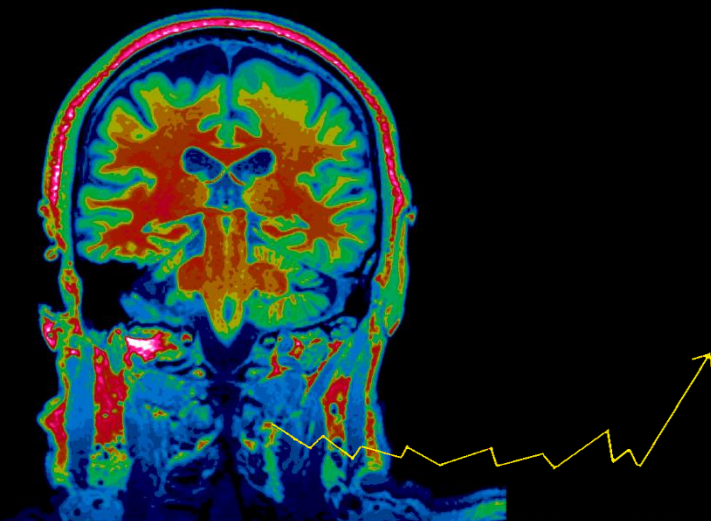


Dementia

Changes and Challenges

**Shared Ideas
To help you
Live Well
With
Dementia**



Dennis Frost

Southern Dementia Advisory Group

2019

Take inspiration and everyday try to;

Be Bold

Be Brave

Be Courageous

Be True to Yourself



And remember,

It's Not Your Fault!



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Dementia

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Why This Booklet?

Many things have been written about Dementia, but too few reflect our lived experience. Often the emphasis is purely clinical and dismisses much of our experience. This often leads to further entrenchment of the stigma around Dementia and to the perpetuation of many miss-truths about Dementia.

I have taken inspiration for this work from Agnes Houston who prepared a leaflet entitled “Dementia & Sensory Challenges” and from many conversations I have had with my many friends living with Dementia. I think it important that I share our experiences and insights.

Through this I hope to do three things;

- First, to help others on their journeys with Dementia,
- Secondly, to inform others who care, and
- Thirdly, to hopefully inspire people to investigate further and to find more and better solutions.

When I speak, it is not just with my voice, but from the experiences of many other, both locally and from around the world.

About Dementia.

Dementia is an umbrella term for somewhere between 100 and 200 different conditions. What they all have in common include the following;

- They are all degenerative diseases of the brain,
- They impact significantly on our ability to perform what were every day and normal tasks,
- They are progressive, with their impact becoming more severe over time,
- Ultimately, they are all fatal (though they can often be “slowed” by the right “care”),
- There are few affective treatments.

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Dementia is not a “disease” of aging. It is statistically more likely to develop as we age, but there are rare forms of Dementia that have been identified in four-year-old children. Younger Onset Dementia is a grouping of different forms of Dementia that are diagnosed in people under the age of 65. At the time of writing there are over 26,000 people diagnosed with Younger Onset Dementia in Australia.

Again, at the time of writing Dementia is the second leading cause of death in Australia (unless you are female, then it is the primary cause of death). It is the only major cause of death that is increasing each year.

Diagnosis

For people diagnosed with Younger Onset Dementia, a diagnosis could take several years. Eighteen months is considered pretty quick. This was near the time my diagnosis took. The process may involve visits to Geriatricians, Neurologists, Psychologists and other health professionals. It will no doubt mean several of the following tests; MRI's, PET scans, SPECT scans, Blood Tests, and of course Neurological and Cognitive tests. Most of the testing is to rule out other conditions.

Contrast this to a diagnosis of an elderly person. A generic diagnosis of Dementia can be rendered in minutes. There may be no indication of the form or type of Dementia. I question the real value of such diagnoses. That is not to say that all diagnoses are as hurried, there are many considered and timely diagnoses.

Two other points about Dementia Diagnosis are worth being well aware of. In the UK it is estimated that despite aggressive diagnosis, only about 50% of people with Dementia are diagnosed. Similar rates are expected in Australia.

The second point, not unrelated, is that the type of Dementia you are diagnosed with might change. Over time diagnoses can be refined and new research can often alter a past diagnosis. This though important, can confuse the person who is diagnosed as well as those around them.

One thing we all look forward to is a more timely and accurate initial diagnoses.

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Who Can Get Dementia?

Simply stated, “you can!” There are several forms that are inherited. Generally inherited forms manifest their symptoms earlier in life. The causes of most forms of Dementia are poorly understood – if at all. The older we become, the greater our chance of developing a Dementia. Some of us were “lucky” and developed our Dementia’s at a relatively young age.

The rates of Dementia are increasing. This is because we are living longer, and the diagnostic process is improving. There may also be some unknown environmental factors contributing to this rise, but this is at best speculative.

Can You Prevent Dementia?

There is no definitive evidence of any guaranteed preventative measures, but you can minimise your risk factors. The best recognised way of doing this is to maintain a “Healthy Heart” lifestyle, though diet and exercise, and to keep your brain active.

Cures?

There are many promises being promoted, but none have delivered. Remember there are well over 100 different conditions classified as a Dementia, conceivably we will need a similar number of cures.

Realistically, if a cure was announced today for my form of Semantic Frontotemporal Dementia, it would likely take between 10 and 15 years for that cure to be trialled in a human population, to be approved by the relevant health authorities before it would become generally available. By then it is unlikely that I will still be alive. Today’s cure is hope for the next generation.

While there are no viable cures, there is much we can do to delay the progress of our Dementia, and to mitigate some of its effects. In effect to continue not only to live, but to live well.

This is the purpose of this booklet. To raise awareness of the effects of Dementia and to offer some ways of coping with them. To help us all to live well.

The Lived Experience.

What I wish to share here is the real experiences not only of myself, but of many others living with Dementia. For any “intervention” to work successfully for people living with Dementia, we need be involved in all aspects of its design, development and implementation. Our lived experience should inform the groundwork of any procedure, program, or device that purports to help us live our lives.

Dementia as A Disability.

Dementia has been recognised as a disability by the United Nations. As such people with Dementia have the same human rights as any other person with a disability under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Governments and many professionals have been slow to realise the implications of this. Indeed, many professionals do not see Dementia as a disability and continue to dismiss its true impact.

The OECD¹ stated that *‘people living with dementia receive the worst care in the developed world’* (2015). Today it is still rare to find people living with Dementia represented at disability conferences. Some forms of Dementia are listed by the NDIS but by no means all.

