



2020

Becoming Dementia Aware

Steps Toward Becoming a Dementia Friend

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SOUTHERN DAG'S



(Notes to accompany our Dementia Friendly Workshop)

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Introduction:

These notes are to accompany our Dementia Awareness presentation, which is designed and presented by people living with Dementia. We take the view of the lived experience, not a clinical overview. All the material and examples are from our collective lived experience, not clinical observations of others. We invite questions and observations from everyone present and try to provide some practical insight to the world of Dementia.

The presentation is in four parts with time for reflection and discussion.

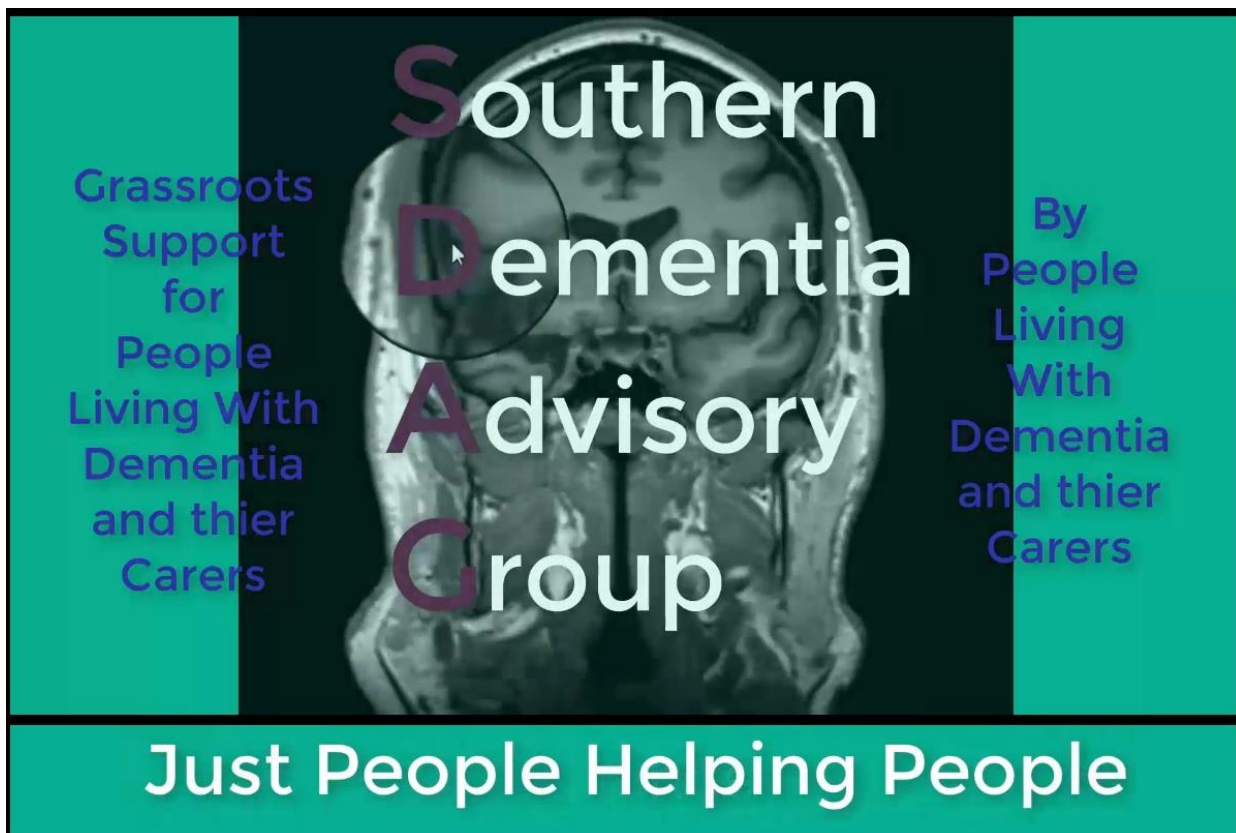
The first part is an overview of Dementia and its prevalence in the Australian community. The next section looks more closely at how Dementia can impact on an individual particularly how it may impact our senses. The third section looks at getting a diagnosis, the risk factors and some strategies you can employ to minimise your chances of developing Dementia, and things you may be able to do to mitigate its impact.

The final section looks at what you can do to help support someone with Dementia and how to become a Dementia Friend. Finally, we hope you will have a more positive attitude towards Dementia and be better able to take up the challenge of becoming a Dementia Friend and to help us all make all our communities more Dementia Aware and more Dementia Friendly.

An Overview of Dementia

Who we are.

This material has been collated, prepared and presented by people living with Dementia. As such this presentation is one, if not the first such presentations worldwide.



Our group the Southern Dementia Advisory Group formed as part of the Dementia Friendly Kiama project in 2014. We are comprised of people living with Dementia and their immediate carers and have morphed well beyond our initial roll of informing and advising the project. The DAGs as we affectingly refer to ourselves

was only the seventh such advisory group in the world, but the first that was formed at a community level rather than at a “national” level. As such we were acknowledged by the World Health Organisation, and the Dementia Alliance International.

We have gone on to not only inform and guide the Kiama Project (which is being acknowledged as the “Gold Standard” in developing Dementia Friendly communities world-wide) but to inform Dementia Australia’s Dementia Friendly program, as well as advise other national programs such as what is being developed in Singapore and other parts of the world today.

What is Dementia?

Dementia is an umbrella term used to describe a group of over 100 medical conditions that have a significant impact on cognitive ability and our ability to do normal tasks. Alzheimer’s disease is the most common of these conditions. Some of these conditions include;

- Alzheimer’s Disease
 - Sporadic Alzheimer’s Disease
 - Familial Alzheimer’s Disease
- Vascular Dementia
 - Multi-infarct dementia
 - Binswanger's disease
- Lewy Body disease
- Parkinson’s disease dementia
- FrontoTemporal Dementia
 - Behavioural-variant FrontoTemporal dementia
 - Semantic FrontoTemporal Dementia
 - Progressive non-fluent aphasia
 - Inherited FrontoTemporal Dementia
 - Frontotemporal dementia with Parkinsonism-17 (FTDP-17)
- Alcohol related Dementia
 - Wernicke’s encephalopathy
 - Korsakoff’s syndrome
- Down Syndrome and Alzheimer’s disease
- HIV associated dementia
- Younger-onset dementia
- Dementia caused by Huntington’s disease
- Creutzfeldt-Jakob disease

There is overlap between some of these terms, and this is only a 'short' list.



