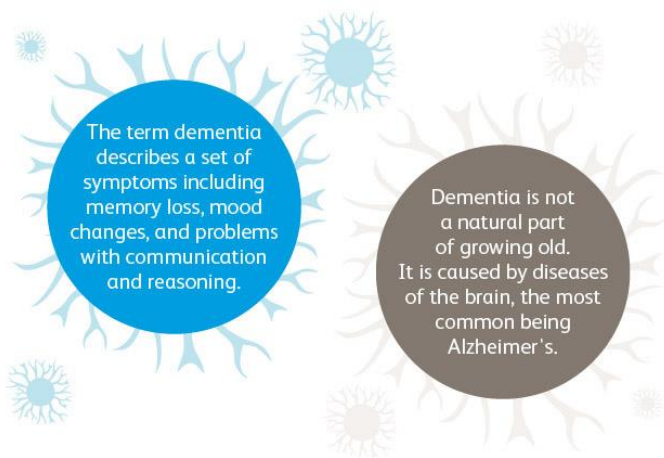
General Information Sheet – Forget-me-not



Table of Contents

What is Dementia	1
Caring for Carers.....	3
Talking to someone with dementia.....	6
Compassionate communication with the Memory Impaired	8

Defining dementia



Statistics¹

Prevalence of Dementia

- There are approximately 413,000 people diagnosed with dementia in Australia;
- There are approximately 25,400 people living in Australia with Younger Onset Dementia (under the age of 65);
- Each week there are more than 1,800 new cases of dementia in Australia; one person every six minutes;
- Without a medical breakthrough numbers are expected to increase to almost 1.1 million people by 2056;
- 1.2 million support people in Australia (2013).

WA statistics

- There are 39,600 people living with dementia in WA;
- By 2056 it is expected that 143,957 people will be living with dementia in WA;
- More than 1 person every hour is diagnosed with Dementia in WA;
- 70% of people with dementia live at home;
- In your street of 100 neighbours, at least one will likely be living with dementia.

Medications

Cholinesterase Inhibitors are used mainly in early to moderate stages of Alzheimer's Disease, some benefit for Lewy Bodies and Vascular Dementia:

- **Aricept** (Donepezil) – available in tablet form
- **Exelon** (Rivastigmine) – Available in capsule, oral solution and patch (slow release) forms
- **Reminyl or Galantyl** (Galantamine) – available in Capsule form



¹ The national centre for social economic modelling NATSEM (2016) *Economic cost of Dementia in Australia 2016 - 2056*

What is Dementia?

Dementia is an 'umbrella' term for a range of illnesses which cause a progressive decline in a person's functioning.

It affects thinking, behaviour and the ability to perform tasks.

A dementia diagnosis affects everyone; from the individual diagnosed, to their family and friends. But, it can particularly take a toll on a spouse, making it difficult to strengthen a relationship already going through so much change.

Because dementia and memory loss affects each individual differently, it's impossible to make assumptions or generalities. From the beginning to end, a couple's journey in dealing with dementia is completely unique to them and constantly changing. Every couple will navigate their illness and the evolution of their relationship in their own way.

A dementia diagnosis affects everyone; from the individual diagnosed, to their family and friends.

What's the difference between dementia and Alzheimer's disease?

Many people often confuse the terms Alzheimer's disease and dementia. Although they are both used interchangeably, there are distinct differences between them.

Dementia

Dementia is not a disease, but a group of symptoms that are associated with a decline in thinking, reasoning and/or remembering. If someone has dementia, they may have difficulty carrying out daily tasks they have performed routinely and independently throughout their lives.

The two most common types of dementia are:

- Alzheimer's disease
- Vascular dementia, which is the hardening of the arteries in the brain that causes blockage in blood flow.

These two conditions account for the vast majority of dementia cases. Both conditions are irreversible, although sometimes their symptoms can be managed.

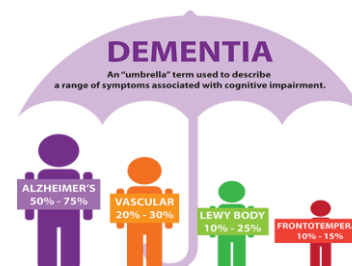


Dementia Awareness

Alzheimer's

Alzheimer's disease is the most common form of dementia, and this progressive brain disorder has no known cause or cure. This disease leads to memory loss, confusion, impaired judgement, personality changes, disorientation and the inability to communicate. Dementia occurs in the mid to later stages of Alzheimer's disease.