As a disability, people with Dementia may have many impairments, most of which will not be “visible”. It is commonly believed that if a ‘program’ or ‘thing’ is developed to be truly Dementia enabling, it will be inherently enabling to almost all disabilities.

It is also important to note that many of the impairments a person with Dementia may have, while similar to a ‘mainstream’ impairment may be vastly different in cause and ‘treatment’.

Consider hearing. Many people will exhibit hearing changes as they age. This is often due to degradation of the sensory system i.e. damage to the mechanisms of hearing or nerve damage. In many cases a simple hearing aid can remedy the condition. A person with Dementia may exhibit similar

¹ The Organisation for Economic Co-operation and Development

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symptoms of difficulty in hearing. Introducing a hearing aid will more likely make the problem worse because the true problem may not be in how the auditory information is received or transmitted, but in how it is processed in the temporal lobe of the brain.

Dementia and Human Rights.

As mentioned, Dementia is covered by the UNCRPD, and receives the lowest recognition of all the disabilities. A very good and easy to understand definition of Basic Human Rights, is to say that 'Our rights are violated when our human dignity is lost'. Dementia does not take our dignity, it is taken by other people's attitudes, actions and inactions. These circumstances are often brought about by poor understanding and many misconceptions that have become ingrained into society.

The Brain and Commonly Recognised Symptoms.

At the risk of making a pun, let us get our head around the brain. I know I want to keep mine in there as long as I possibly can, then I will donate it for research. The brain is the most complex organ in our bodies. Some people even believe it to be the most complex object in the known universe. The following diagram (*Figure 1*) is a common and simplified representation of the brain. It is important to note that while it is divided into a number of discrete 'lobes' there is no 'hard' boundary between them, they are interconnected and as we increase our understanding can be subdivided into smaller and smaller functional areas. Ultimately, we can get to the cellular level and describe individual Neurons (*Figure 2*). It is also important to note that the brain contains many other types of cells that are essential for our functioning.

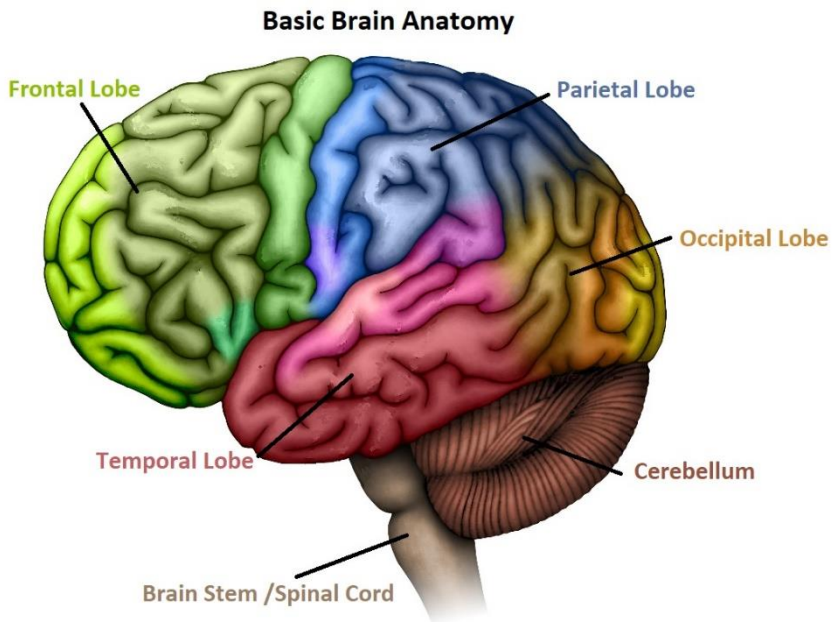


Figure 1: Basic Brain Anatomy

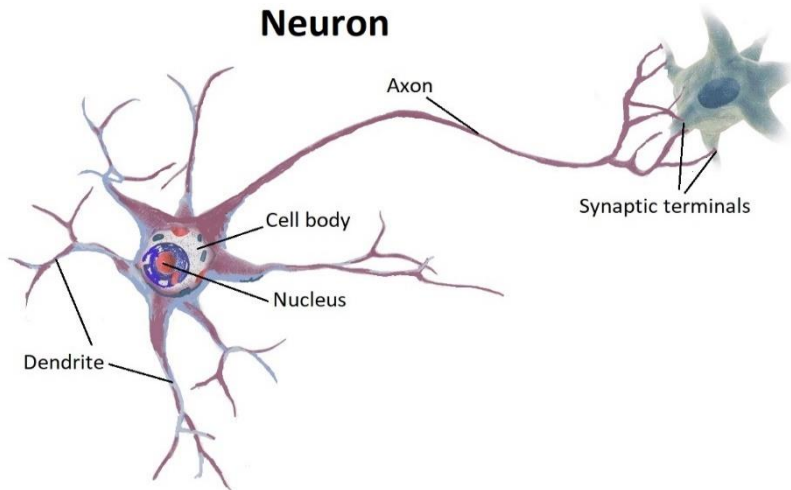


Figure 2: A Stylised Neuron

Often associated with Dementia is the formation of tangles and plaques from dead neurons (*Figure 3*). These Amyloid Plaques accumulate in the spaces between neurons.

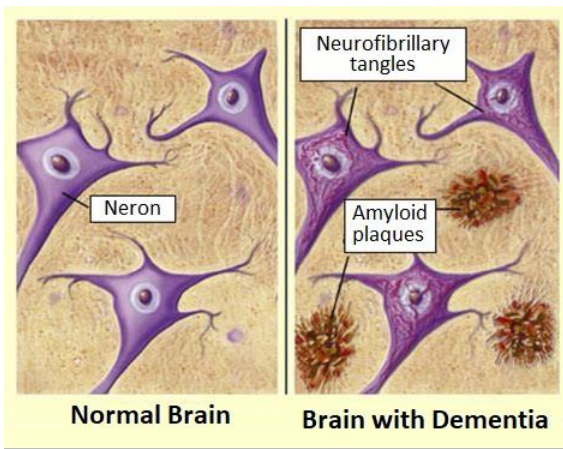


Figure 3: Amyloid Plaques and Tangles

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The result of these accumulations can result in 'shrinkage' of the brain (shown in *Figure 4*), this is commonly verified by autopsy.