Prevalence of Dementia in Australia.

Dementia is the second leading cause of death of Australians contributing to 5.8% of all deaths in males and 11.3% of all deaths in females each year

In 2016 dementia became the leading cause of death among Australian females, surpassing heart disease which has been the leading cause of death for both males and females since the early 20th century. In 2017, dementia remained the first leading cause of death in females, and the third leading cause of death in males. Overall, accounting for 13,729 deaths

In 2019, there was an estimated 447,115 Australians living with dementia, there is an estimated 27,247 people with younger onset dementia (under 65).

Without a medical breakthrough, the number of people with dementia is expected to increase to 536,164 by 2025 and almost 1,100,890 by 2056.

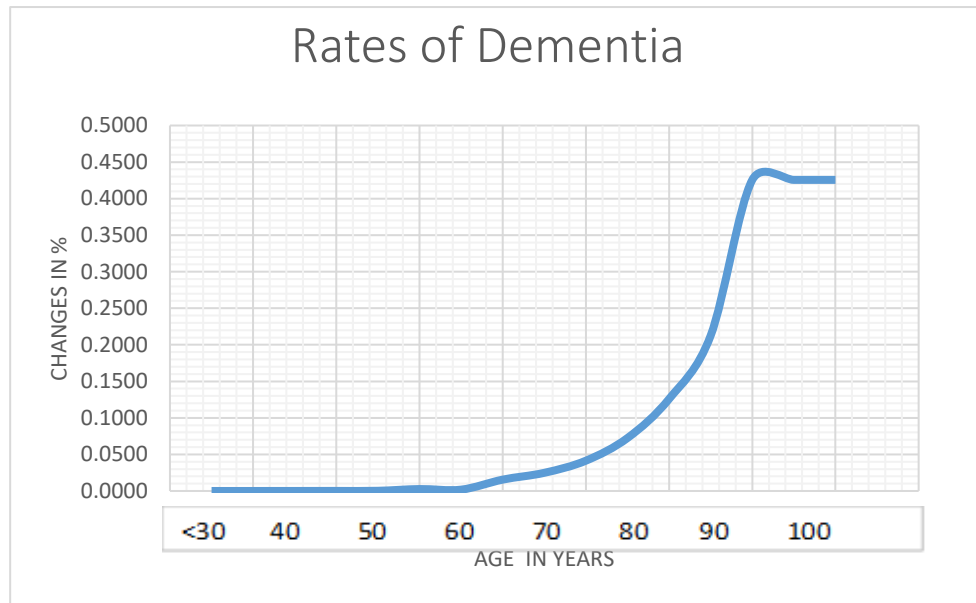
Currently an estimated 250 people are joining the population with dementia each day. That's more than one person being diagnosed every six minutes. The number of new cases of dementia will increase to 318 people per day by 2025.

An average of 36 people died per day where dementia was the underlying cause of death.

Rates of Dementia Vs Age

(approx.)

- 00 – 50 → 1 : 10,000
- 50 – 55 → 1 : 400
- 55 – 60 → 1 : 500
- 60 – 65 → 1 : 65
- 65 – 70 → 1 : 40
- 70 – 75 → 1 : 13
- 75 – 80 → 1 : 7
- 80 – 85 → 1 : 5
- 85 – 90 → 1 : 4
- 90 – 95 → 1 : 3
- 95 + → 1 : 2



For every person diagnosed with Dementia, there is likely these other people that are impacted;

- A partner.
- A sibling.
- Several Children or even parents.
- A dozen or so friends or colleagues.

That's 447,115 times fifteen or over 6 million people are affected, or over 25% of our population.

How Dementia impacts people and sensory changes,

Dementia is a degenerative disease of the brain. It is characterised by having significant impacts on our ability to do everyday activities. It is almost always terminal. It is not a normal part of aging, but it is very common. There are very few effective treatments, most of the available treatments treat the symptoms not the causes.

The following table illustrates some aspects of how Dementia is perceived both by the community and by us living with Dementia.

What People See	What We See	What We Experience
"Funny Old Person's" Disease	Isolation	Anxiety
Memory Loss	Loss of Friends	Loss of Friends
Wandering	Confusion	Confusion
Confusion	Loss of Independence	Changes in how we experience Time
Incontinence	Difficulty Doing Everyday Tasks	Exhaustion
Behavioural Issues	Social Neglect	Dry Skin
"Old People's Care Homes"	Stigma	Changes in Empathy
Locked Wards	Terminal Disease	Emotional Changes
Loss of Empathy	Hurt Partners	Hidden Obstacles to our Basic Human Rights
Carer Burden	Financial Loss	Fear
		Changes in Sense of Taste
		Degraded Sense of Smell
		Pain
		Confused Memory
		Degraded Facial Recognition
		Increased rates of Infections ie UTIs
		Being Ignored
		Degraded Language Skills
		Confused Sensory Inputs
		Losing our ability to speak and be heard!

What We Need



Community Awareness

People to be Informed about the Diversity of Dementia

More Understanding

People to take More Time with Us.

Social Stigma reduced to zero.