Doctors can accurately diagnose the dementia symptoms in 90% of cases.



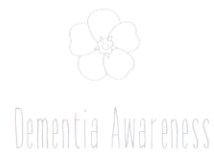
Vascular dementia

Vascular dementia is cognitive impairment caused by damage to the blood vessels in the brain. It can be caused by a single stroke, or by several strokes occurring over time.

Vascular dementia is diagnosed when there is evidence of blood vessel disease in the brain and impaired cognitive function that interferes with daily living. The Symptoms of vascular dementia can begin suddenly after a stroke or may begin gradually as blood vessel disease worsens. Vascular dementia may appear similar to Alzheimer's disease.

Lewy Body disease

Lewy body disease is characterized by the presence of Lewy bodies in the brain. Lewy bodies are abnormal clumps of the protein *alpha-synuclein* that develop inside nerve cells. These abnormalities occur in specific areas of the brain, causing changes in movement, thinking and behaviour. Lewy body disease sometimes co-occurs with Alzheimer's disease and/or vascular dementia.



Frontotemporal dementia

Frontotemporal dementia involves progressive damage to the frontal and/or temporal lobes of the brain. Symptoms often begin when people are in their 50s or 60s and sometimes earlier.

Because the frontal lobes of the brain control judgement and social behaviour, people with frontotemporal dementia often have problems maintaining socially appropriate behaviour. They may become rude, neglect normal responsibilities, be compulsive or repetitive, be aggressive, show lack of inhibition or act impulsively.

*All information provided has been collected from Dementia Australia, support pages from dementia friendly websites and numerous online searches to find relevant information that could be useful to people effected by memory loss.

Caring for Carers

Summary

- 1) If the carer is tired or stressed, it can become harder to care for a person with dementia.
- 2) It is important for carers to continue activities they enjoy
- 3) For some men, taking responsibility for household jobs and being a carer may mean learning new skills;
- 4) Carers may experience feelings of guilt, loss or anger;
- 5) Carers should take a break from caregiving to avoid becoming worn down;
- 6) Support and respite care are available for carers and can provide comfort and practical assistance.

Carers of people with dementia are not alone

A large number of carer support groups exist throughout Australia. Many people find comfort and practical assistance by attending meetings with others who know what it is like to care for a person with dementia. Support groups bring together families, carers and friends of people with dementia.

The physical and emotional demands of caring for someone with dementia can be high. As the amount of care that is needed increases, more time and energy is required from the carer. If you are caring for a person with dementia, you need to look after yourself or the demands may wear you down.

If you are worn down, caring will become even more difficult and it will not be easy to continue balancing your own needs as a carer with those of family and the person with dementia. You need support and assistance to care for someone with dementia.



Carers may experience feelings of guilt, loss or anger

Managing stress as carers

Everyone has different ways to manage stress. Managing stress improves your wellbeing and may help in your caring role, so it can be useful to learn some better ways to manage it. Bookstores and libraries have a range of books and tapes on different ways to manage stress. Some suggestions for managing stress include

- A consistent schedule can make life easier when living with a person with dementia;
- It often helps to remember that the person with dementia is not being difficult on purpose, but that their behaviour and emotions are affected by dementia;
- Learn as much as possible about dementia, and encourage your friends and relatives to do so as well;
- It is important to talk things over with family, friends and other people in a similar situation;
- Take care of yourself by looking after your diet, getting regular exercise and maintaining your social contacts and lifestyle;
- Be realistic about what you can expect of yourself and recognize that you will be a better carer if you take care of yourself

Remember that the person with dementia is not being difficult on purpose.

Asking for help

As a carer, you can take care of yourself by being open about what help you need now and planning ahead for what help you may need in the future. Help often, but not always, comes from relatives, friends and neighbours. Seeking outside help is also important for many carers. Doctors, psychologists, social workers and counsellors all have experience helping people who are caring for others.

Some suggestions for reaching out to others include:

- Aim to share the care of the person with dementia;
- Don't hesitate to ask for help;
- Suggest specific ways that friends and relatives can help, such as bringing a meal, helping with the housework or shopping;
- Organised regular breaks – this is very important. Some friends and relatives may be able to care for the person with dementia on a regular basis. Local day centres can also offer suitable programs for people with dementia and respite for carers.

Men caring for a person with dementia

Many men find themselves caring for a person with dementia. Most of these men are caring for their partners, although male carers may also include sons, brothers and friends.