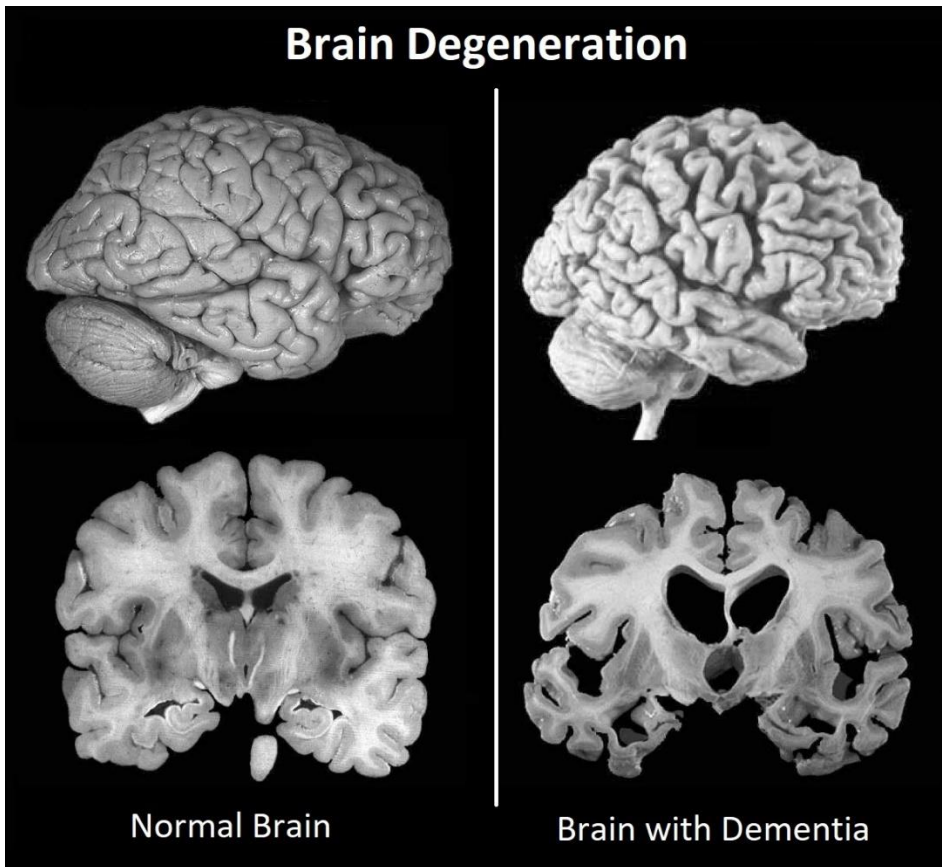


Figure 4: A comparison of a normal brain and a brain with Dementia

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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	Repeating same actions and comments without conscious awareness of doing so.
Inhibition of behaviour	Loss of flexibility in thinking.
Planning and anticipation	Distractibility.
Self-Monitoring	Mood swings.
Personality	Diminished abstract reasoning.
Emotions	Difficulty with problem solving.
Organisation	Difficulty in finding and correct usage of words.
Concentration	Loss of simple movement of some body parts
Expression of language	
Smell	

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

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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.
Musical awareness	Short-term memory loss.
	Impaired long-term memory.
	Aggressive behaviour.
	Changes in sexual interest.
	Persistent talking.
	Difficulty in locating objects in the environment.
	Inability to categorize objects.

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

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Occipital Lobe.

Functions Include:	Some Symptoms of Impairment:
Vision	Impaired vision.
Reading (perception of written words)	Difficulty in understanding the meanings 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.

How Our Senses Might Be Affected.

As a general observation, there is little direct impact on our “physical” senses. That is to say, the cells and mechanisms that “sense” our environment, such as touch receptors, are largely intact and function as they did. The problems occur in the brain where this sensory information is processed and interpreted.

As an example, let’s consider our sense of hearing. We experience much of our world through this sense and it plays a big part in communication.

Most people are familiar with the outer, middle and inner ear (*Figure 5*) but are unfamiliar with how the inner ear or cochlea connects to the brain via the auditory nerves (*Figure 6*).

The sound information from the cochlea travels via the auditory nerves to the

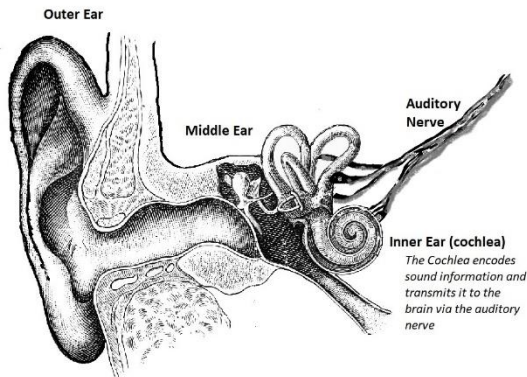


Figure 5: Sense of Hearing - The Outer, Middle and Inner Ear.

cochlear nucleus in the brainstem. From there, the signals travel to the inferior colliculus in the midbrain. The inferior colliculus integrates auditory input with limited input from other parts of the brain and is involved in subconscious reflexes such as the auditory startle response.

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The inferior colliculus transmits to the medial geniculate nucleus, a part of the thalamus where sound information is relayed to the primary auditory cortex in the temporal lobe. Sound is believed to first become consciously experienced at the primary auditory cortex. Around the primary auditory cortex lies Wernicke's area, a cortical area involved in interpreting sounds that is necessary to understand spoken words.

The Auditory Pathways

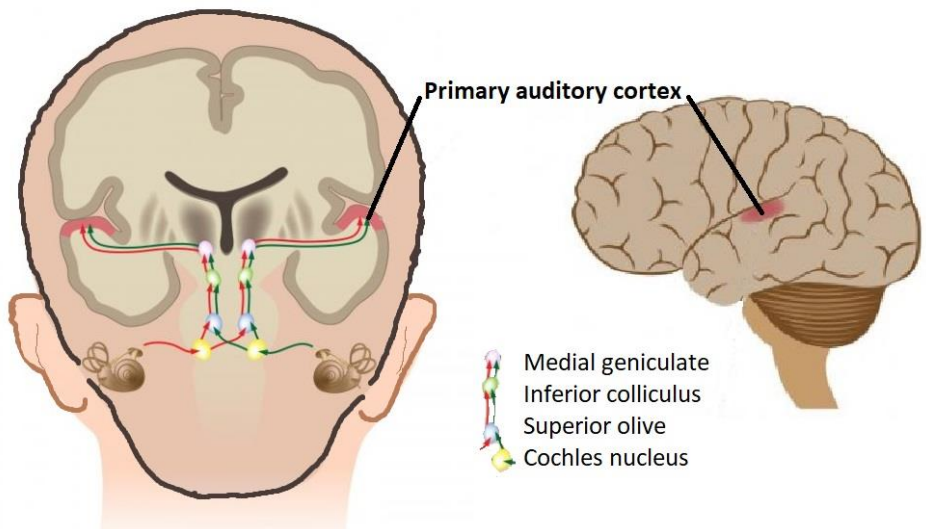


Figure 6: Sense of Hearing - The Neural Pathways.