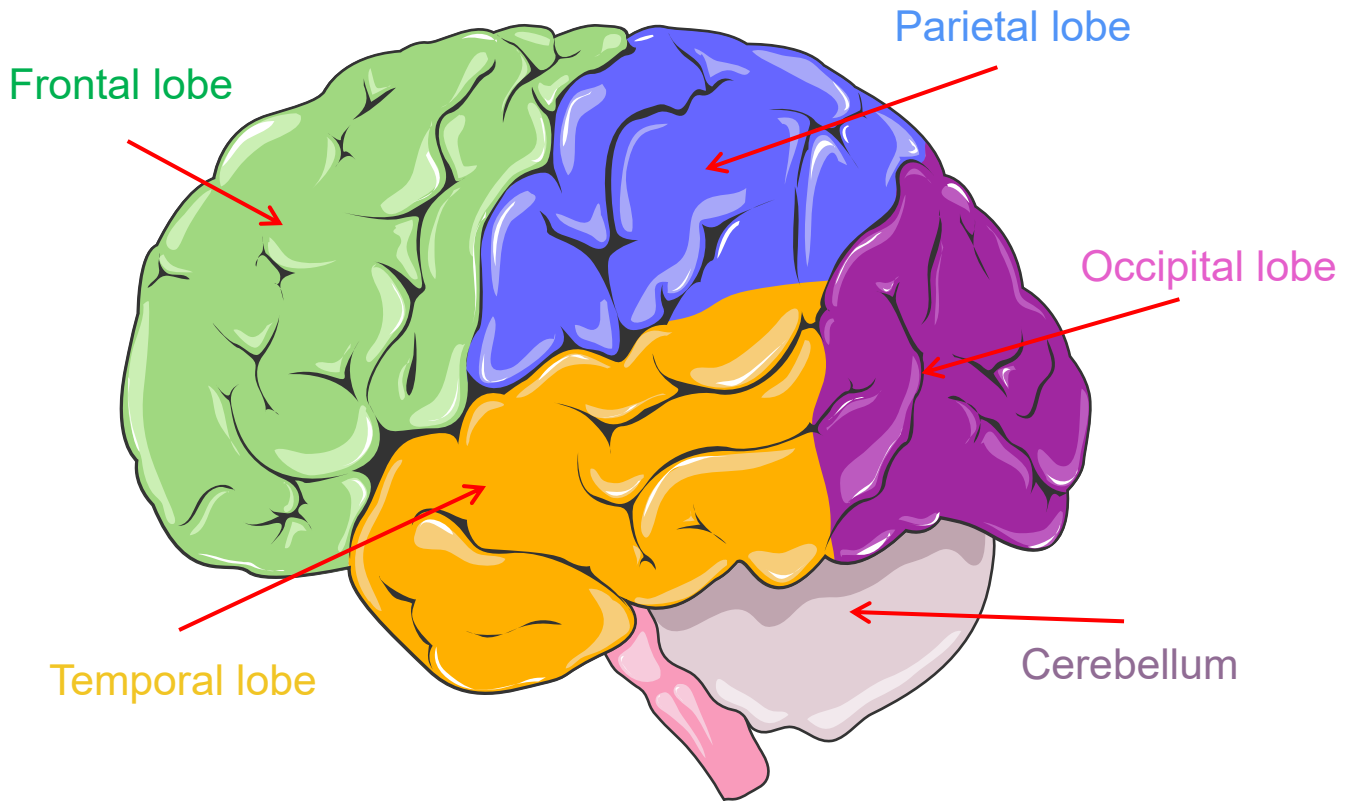
Our Basic Human Rights

Better Services

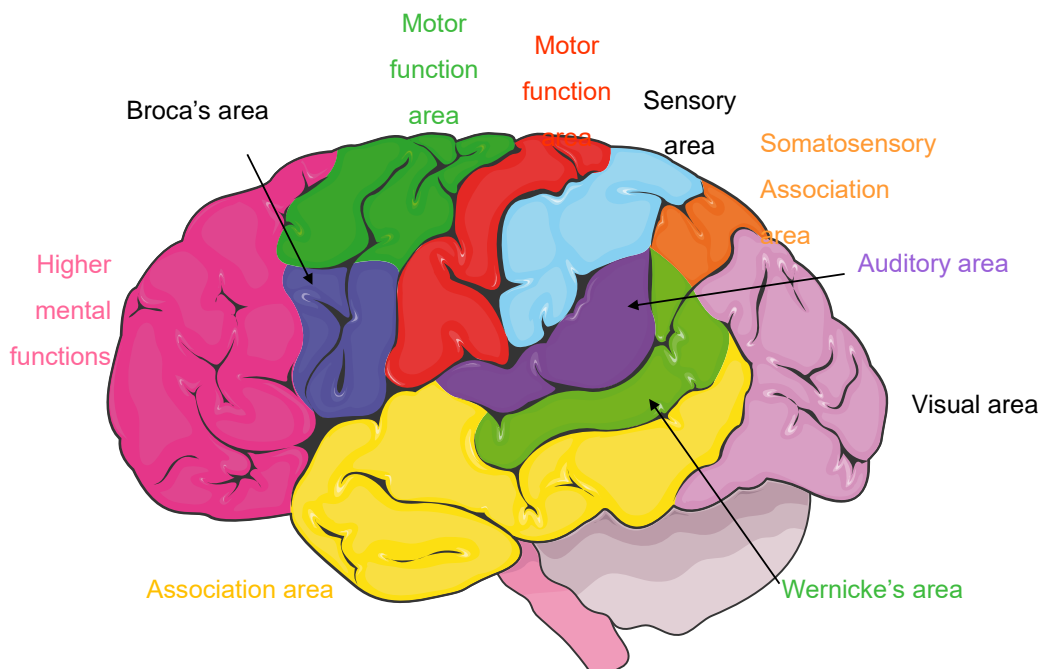
"All We Need Is A Little Help From Our Friends"

Become Dementia Aware You Can Make a Difference! Become a Dementia Friend

Dementia is a degenerative condition of the brain. It has been said that the human brain is the most complex known thing in the universe and our current level of understanding of the brain is very low. The type of dementia and how it manifests itself (its symptoms) are related to the part(s) of the brain that are affected. For example, FrontoTemporal dementia is identified by degeneration of parts of the Frontal lobe and Temporal lobes.



Functional areas of the Brain



Common Symptoms and Changes

Each of the major areas of the brain is associated with functions. Damage to an area will cause changes to these functions. These changes are manifest as some of the symptoms of Dementia and are used to help identify the type of Dementia. The major functions of these areas of the brain are set out below with some of the symptoms. Some functions cross regions or more likely have different aspects controlled in different areas. *(It is also worth noting that the following tables are not definitive and will likely change as our understanding progresses.)*

Frontal Lobe.