In many homes, it is often (but not always) the woman who takes the main responsibility for meal planning, cooking, cleaning and laundry, and for many of the other jobs that keep a household running. If the woman has dementia, she will gradually be unable to continue doing these tasks.

The man in the caring role may need to begin helping the person who has dementia, perhaps by asking to show them how to do things.

For some men, taking responsibility for these jobs may mean learning new skills or ways of doing things.

Some issues that men can face include:

- Helping with personal and intimate care – such as bathing, toileting, applying make-up, putting on pantyhose or arranging for hairdressing, all of which – for many men – are entirely new experiences;
- Helping with new everyday tasks – such as buying bras or helping a woman to try on new clothes in a women's change room;
- Losing the emotional support of a partner – men often rely on their partners for emotional support and to maintain friendships and family contacts, so men should make sure they have both social and emotional support.



*The complex and changeable emotions
you feel are completely normal.*

Common feelings experienced by carers

As a carer, you are likely to experience a range of difference, and often quite extreme, feelings. This is particularly difficult because, as dementia gradually causes the person's abilities and personality begin to change, the nature of relationships will also change. There is no simple way to deal with these feelings, but it may help to understand that the complex and changeable emotions you feel are completely normal.

Some feelings commonly experienced by carers of people with dementia include distress, frustration, guilt, grief and loss, exhaustion, annoyance and anger.

Guilt experienced by carers

It is quite common to feel guilty about things such as:

- The way the person with dementia was treated in the past;
- Feelings of embarrassment about the person's off behaviour;
- Losing your temper;
- Not wanting the responsibility of caring.

If the person with dementia goes into hospital or residential care, carers may feel guilty that they have not kept them at home for longer, even though everything that could be done has been done. You may feel guilty about past promises that cannot be met, such as "I'll always look after you."

Grief and loss experienced by carers

Grief is an emotional response to loss. The loss could be the loss of a relationship, moving house, loss of good health, divorce or death. If someone close to us develops dementia, we are faced with the loss of the person we used to know and the loss of a relationship.

People caring for partners are also likely to experience grief at the loss of the future they had planned together. Grief is a very individual feeling and people will feel grief differently at different times.

Anger experienced by carers

It is natural to feel frustrated and angry. You may be angry at having to be the caregiver, angry with others who do not seem to be helping out, angry at the person with dementia for difficult behaviour and angry at health providers and support services for not having answers.

Coping with feelings as a carer

If you are a carer, some helpful tips for dealing with feelings of guilt, loss and anger include:

- **Feel the pain** – allow yourself to really feel what you are feeling. Denying the feelings only intensified and prolongs the pain.
- **Cry** – tears can be therapeutic.
- **Talk** – Share the pain to help diminish grief. It can be helpful to talk to a person outside the family, such as a counsellor.
- **Keep a journal** – a private place where anything can be written, including unfulfilled wishes, guilt, anger or other thoughts and feelings.
- **Let go** – try not to be engulfed by bitterness.
- **Find comfort** – Different people have different ways to find comfort, including rituals like prayer, meditation or other activities.
- **Hold off on decisions** – tread carefully before making decisions and thoroughly explore all options before you take any major steps.
- **Be kind to yourself** – be patient with your feelings, and find a balance between the happy and sad person, the angry and peaceful, the guilty and glad.
- **Learn to laugh again and rediscover your sense of humour** – finding joy in life can be one way to honour the happy times that you used to share with the person you are caring for.



Talking to someone with Dementia

People with dementia remember more than it may appear, says a small study done in 2008 by the UK University of Dundee. All knowledge isn't lost forever, as it may appear when the person is asked something and blanks on a correct response. Researchers found that when subjects were asked the meaning of words, they often couldn't say. But when the same information was asked in different ways, with more context, they often did remember. Here are some tips on how to talk to someone with dementia to boost their understanding:

Be as clear and specific as possible

Instead of: *"Do you remember Mary?"*

Try: *"here's Mary, your cousin. She used to live next door to you in Norwich."*

Instead of: *"What do you want for lunch?"*

Try: *"Do you want to eat a turkey sandwich?"*

Use short sentences. Give one instruction at a time

Instead of: *"I got your bath ready so you can get cleaned up and get some fresh clothes on."*

Try: *"Let's go have a bath."*

Use the person's name often

This is a reminder to the person with dementia that you are still talking to them and helps to maintain their concentration and keep the conversation going.

Have patience

Give your loved one extra time to process what you say. If you ask a question, give a moment to respond. Don't let frustration get the better of you, if you can.