Disturbances (such as stroke or trauma) at any of these levels can cause hearing problems, especially if the disturbance is bilateral. In some instances, it can also lead to auditory hallucinations or more complex difficulties in perceiving sound.

With degeneration of the brain as a result of Dementia particularly the temporal lobe, aspects of how we perceive sound can be compromised.

Commonly people with Dementia may show distress when they experience loud noise or certain frequency sounds. This reaction is not because these triggers are exceptional (most people without Dementia would be

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comfortable or not even aware of these triggers), but because of how this information is processed in the temporal lobe.

A visual analogy to how our senses may be affected is illustrated below. In this example I am taking a 'normal' image and separating its colours out into Red, Green, and Blue channels, then recombining them to give the original image. This is analogous to how we might process separate sensory inputs in our brain to arrive at a resultant interpretation.

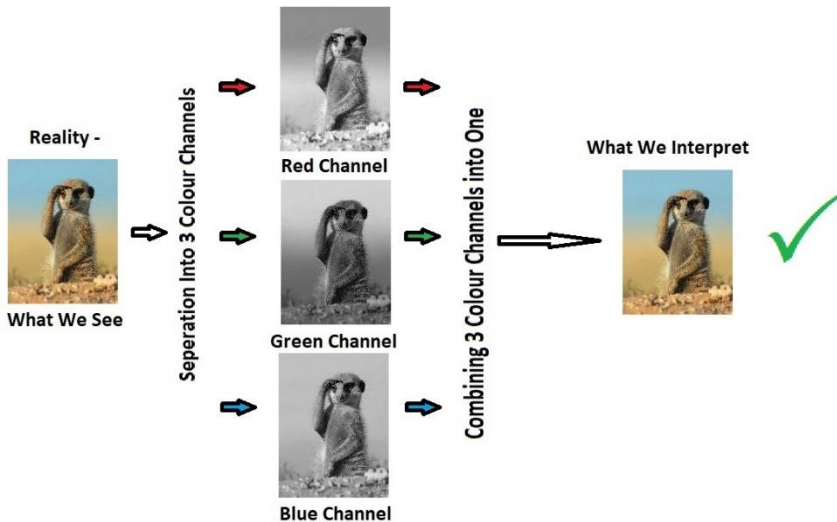


Figure 7: A Normal View of an Object

The second image shows what might happen if one channel is corrupted or mis-processed. The result being it becomes a little bit harder to interpret the world.

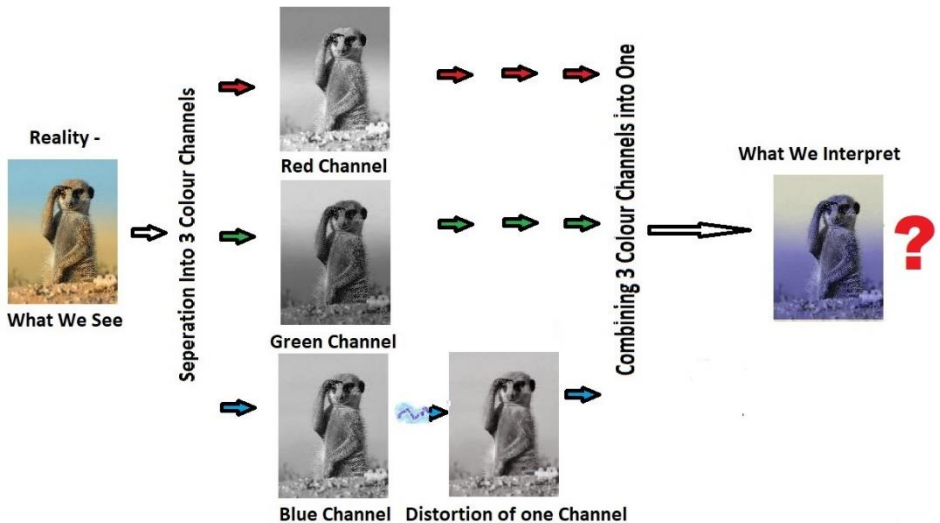


Figure 8: What We Might See with a Distorted Sensory Perception

The result in this example might be that it takes us longer to interpret the image of the Meerkat in the image, or to consider briefly that the Meerkat may be in the sea, rather than the Kalahari Desert.

Coming to Our Senses.

What is a sense? It is a physiological capacity we have, to provide data about the world, for our perception. Senses enable us to both make “sense” of the world and function as an organism.

Commonly we can think of our senses as a series of specialised tissues that react to the environment, encoding data that is transmitted via nerves to our brains, as illustrated above (*Figure 6*). Some of our senses may be far more complex than this simple model and be dispersed throughout our bodies, or even use chemicals to transmit information.

How many senses do we have? Compared to how much sense we have? Is an interesting set of questions. I’ll ignore the second but make you wonder about the first. As children we are often taught that we have five senses; sight,

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hearing, touch, taste and smell. This is a simplified view. Some of our senses can be broken down into separate but related senses. For example, consider our sense of touch, it can be separated into several different sense areas, such as pressure, pain and heat.

We are all aware that some other animals sometimes have can sense things we cannot or use their senses in ways we don't normally. To illustrate what I mean by this consider the following examples. Sharks and many marine creatures can sense electric fields. Many insects and birds can sense light in the ultraviolet band. Elephants can 'hear' infrasonic sounds with their feet. Birds can sense the Earth's magnetic field and use it for navigation and Bats can use ultrasonic sound to 'see' the world (echo location). This list could be expanded to fill several books. Given this "extra-sensory" concept our human senses might be more complex than you first thought.

The following list separates out our "common" senses into several functional areas that better define them and will better enable us to understand some of the impacts of dementia. It is important to realise that in order to make 'sense' of the world, the input from these senses is interpreted and combines in different regions of the brain, and this is often where our problems lie. See the section, ***To Make Sense, It's Not Just One Sense!*** (on page 35).

Sight:

What we see with our eyes. Shape, colour etc.

Taste:

We taste mainly with our tongue, but taste-buds extend beyond our mouth. We are familiar with sweet, salty, sour, and bitter tastes. Umami is a fifth taste only identified recently.

Touch:

This is distinct from pressure, temperature, pain, and even itch sensors. We think of our skin being our main organ of touch. Touch implies contact.

Pressure:

Obvious but hard to explain. If you like, pressure begins to quantify the force of touch, but it may not involve a physical contact.