Functions Include:	Some Symptoms of Impairment:
Judgment	Changes in personality and social behaviour.
Foresight	Loss of spontaneity in interacting with others.
Initiation	Difficulty in sequencing – planning and completing complex tasks in correct order.
Problem Solving	
Inhibition of behaviour	Repeating same actions and comments without conscious awareness of doing so.
Planning and anticipation	
Self-Monitoring	Loss of flexibility in thinking.
Personality	Distractibility.
Emotions	Mood swings.
Organisation	Diminished abstract reasoning.
Concentration	Difficulty with problem solving.
Expression of language	Difficulty in finding and correct usage of words.
Smell	Loss of simple movement of some body parts
	Changes in food preferences.

Table 1: The Frontal Lobe: Functions and Some Symptoms of Impairment

Temporal Lobe.

Functions Include:	Some Symptoms of Impairment:
Memory	Difficulty remembering names and faces.
Hearing	Difficulty understanding spoken language.
Understanding Language	Difficulty with identification of, and verbalisation about objects.
Organization and sequencing	Difficulty with concentration. Short-term memory loss.
Musical awareness	Inability to categorize objects.
	Impaired long-term memory.
	Aggressive behaviour.
	Changes in sexual interest.
	Persistent talking.
	Difficulty in locating objects in the environment.

Table 2: The Temporal Lobe: Functions and Some Symptoms

Parietal Lobe.

Functions Include:	Some Symptoms of Impairment:
Touch	Difficulties naming objects.
Differentiation (of size, shape, colour etc)	Lack of awareness of body parts and surrounding space.
Spatial perception	Poor visual perception.

Visual perception	Difficulty drawing.
Maths skills	Difficulty performing math calculations.
	Difficulty writing words.
	Inability to attend to more than one object at a time.
	Inability to focus visual attention.
	Problems with reading.
	Poor hand-eye coordination.
	Confusion of left-right orientation.

Table 3: The Parietal Lobe: Functions and Some Symptoms

Occipital Lobe.

Functions Include:	Some Symptoms of Impairment:
Vision	Impaired vision.
Reading (perception of written words)	

Table 4: The Occipital Lobe: Functions and Some Symptoms

Cerebellum.

Functions Include:	Some Symptoms of Impairment:
Coordination of voluntary movement	Inability to judge distance and when to stop.
Balance and equilibrium	Slurred speech.
Some Reflex motor actions	Tremors.
	Involuntary movement of the eyes
	Lack of coordination.
	Inability to perform rapid alternating movements.

Table 5: The Cerebellum: Functions and Some Symptoms

Brain Stem.

Functions Include:	Some Symptoms of Impairment:
Breathing	Decreased vital capacity in breathing.
Swallowing	Difficulties swallowing food and water.
Balance	Problems with balance and movement.
Sleep and alertness	Sleeping difficulties.
Heart rate	Dizziness and nausea
	Difficulty with organization and perception of the environment.

Table 6: The Brain Stem: Functions and Some Symptoms

It is important to note that no individual will exhibit all the symptoms from any section, and that the severity and impact will vary between individuals. Also, the severity will likely increase as the disease progresses.

Sensory Impacts

How we (our brain) interprets the world comes from information from our senses. Often dementia will impact on how our brain interprets this sensory input. We generally acknowledge 5 senses, but we do have more and they often work together to represent the our view of the “world”. The following table illustrates a number of different sensory aspects:

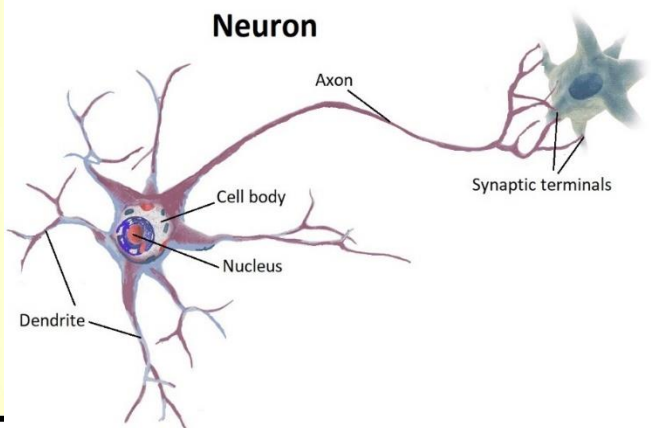
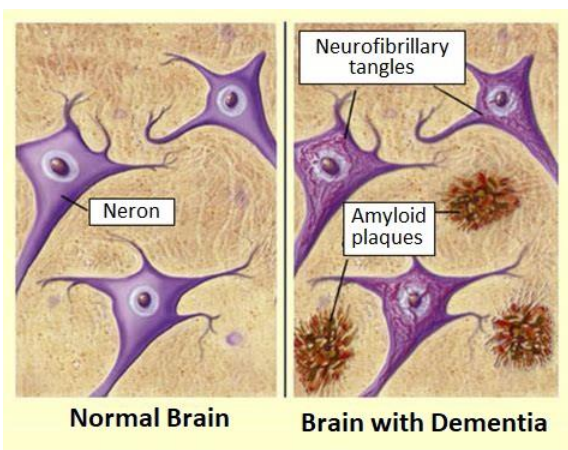
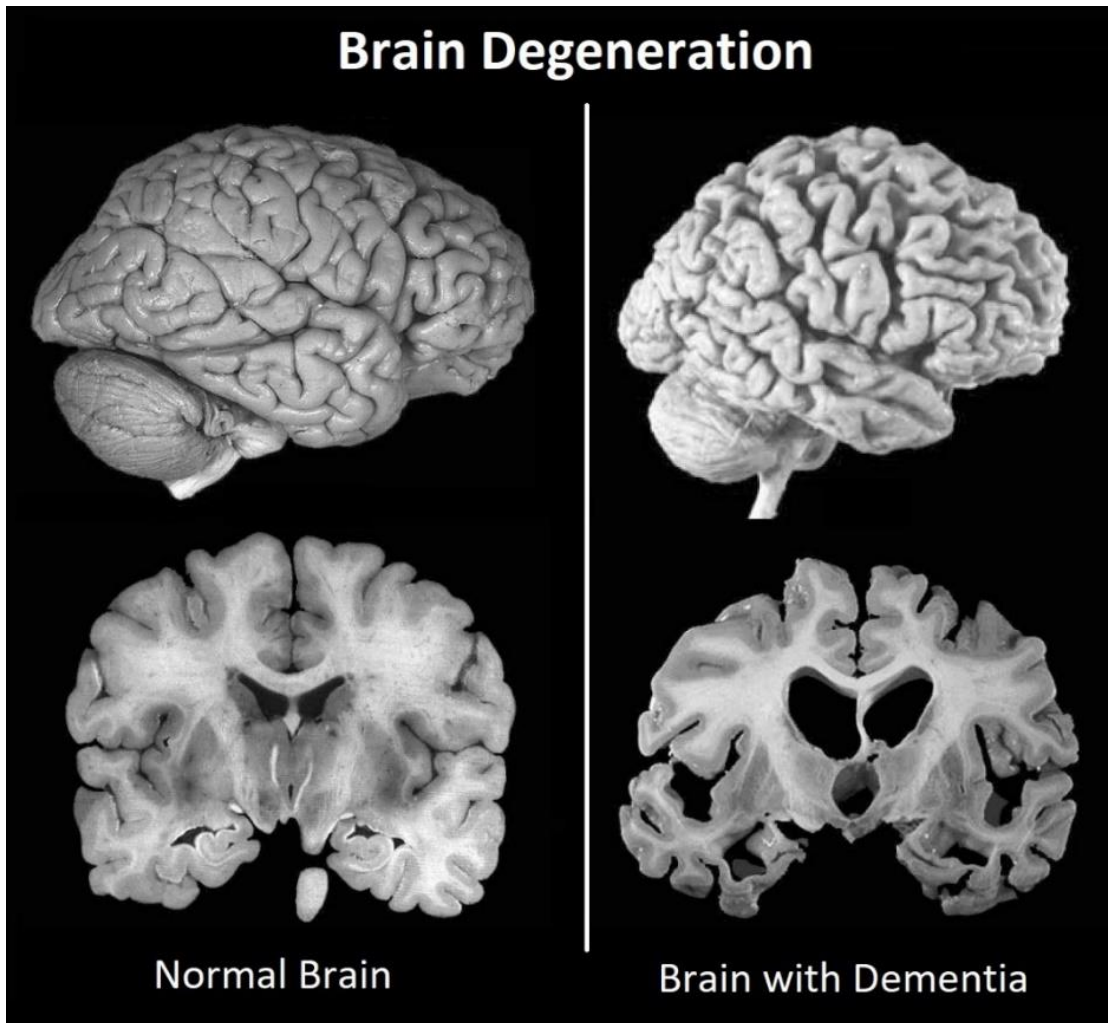
Sense	Description
Sight	Shape, colour etc. What we see with our eyes.
Taste	(sweet, salty, sour, bitter, and umami)
Touch	Distinct from pressure, temperature, pain, and even itch sensors.
Pressure	Obvious but hard to explain.

Itch	Surprisingly, this is a distinct sensor system from other touch-related senses.
Thermoception	Ability to sense heat and cold.
Sound	Detecting vibrations along some medium, such as air or water that is in contact with your ear drums. This is fundamental to our ability to communicate with others.
Smell	Our olfactory sense. When combined with taste pretty much describes our food.
Proprioception	This sense gives you the ability to tell where your body parts are, relative to other body parts (close your eyes and touch your nose).
Tension Sensors	These are found in such places as your muscles and allow the brain the ability to monitor muscle tension.
Nociception	In a word, pain It is its own unique sensory system. There are three distinct types of pain receptors; cutaneous (skin), somatic (bones and joints), and visceral (body organs).
Equilibrioception	The sense that allows you to keep your balance and sense body movement in terms of acceleration and directional changes.
Stretch Receptors	These are found in such places as the lungs, bladder, stomach, and the gastrointestinal tract. A type of stretch receptor, that senses dilation of blood vessels, is also often involved in headaches.
Chemoreceptors	These trigger an area of the medulla in the brain that is involved in detecting blood born hormones and drugs. It also is involved in the vomiting reflex.
Thirst	This system more or less allows your body to monitor its hydration level and so your body knows when it should tell you to drink.
Hunger	This system allows your body to detect when you need to eat something.
Magnetoception	This is the ability to detect magnetic fields, which is principally useful in providing a sense of direction when detecting the Earth's magnetic field. Unlike most birds, humans do not have a strong magnetoception.
Time	This one is debated as no singular mechanism has been found that allows people to perceive time. However, we have a startling accurate sense of time, particularly when young.
Humour	Not defined as a human sense as such but very relevant to us, and last if not as equally important;

We could also as a sense of “Justice”. This is very relevant to our sense of self and the discrimination and stigma we experience.

Because of Dementia’s impact on our cognitive ability it takes more time to process some sensory information, and sometimes this can be overpowering and lead to confusion and many other symptoms.

A 'normal' brain compared to a brain diagnosed with Dementia (Post-Mortem)



Getting a Diagnosis, Risk factors and how things you can do to reduce your risk factors,

Are you concerned about yourself or someone close to you having a Dementia?

The following list covers many of the common areas of concern, if changes occur in these areas it is worth investigating further. The cause may well be something else that can be easily treated and bring peace of mind. Recent memory loss.

- Difficulty performing familiar tasks.
- Problems with Language.
- Disorientation in space and time.
- Poor – decreased judgement.
- Problems with abstract thinking
- Misplacing things
- Changes in mood or behavior
- Changes in personality
- Loss of initiative.

NOTE: Changes are normal. It is a persistent change over several of these points that has an impact on your ability to do everyday tasks that is significant.

Many of the symptoms of Dementia may appear many years before the disease becomes apparent or can be properly diagnosed. Usually it is only in hindsight that we recognise these early symptoms but at the time they are not indicative of Dementia.