Understand there will be good days and bad days.

While the general trend of dementia sufferers is a downward decline, people with dementia will have ups and downs, just like anyone else.

Being reasonable, rational and logical will just get you into trouble.

When someone is acting in ways that don't make sense, we tend to carefully explain the situation, calling on his or her sense of appropriateness to get compliance. However, the person with dementia doesn't respond to arguments, no matter how logical. Straightforward, simple sentences about what's going to happen are usually best.



People with dementia do not need to be grounded in reality

When someone has memory loss, he often forgets important things. When we remind him of this loss, we remind him about the pain of that loss also. When someone wants to go home, reassuring him that he is home often leads to an argument. Redirecting and asking someone to tell you about the person he has asked about or about his home is better in calming a person with dementia.

Therapeutic lying reduces stress.

We tend to be meticulously honest with people. However, when someone has dementia, honesty can lead to distress both for you and the one you are caring for. Does it really matter that your loved one thinks they are the volunteer at the day care centre? If they are not in danger of harming themselves, or someone else, believing they are doing something, or have done something even if they haven't, is not harming anyone.

It is perfectly normal to question the diagnosis when someone has moments of lucidity.

One of the hardest things to do is to remember that we are responding to a disease, not the person who once was. Everyone with dementia has times when they make perfect sense and can respond appropriately. We often feel like that person has been faking it or that we have been exaggerating the problem when these moments occur. You are not imagining things – they are just having one of those moments, to be treasured when they occur.

Making agreements doesn't work

If you ask your loved one to not do something ever again, or to remember to do something, it will soon be forgotten. For people in early stages of dementia, leaving notes as reminders can sometimes help, but as the disease progresses, this will not work. Taking action, rearranging the environment, rather than talking and discussion is usually a more successful approach.

Doctors need information

Telling your doctor what you see at home is important. The doctor can't tell during an examination that your loved one has been up all-night pacing. Communication is key to getting the help you need.

It is easy to both overestimate and underestimate what your loved one can do.

It is often easier to do something for your loved one than to let them do it for themselves. However, if we do it for them, they will lose the ability to be independent in that skill. On the other hand, if we insist individuals do something for themselves, and they get frustrated, we just make our loved one's agitation and probably haven't increased their abilities to perform tasks. Not only is it a constant juggle to find the balance but be aware that the balance may shift from day to day.



Compassionate communication with the memory impaired

Communicating with those with memory loss can be challenging for both carer and the person with the memory loss, however, there are some simple strategies that can make things easier and allow for positive and rewarding communication.

“Nobody’s going to make decisions for me, you can go now, and don’t come back”

Don’t:

Confront: “I’m not going anywhere, and you can’t remember enough to make your own decisions.”

Do:

Respond to the feelings, accept the blame and reassure and distract, “I’m sorry this is such a tough time. I care about you and we are going to get through this together. You know what? James has a new job and he seems really excited.”

“Joe hasn’t called for a long time, I hope he’s okay.”

Don’t:

Remind: “Joe called yesterday, and you talked to him for an hour.”

Do:

Reassure and distract – “You really like talking to Joe, don’t you? Let’s call him when we get back from our walk.”

“Who are you? Where’s my husband?”

Don’t:

Take it personally: “What do you mean who’s your husband? I am!”

Do:

Go with the flow, reassure and distract: “He’ll be here for dinner. Come on, how about some milk and cookies? Would you like chocolate chip or oatmeal?”

“I’m going to the shop.”

Don’t:

Repeat differently: “please put your shoes on. You’ll need to put shoes on.”

Do:

Repeat exactly the same words: “Please put your shoes on. Please put your shoes on.”



Dementia Awareness

Forget-me-not memory cafés

Roleystone

1st Friday of every month – 10am – Avacados; 2 Mount Street, Kelmscott

Cornells

2nd Wednesday of every month – 10am – Kelly's Café; Birnam Road, Canningvale

Rockingham

3rd Monday of every month – 10am – Clipper Inn; Patterson Road, Rockingham

York

4th Friday of every month – 10am – Grannies Home Kitchen, Avon Terrace, York

Toodyay

2nd Tuesday of every month – 10am – Cola Café; Stirling Terrace, Toodyay

Northam

*Starting September 2019

3rd Tuesday of every month – 10am – Riversedge Café; 2 Grey Street, Northam



Dementia Awareness Fremantle Hospital

*Starting October 2019

3rd Thursday of every month – 10am – Hospital Café; B5, Alma Street Fremantle