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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 our ear drums. This is fundamental to our ability to communicate with others. Because we also hear in stereo, we can use this sensory information to help locate objects in space.

Smell:

Our olfactory sense. When combined with taste pretty much describes our food.

Proprioception:

This sense gives you the ability to tell where our body parts are, relative to other body parts (e.g. 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 us to keep our 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.

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Chemoreceptors:

These trigger an area of the medulla in the brain that is involved in detecting blood born hormones and drugs. It is also involved in the vomiting reflex.

Thirst:

This system allows our body to monitor its hydration level and so our body knows when it should tell us to drink.

Hunger:

This system allows your body to detect when we 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 us 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;

Justice

Very relevant to our sense of self and dignity – our sense of Justice. This may just be the most important sense of all.

Sensory Challenges.

The challenges we face with the changes to the way we experience the world though our senses fall into the following areas;

- They vary between individuals – even with the same diagnosis, depending on the exact ‘micro’ regions of the brain that are affected.
- They change with time. Generally, they will become worse as our conditions advance, but it is important to note that their severity may depend on many things that are happening to us. For example, if we are tired some problems will become more severe.
- No-one can predict the next change, either its nature, its timing or its severity.
- These complex mechanisms are poorly understood. As such many of our problems are dismissed or we are referred on for further testing to rule out all the obvious well-known causes.

What complicates matters more, is that because dementia is diminishing our communication skills, memory, motivation and abstract reasoning skills, we may be unable to clearly articulate what is happening to us. Unfortunately, our attempts to express these changes and the changes themselves are often interpreted as ‘behavioural issues’. Actions based on this erroneous interpretation are infringements on our basic human rights, even when enacted with the best intentions or ignorance.

In short, we don’t know what to expect day to day and our concerns are often dismissed.

The Duck Analogy.

Our cognitive impairment generally means that we must put in an increasingly greater effort to carry out normal tasks, let alone more complex tasks. This often means it may take very little extra stimulation to push us to breaking point. This is further compounded by some of our other symptoms of impaired judgment etc.

We may appear to be coping and functioning normally, but behind the scenes we are using far more of our cognitive reserve to maintain this state. We are

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much like the duck on the water, that appears placid and in control of itself, but under the water its legs are paddling furiously just to maintain its position.

My Lived Experience- To Date: Observation and Solutions.

I now will share with you my experience with Dementia, and some of the coping mechanisms I have discovered. What follows is not only reflects on my experience, but that of others all with their own form of Dementia.

This will be sequenced chronologically according to when I became aware or experienced the challenges. This may reflect on how my Dementia is progressing, but also keep in mind my sense of time is altered and my memory is sometimes dispersed.

Facial Recognition.

I'll begin with this area, even though it's not a sense it will illustrate some of the complexities of Dementia. This is what began my journey with Dementia. Over a period of a couple of months I realized that I had difficulty in recognising my work colleagues. It occurred to me that I was basing my recognition on their voice, how they dressed, their location and even on how they smelt, but not on their faces.

This led me to my GP and then the torturous path to a diagnosis of Dementia. I encountered several health professionals (and I use that word lightly) that dismissed my concerns. I now know that about 5% of the normal population have this problem. It is more correctly referred to as **Prosopagnosia** or face blindness.

I am involved in a longitudinal study that in part maps the progression of my impairments. As part of this I have annual 'testing' to measure among other things my ability to identify peoples emotional state from their faces. When for example I see a face with a smile on it, I don't see happiness, I see a person pretending to be happy, a person trying to deceive me, in effect an actor.

I find this interesting, because I'm the one that is supposed to have the problem, but I can see more clearly the underlying emotion in these cases.

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In everyday life this prosopagnosia poses many social challenges. I identify most people by all the features unique to them, not their faces. I suspect most people are using similar techniques for identification but are unaware of it. Most of my friends are aware of my condition and often offer additional identifies voluntarily. For example, I have one friend (who I usually easily identify) who tells me she always wears the same perfume when she knows she will be seeing me.

One interesting consequence of this condition is how store “greeting staff” appear to me. Their smiles – generally ear to ear, appear totally false to me. I see a person who is out to deceive me, as such I will ignore them. To me this is no were as rude as the outright lie they are acting out. In one case when they were particularly persistent and annoying, I reported them to their management as they appeared to be acting as stalkers rather than employees.

Another consequence of this is that I will occasional identify a person from a distance based on their walk, style of clothing etc. Sometimes this will divert my attention while I try and gather more information to make a positive identification. This is often the case for people I have not seen for some time.

It also manifests itself sometimes as a ‘super-power’. I have identified people in crowded environments purely from the style of their hair when viewed from behind. I have done this on several occasions, while ‘normal’ people are still trying to see the faces in the crowd.

Smell and Taste

Changes in my sense of smell were the first challenges I noticed after my diagnosis. I became acutely aware of this when we were out browsing some boutique shops. In a row of about 1 dozen shops we were making our way through each shop sequentially, some we merely looked through the window and dismissed them of no interest, others we would enter and explore. I began to notice an odour that became more intense as we progressed though some of the shops. About three shops further on we encountered a craft soap shop. The odour was so intense that I couldn’t enter, indeed I had to walk away to find fresh air. No one else noticed it, indeed they were unconcerned.

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The only way I can describe the scent is as sickly sweet. To me it was overpowering and caused distress. I now find this reaction to many perfumes and cleaning products. Lately I find the intensity of this reaction to be diminished, not as overpowering as it was, but still powerful enough to cause me distress. But I find the number of odours to which I am sensitive to be increased. This has another impact I will discuss shortly.

My sense of taste is slightly diminished, but more importantly my ability to combine smell and taste to interpret food is severely compromised. Indeed, it is best to say these two senses we use together to derive pleasure from our food are interpreted as acting independently for me. When I place food in my mouth and eat, I am aware of its taste (sweet, bitter, sour, salty or umami), its texture, and its temperature. The aroma is a separate sensation, and I can't associate the aroma with the food in my mouth.

The result is food is either tastes bitter or sweet. Who enjoys bitter food with no other flavour? For example, a common food like lettuce tastes bitter to me. Any pleasant lettuce odours (if there are any) are lost on me. As such I have developed what I believe is a perfectly understandable preference for foods that are more sweet than bitter. This has led to some complications such as a diagnosis of Type II Diabetes.

My solution to this (and I have tested negative for Type II Diabetes for two years now) was to replace my favourite sweet marmalade for a muesli style cereal with added fruit to provide a sweeter taste.

Touch.