Getting a Diagnosis

Getting a diagnosis of Dementia (let alone an accurate diagnosis) can be difficult and take a long time. The starting point would be to talk to your GP. While most GP's are not skilled at diagnosing Dementia, they can rule out many other causes of your concerns by normal blood tests, MRI's etc. You may then be referred onto specialist in other fields.

One simple screening test you may be given may be described as a "mini-mental". You may be asked some simple questions such as "who is the current prime minister of Australia?", to count backwards from 100 in multiples of 7 or draw a clock face. What is important with these simple tests is not so much on how you perform, but on how your performance varies over time.

Once (and if) diagnosed you may be able to put in place strategies that will delay the progress of the disease and maintain your quality of life. Some of the symptoms may even be treatable. Hence, getting an accurate and early diagnosis can be beneficial.

Risk Factors

Some of the risk factors associated with dementia can be managed through lifestyle changes or appropriate medical treatments. The risk factors for Dementia are similar for that of many chronic conditions, such as;

- Cardiovascular (Brain infarcts, heart disease, hypertension, smoking)
- Diabetes
- High cholesterol
- Family History
- Head Injury

Many of these factors we can control.

Minimising Your Risk and Maximising Your Health

To reduce your chances of developing Dementia you should consider the following.

- Aim for a heart healthy lifestyle.
- Keep physically active
- Keep socially active and connected to others.
- Keep your brain active, continue your education throughout your life

There are a few forms of Dementia that have a significant genetic component and cannot be minimized by today's technologies, likewise there may be environmental factors as yet unrecognized, that may contribute to our chances of developing Dementia.

By adopting healthy lifestyle choices, we can reduce our risk factors. The earlier in our lives we make these choices the bigger the impact they may have.

While there is no way of being able to guarantee our future health, there are things we can do to mitigate the impact that Dementia may have on us and others. One such thing is to help move our community to be a more Dementia aware and enabling. It is important to recognize the rights of people with Dementia under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

What you can do to help people living with Dementia and how to become a Dementia Friend.

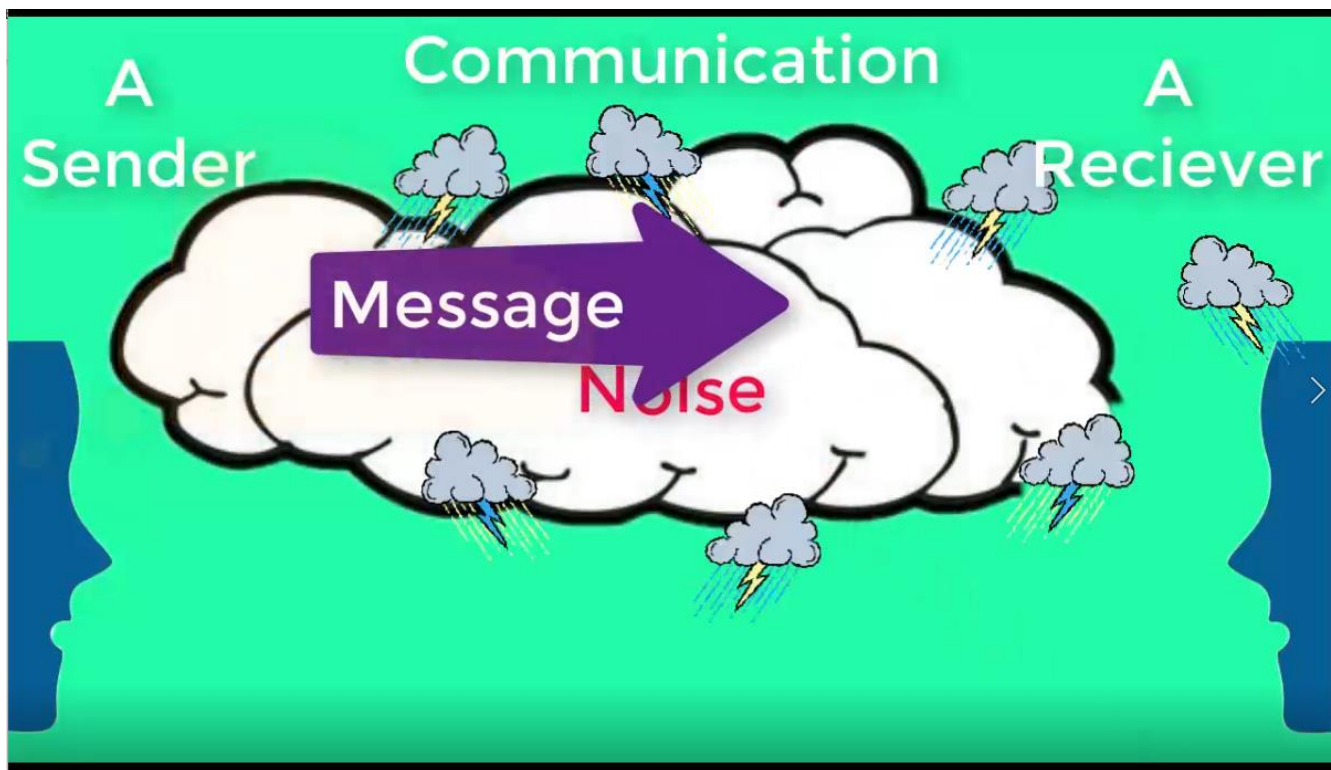
The chances are you probably know someone with Dementia, even if you don't know that they have Dementia. Consider the following points when interacting with a person with Dementia (or anyone really);

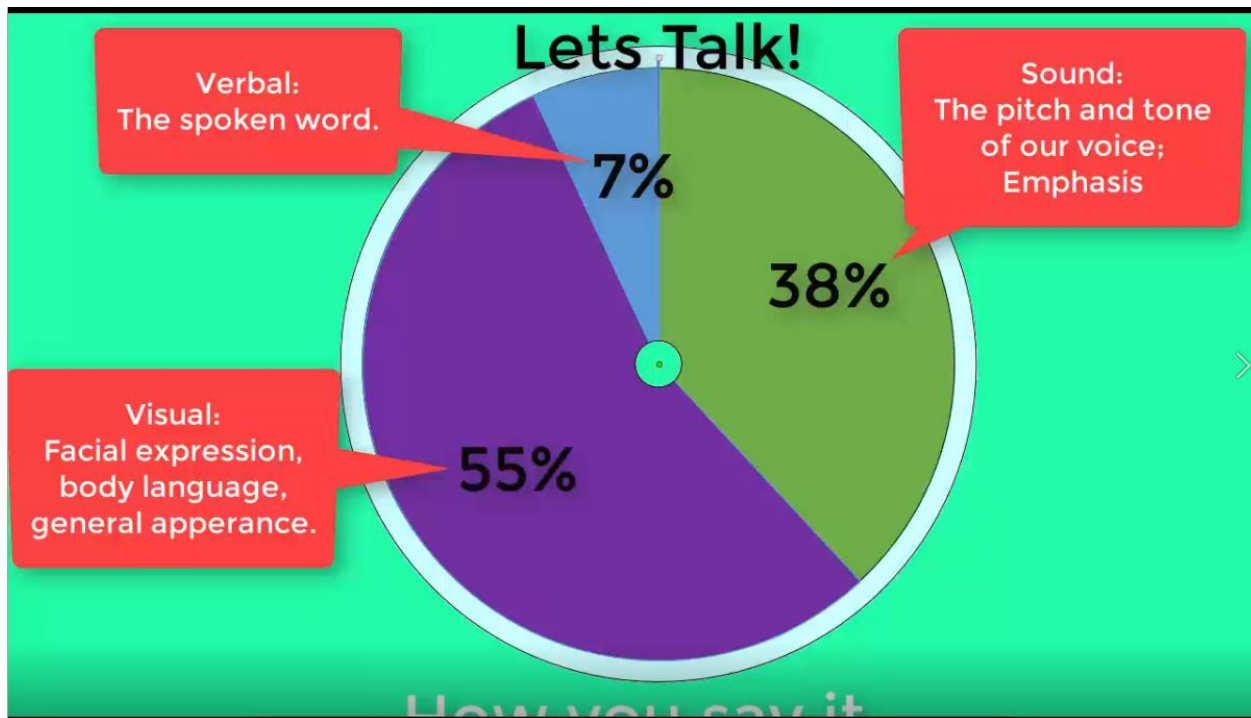
- See the person not the disease.
- Be genuine and get to know the person.
- Support them socially.
- Give them time to respond and understand that all responses may not be verbal.
- Take the extra time to listen to them.
- Respect their basic human rights and stand up for them.

Communication

Interpersonal communication can be difficult at the best of times but if one person has cognitive impairment or Dementia it can be much harder.

- Take the time to understand the person
 - Their background
 - Their symptoms
 - How they are feeling now
- Much of what they say may be masked by their symptoms.
- Assume nothing!
- Remember communication is more than words!





Become A Dementia Friend

Show your support and willingness to help by becoming a “Dementia Friend”. By being here you have taken the first step. Don’t be afraid to apply what you have learnt today.

Start a conversation about dementia with your neighbour, your children and our representatives (Clubs, service groups, sporting groups, etc).

Attend our social activities and create your own.

Have your “Dementia Friend” status recognised by completing the Dementia Friend training at www.Dementiafriendly.org.au

Encourage others to get involved. Remember the more we make our world “Dementia Friendly” the better it may be for us in the future, particularly if we too develop Dementia.

Get Involved Locally

Join the Kiama Dementia Alliance (the best in the world!)

Come along to our activities and bring a friend with Dementia.

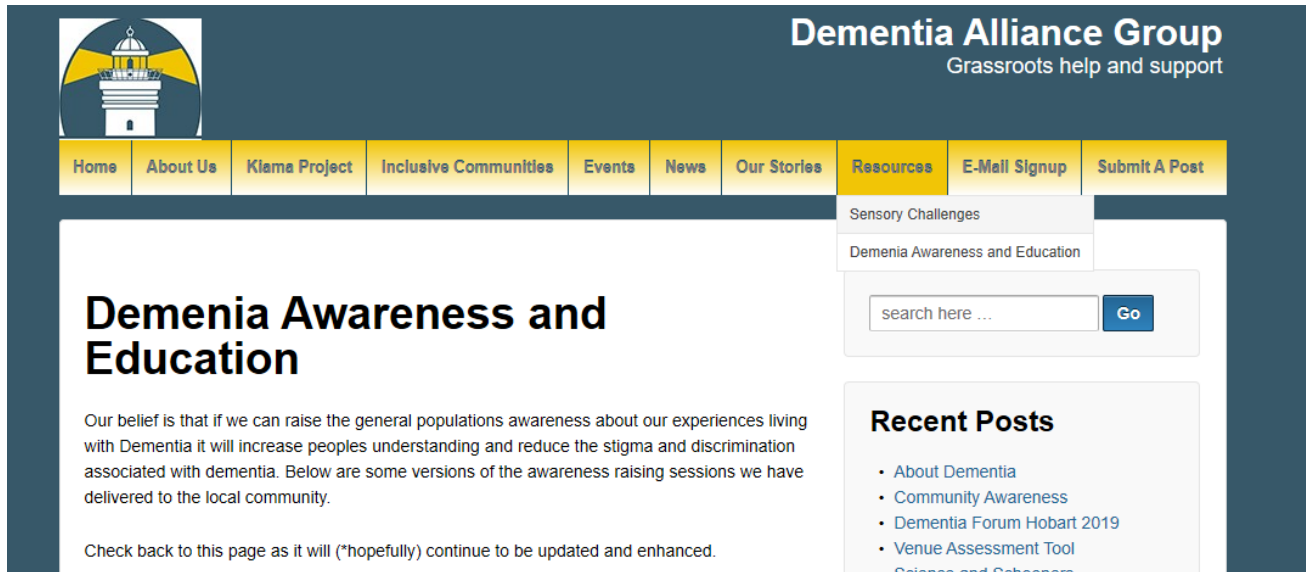
Start conversations with your friends and colleagues.