Again, changes in my tactile sense was something I identified early on and something that was disregarded by a neurologist. Sometime ago I placed both my hands, palm down and side by side on a woven placemat. As I brushed the fabric (about a 1mm weave) I realized I was getting a different impression from my left to right hand. I rotated the mat to rule out variations in its weave. This confirmed my impression that the difference was not the mat, but in how I was processing the tactile input. I have repeatedly confirmed this anomaly across many objects. For example, sitting here now I can rub my thumb against my forefinger on each hand and have different sensations of

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roughness/smoothness between hands. This bilateral tactile asymmetry extends to my feet.

I had mentioned this to both my GP and to my Neurologist. My GP confirmed my observations but the Neurologist, while accepting them dismissed them as of no concern.

Related to this is my ability to properly grip some objects for example knives and forks. Around the same time, I began to drop these normal objects, with the realization that they just didn't feel right. They all seemed too light and small to hold properly. Note that I had been using this cutlery for 10 or more years without incident. The solution was relatively simple, we purchased a new set that was slightly thicker and a little heavier. This now feels more comfortable and natural in the hand as I have not dropped an item since then.

Sight.

Wearing glasses, I have annual ophthalmology examinations, as my vision is excellent. I can spot a fly on a wall at 100 metres and tell you how many legs it has. Sight is a major sense that helps us navigate our way and communicate with others. I'll now offer you some observations about my experiences with this sense.

Firstly, I'd like to discuss lighting and navigation. My ability to navigate the familiar environment is good, but I noticed that in situations of dim lighting or strong contrasting shadows and light, I am hesitant and will often rely on touch for stability and to aid in navigation. I recently spend a relatively large amount of time (several minutes repeated several times a day over several days) trying to find a familiar object in a 'messy' cupboard, with no luck. Then a day or two later, when I awoke in the morning at 5:30 I thought I would have another look. In near complete darkness, (the only illumination was from a LED on an internet router) I walked to the cupboard, reached in and picked up the object. I have shared this with many people with Dementia and many have similar experiences. It appears that either darkness or good even lighting pose no problems, but deep shadows or reflective light does.

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I resolved much of these problems at home by replacing all the old energy efficient fluorescent lights with equivalent LED globes. They appear not only to be much faster acting but provide a slightly brighter and more uniform light.

People have told me that people with Dementia don't like mirrors. This is often followed with some fanciful reasons they use to justify this belief. What the issue is, is not the existence of mirrors but the placement of mirrors.

I find unexpected flashes of light to be highly distracting. Because the flash is by its nature momentary, I can't readily associate it with an object. I will often spend a lot of conscious thought on ray-tracing to identify the likely source of a flash. Most normal² people would not need any effort to do this or more likely dismiss the flash, but not necessarily so for people with Dementia. We need more cognitive processing to do the same and therefore it may become a conscious effort. This is a big issue for me when I see a 'flash' of light reflected in my glasses from behind.

The reaction also depends on the environment and expectations of being in that environment. Sitting at home, I would anticipate such events to occur at particular times of the day. In that environment I have no problem in assigning the cognitive effort to solve the puzzle. If I was driving, I would have different expectations and generally dismiss such an event.

It is also worth noting that the technology used in modern cars has gone a long way to minimise things like this occurring. Most cars will auto-dim headlights, my driving mirror will auto tilt to reduce refracted light. Dashboard lights auto-dim to adjust to ambient lighting.

Thermoception.

A couple of years ago I was preparing some food on the barbeque. I remember dropping a cooked prawn back onto the hotplate, then picking it up with my fingers to test. When I put it in my mouth, I realized it was hot. I hadn't noticed that the barbeque plate was hot when I touched it. I now realize it takes me a bit longer to determine by touch if an object is hot or

² By normal I mean people who are not yet diagnosed with Dementia.

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cold. My solution is now to be more cautious in environments where I expect to encounter heat. For example, around ovens.

However, this is not always practical. I have just conducted a little experiment using a hand-held infrared thermometer. The outside air temperature according to the Bureau of Meteorology is 32°C. My reading is 34°C for the outside temp 26°C inside. Being a pleasant sunny summers day, I have done all the washing (most things got dry in about 30 minutes). The clothesline is located on the back lawn and accessed by a 3m concrete path. I have just taken some temperature readings around there, and the lawn returns a temperature approx. 44°C while the concrete path returns temperatures ranging from 54°C to 58°C. The hottest spot coincides with where I stand to take down the clothes from the line, barefoot. It would normally take three to five minutes of standing before I begin to notice how hot the concrete is. On several occasions I have received minor burns on my feet, because I haven't sensed the heat until it was too late. I am not, nor ever have, or will ever be in the habit of putting on shoes to walk the 6 metres to and from the clothesline, nor would I stand on the grass because of the odd bindii³.

Recent research conducted at residential facilities suggest that people with Dementia are less stressed and less agitated in areas that are in the range of temperature between 20°C and 23°C. The same research also discovered that staff performed better under these same conditions.

Thirst and Hunger.

Similarly, a few summers ago I spent about three hours working in the garden. It was a pleasant day not too hot with temperatures in the low to mid 20's and a slight breeze. When I came inside in the late morning, I realized I was not thirsty. I was conscious that I had been perspiring and should normally be thirsty. So, I drank some water. It was only as I began to drink, that I began to feel thirsty. (I wound up drinking about 1 ½ litres of water).

Likewise, I rarely feel hungry until I begin to eat. This often is a problem because that feeling of fullness doesn't occur till well after I've eaten. This

³ The Bindii is a small sharp spiked plant that commonly infest lawns and walkways.

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makes it very easy to overeat. My partial solution to this is eating at set and regular times. This works very well at home, but when I'm out it is rare that I can eat at my regular time so, I will often miss a meal under these circumstances.

Itch.

Increasingly parts of the body are becoming itchier. Itching is not continuous but seems to be more pronounced when there is a change of state or activity. For example, after first rising my whole body begins to itch. This persists though breakfast usually until I begin the day's activities. Its timing is best characterised by being present during periods when there is little 'mental' engagement in a task and reduces when I become engaged in an activity.

Time.

Perception of the passage of time impacts on many diverse aspects both of our physical being and our social interactions. For example, when interacting with others, if our perception of time spent waiting is distorted it will intensify our frustration and boredom.

Perceptions of the passage of time is a multi-edged sword for the following reasons.