And remember – “We all get by with a little help from our friends”

Resources and Further Help

A form of this presentation can be viewed anytime online from our website

www.SouthernDag.org under our Resources page.



The screenshot shows the website header for the Dementia Alliance Group, with the tagline 'Grassroots help and support'. The navigation menu includes Home, About Us, Kiama Project, Inclusive Communities, Events, News, Our Stories, Resources, E-Mail Signup, and Submit A Post. The 'Resources' menu is open, showing 'Sensory Challenges' and 'Dementia Awareness and Education'. The main content area features the title 'Dementia Awareness and Education' and a paragraph stating: 'Our belief is that if we can raise the general populations awareness about our experiences living with Dementia it will increase peoples understanding and reduce the stigma and discrimination associated with dementia. Below are some versions of the awareness raising sessions we have delivered to the local community.' A search bar and a 'Recent Posts' section are also visible.

Our belief is that if we can raise the general populations awareness about our experiences living with Dementia it will increase peoples understanding and reduce the stigma and discrimination associated with dementia. Below are some versions of the awareness raising sessions we have delivered to the local community.

Check back to this page as it will (*hopefully) continue to be updated and enhanced.

The direct link is:

<https://www.southerndag.org/dementia-awareness-and-education/>

Links to some other useful resources

- To view copies of the material shown today and find out more about the DAGs or even to sign up to our events notices please visit www.SouthernDag.org
- General information from Kiama Council www.kiama.nsw.gov.au
- To find out more and become a Dementia Friend, <https://www.dementiafriendly.org.au/>
- Dementia Australia (Help Line **1800 100 500**) www.Dementia.org.au
- Dementia News from the Illawarra and Shoalhaven area <http://dementiaillawarra.com/>
- To join and hear the voice of Dementia worldwide <https://www.dementiaallianceinternational.org/>
- To become involved in research and to contribute to our better understand of Dementia and to contribute towards future treatments, cures and hopefully prevention. <https://www.stepupfordementiaresearch.org.au/>
- To keep in touch with our group or to ask us questions

e-mail → info@southerndag.org

Take Care of Your Friends

TAKE C.A.R.E OF YOUR FRIENDS

CLEAR AND SIMPLE

- Be Patient
- Use short sentences and simple language
- Speak clearly
- Keep calm

ACKNOWLEDGE OUR CONCERNS

- Smile, but be genuine
- Maintain eye contact
- Be attentive and listen
- Be prepared to spend more time
- Be at ease, if you're at ease, it easier for us to be at ease.

RESPECTFUL REASONABLE AND REASSURING

- Be friendly and caring but above all genuine
- Be reasonable in what you ask. We are all individuals
- Give us time to respond. Your answer may not come now but latter.
- Seek quiet, uncluttered and familiar places to interact with us
- Be encouraging and supportive

ENGAGE WITH US TO BUILD TRUST AND PROVIDE COMFORT

- Be friendly
- Be Honest
- Build a trusting relationship
- Maintain a comforting presence
- Ask appropriate questions and acknowledge our responses

To Those Who Care

Keep placid amid our noise and confusion and remember what peace there may be in silence.

Speak your truth quietly and clearly; and listen to us, even if we seem dull and ignorant; we too have our story.

Avoid being loud and aggressive to our person; it is vexatious to our spirit. Don't compare yourself to us, you may become vain or bitter, for always there will be greater and lesser persons than ourselves.

Enjoy our achievements as well as our plans. Keep interested in our own life, however humble; it is a real possession in the changing fortunes of our lives.

If we exercise caution in our business with you, it is because the world is full of trickery. But let this not blind you to what virtue there is in us; we may strive for high ideals and falter, but everywhere there is life full of heroism.

Be yourself. Especially, do not feign your affection. Neither be cynical about our abilities nor patronising; for in the face of all aridity and disenchantment, our spirit still lives.

We take kindly the counsel of your years, and gracefully seek your compassion.

Nurture our strengths and help us in our misfortune. Do not distress yourself with dark imaginings. Many of our fears are born of fatigue and loneliness.

Beyond a wholesome discipline, be gentle with us. We are all children of the universe, no less than you, or the trees and the stars; we all have a right to be here and to be heard.

And whether or not it is clear to you, no doubt the universe is unfolding as it should.

Therefore, be at peace with us and with your God, whatever you conceive Him to be.

And whatever our labours and aspirations have been in the past, in the noisy confusion of life, keep peace with us. With all its sham, drudgery and broken dreams, it is still a beautiful world.

Be cheerful. Strive to be happy.

Dedicated to those who care about us and to those whose help makes our lives easier, from all of us with a Dementia.

Adapted from Desiderata (Max Ehrman 1927) by Dennis Frost PWD 2016

A Quick Introduction to a small part of the experience of Living With a Cognitive Impairment.

Instructions:

1. Place this form (this side up) on the desk in front of you.
2. Stand and take your pen (of a suitable colour other than Primrose) in your dominant hand.
3. Now turn 90 degrees to your left if you are right handed, or 90 degrees to your right if you are left handed.
4. Lift one leg off the ground and remain balanced on one leg.
5. Without putting both feet on the ground or turning (you may hold the desk to steady yourself) turn your head to face this sheet of paper.
6. Now turn it over and complete the several simple questions using your non-primrose pen.

If you have any questions please ask the inquisitor.

Question 1:

In the space provided write your name in the form

Firstname last, Lastname First

NAME:

--	--

Question 2:

AGE: How old will you be next birthday? (Answer in years and months)

--	--

Question 3:

Read the following sentence and identify the spelling mistake and circle the misspelt word.

Aye I eye and Aye-Aye.

Question 4:

Do you know what an Aye-aye is? Answer Yes or No

Question 5:

Was this exercise easy? On a scale of 1 to 5 with one being very easy and 5 being near impossible circle your choice.

1	2	3	4	5
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This page has been left blank intentionally for your notes and questions. If you should have any questions outside this forum please feel free to e-mail them to info@southerndag.org.

Notes:

Dementia



Awareness