- Most people with Dementia are aware that it is a terminal disease, and their time is limited. As such a few minutes 'wasted' waiting for someone or something is a measurable amount of our remaining time on earth, and gone with no return.
- Because we know we have impaired short-term memory, we realize that we may forget the purpose of our waiting and become frustrated. This is a real problem with conversations. When one person is dominating a discussion, we may become agitated and frustrated because we realize we will likely forget our contribution.
- We may have difficulty in planning and sequencing steps in a non-trivial task. This may lead to delaying an activity, that could further confuse the task.

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- We may have impaired motivation. This may compound frustration when we have a distorted sense of the passage of time. (I'll get around to explaining this tomorrow, well sometime later).

To give a real and personal example I sometimes encounter when cooking. Occasionally I will get some of the preparatory tasks out of sequence and on rare occasion have missed a key ingredient, such as the coffee in a cup of coffee, or the yeast in bread. These are all 'learning' experiences, but the biggest problem and source of frustration is timing, particularly when baking. If I stay in close proximity to the oven and can watch it for the required time, things turn out OK. However, if for example the bread requires 30 to 35 minutes to properly bake, I find that amount of time too long to do nothing as it were. I will usually, go and do something more engaging such as check e-mail and plan to return and check about 5 minutes before the required time. Quite frequently I will become engaged in what I am doing and lose track of time. This usually results in a rush/panic at the end and occasionally in a 'burnt offering'. I find using timers etc to be of little value, because they require me to be near them and/or give them my attention, which is more boring/frustrating than just watching the oven in the first place.

My best solution to this problem is to have my partner check the ovens progress near the appointed time and for her to remind me of its status.

Magnetoception.

Magnetoception is poorly developed in humans. Most people would have no functional awareness of this sense. I have very good spatial awareness and can generally locate myself very well in three-dimensional space. In the early 1980's when I first travelled to the U.S.A. I realised I was having difficulty in orientating myself. I was able to account for cultural differences, the language differences and even the fact that they all drove on the wrong side of the road. I soon found and adopted a simple solution. For example, if I was going to go to the North, I would orient myself to what I believed north was, then go in 180° – the opposite direction. This worked remarkable well.

More recently in Budapest I experienced the same issue but this time I had Dementia. The sun and moon both appeared to rise in the wrong direction.

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This made me recollect my previous experiences in the Northern Hemisphere and a similar experience I had recently in Longreach, QLD. Everything in Longreach was on the opposite side of the street to how I remembered it from the past. This made me think, what does Longreach in the Southern Hemisphere have in common my experiences in the Northern Hemisphere. My answer and explanation relate to the angle the lines of the Earth's Magnetic field have. In the Northern Hemisphere their polarity is reversed and in Longreach while of 'normal' polarity, they are much steeper than at home because Longreach lies on the Tropic of Capricorn (~23° South whereas home is ~35° south).

I believe my disorientation is due to the differences in the Earth's magnetic field. I may be wrong, but nobody can offer me an alternative explanation, yet alone a better one.

Sound and Hearing.

My hearing is relatively normal. That is to say, I can hear pretty much over the normal range of volumes and frequencies. My problems are not uncommon among people with Dementia.

Loud sounds are not a problem, though my preferences for things like a Television or radio is to have the sound turned down, generally a little lower than other people would. This does aid me when someone speaks, it makes it easier for me to distinguish them from the background sounds. Now a very necessary exception to this practice is music. Good music needs to be played loudly! Unfortunately, very little good music has been produced since the 70's.

What I do find distressing is sudden and unexpected loud noises, such as the sound of a glass being dropped on the floor. Likewise, low level reflected sounds you commonly find in restaurants when sound is being reflected from hard surfaces can become distressing. In my conversations with other people living with Dementia, this experience is not uncommon, though rarely recognised by others.

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A few lucky individuals I know, have received a diagnosis of Hyperacusis⁴. Simple put this means we have an increased sensitivity to some frequencies and volume ranges of normal environmental sound. It results in some common everyday sounds becoming painful and loud, resulting in anxiety, stress and phonophobia.

The coping mechanism we adopt is avoidance behaviour, which means we often avoid some environments and social situations.

The only people I know aware of Hyperacusis are people living with Dementia. One implication of this lack of awareness in the general population, is like so many other symptoms we have, we are not believed and dismissed. Just because it doesn't affect you doesn't mean that it doesn't affect us or cause us pain.

Our level of distress is often increased because those around us are unaffected by these sounds, (sometimes they may actually and unknowingly contribute to them) and often downplay our real distress.

A simple solution that was suggested by a professional involved a hearing aid. This amplified all sounds, removed any directional information and in general not only made the situation worse but added more problems. (See ***The Role of Technology***. Page 42)

Nociception, and Levels of Pain.

I have a hobby of building a 1/87th (HO) scale model railway. One common activity involves the use of sharp knives and scalpels to cut and shape plastics and wood. I sometimes find myself about to drop a small part and realise that it is slipping from my fingers because of the copious amount of blood seeping from a small cut that I was until then unaware of. Fortunately, even though I take low levels of blood thinners I usually stop bleeding quickly.

It often takes some time for the sensation of pain to occur. This is particularly the case when I am fully occupied on a task. Also, things that may have once

⁴ Hyperacusis (or Hyperacusis) is a recognised debilitating hearing disorder, occurring in between 4% to 15% of the population.

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caused at least a stinging sensation or a short stabbing pain such as having a needle inserted to draw blood, now rarely cause any pain-like sensation. Even though I can feel the pressure of the needle on my skin, the sensation of it piercing my skin, and it being stirred around in my arm, (in an attempt to find a good vein) I don't feel the pain. The only pain I feel is when I remove the dressing latter. For that reason, I generally decline adhesive dressings as my blood will generally do a good job of clotting within about a minute or so (it gets a lot of practice!).

As I also have arthritis, I am often asked about pain levels. Health professionals now all use an imaginary scale of pain, 1 to 10, where 10 is the most severe pain you can imagine. I find this a little amusing because a supposed commonly occurring symptom of Dementia is a reduced or impaired imagination.

I often confuse them by asking them, "how do I compare two different types of pain"? One being a very intense but short duration pain such as hitting your thumb with a hammer, and the other being a very low intensity pain just above the threshold of feeling, that persists for long periods of time. The following diagram (*Figure 9: Pain Intensity and Time*, page 31) illustrates this idea.

The blue line illustrates a short (15 to 30 minute) high intensity pain episode. In this example, I've repeated it twice at reducing intensity after 4 to 5 hours. Compare this to the orange line that fluctuates over a very low level but continues for 24 hours. The higher intensity pain is approximately 10 times the level of the low intensity pain, similar to the concept of the pain scale. Now if we integrate the areas under both curves, the area of long acting low-level pain is 20% more than that of the short intense pain.

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Clearly, the continuous low level of pain, cause more pain over the day than the intense pain.

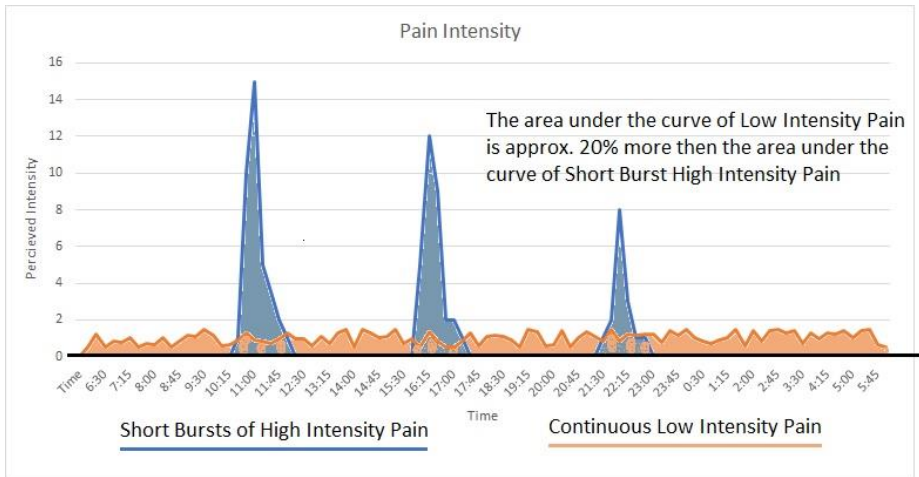


Figure 9: Pain Intensity and Time

I currently experience an almost continuous level of low-level pain. Its small fluctuations are generally enough to break my sleep.

Motivation.

Apathy or loss of motivation is a symptom commonly reported with many forms of Dementia. It is due in part to degeneration of parts of the brain associated with motivation and reward. Another big cause of loss of motivation relates to the realization of our increasing limitations.

I now find it very hard to get motivated to some things I once was good at. For example, I have been planning to lay about 1m of additional track on my model railway for about 2 years. I have done a lot of the preparation, but I find it very easy to get diverted to some other project. One reason that robs my motivation is the knowledge that some of the tasks I once performed without difficulty such as cutting the track and fitting and aligning the new section, adding electrical connections and control circuitry now pose major challenges for me. My fine motor skills have deteriorated, this impacts on tasks such as soldering the track and electrical connections. I also know it is increasingly difficult to sequence and co-ordinate all the small component

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tasks. Most of these things I would have done on the fly, without a lot of planning, but now are near overwhelming. As such, why bother?

Simply put, the realization of my increasing limitations decreases my desire to test them.

This does not mean I will not find the motivation, just that it is harder and takes longer.

Balance.

In a well-lit and uncluttered environment, balance is not a problem. It is easy to move around unhindered. When the environment is familiar and the lighting is poor, a couple of touch points can restore any disorientation and balance issues.

The real challenge comes with changes in elevation and turning. Bending down to retrieve a cup from a cupboard stresses my balance, as does abrupt changes in direction when walking. Likewise, standing after a period of sitting, can be disorienting, especially in low light.

Climbing a ladder is almost impossible. The impact of a couple of rungs on a ladder on my Cochlea (see *Figure 5*) should be minimal. The issue probably lies with my Cerebellum (see *Table 5*). Sensory inputs are not being possessed or interpreted normally or quickly enough, giving rise to conflicting sensory interpretations of the world. The duck is paddling frantically, just to stop falling!

Noisy Environments, Sensory Overload and Confusion.

In quiet familiar environments most of my sensory challenges are minimal and require very little adjusting too. This goes well beyond just being at home, there are many other locations, less frequented that are familiar (or familiar enough to be non-threatening). Problems can occur anywhere and can be escalated by noise, too much sensory stimulation and conflicting messaging.

Noise is not just limited to confusing audio stimulation (see *Hyperacusis page 29*), but also includes;

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- Visual noise. A cluttered environment or light and images being reflected on surfaces (including mirrors and other shiny objects).
- Olfactory noise. Smells or odours that are out of place or too strong. For example, many people seem to bathe in their favourite perfume and are oblivious to the fact that 'less is more'. There are also several horse studs located 2.5 to 3 km east of home. When a gentle breeze blows from the east I can smell horse (particularly horse urine). No one else notices this but it is enough to keep me from spending too much time outside on these days.
- Unclear messages. This comes from two areas, signage and verbal communication.

Sensory overload can occur across the senses. It is simply too much information coming in to be processed easily. A good analogy could be giving too many instructions for a task. Sometimes the fine detail may be required, but the objective can be lost in the details given. Like a house of cards, one misinterpreted detail renders the whole process a shamble.

Excessive noise of any from makes it harder for the neurological processing of the sensory data and often results in a confused interpretation of the environment. This may, itself be disorienting and increase confusion and stress.

What may be overwhelming and noise to a person with Dementia can present no problems for someone in normal health. This doesn't lessen the severity or impact for the person with Dementia.

Familiar Environments and Change.

What makes an environment familiar?

Home is familiar, things change, but change is slow, usually planned and anticipated.

Some Cafes, restaurants and retail outlets are familiar, and hence comfortable. A change in décor or staff (see **The Role of People. Page 42**) can destroy this familiarity and comfort. Given a choice keeping with the familiar

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is the first option. I'll discuss this more when I talk about the role technology can play (see ***The Role of Technology***, page 42).

Contrast this for similar places. I often travel by air and invariably have difficulties navigating these environments. I have no problems with wayfinding just negotiating the variations on procedure and instructions between different airports. The principles of layout and design is common across most airports, but how some procedures are implemented varies greatly between airports.

The Impact of Time of Day and Tiredness.

All the impacts of Dementia are amplified and become more apparent when we are tired. This is simply because we have exhausted what little cognitive reserve we have, reducing our capacity to deal with normal sensory inputs. Tiredness can be brought on by the time of the day or by exhaustion. Generally, we all feel tired after a long day, and can become exhausted because of physical, emotional, or cognitive exertion.

Another observation is that we seem to fall into one of two groups, those who rise and function early, or those who rise and function later in the day. A simplistic classification, but some do appear to be at the peak of their performance mid-morning and other mid-afternoon. What unifies us is that our functional day is shorter, we become tired quicker than we did before our diagnosis.

This may be noticeable in changes to our sleep patterns.

Sleep.

I find it very much harder to compensate for late nights and broken sleep patterns. I have only been able to "sleep in" twice in the last six years, both times it was after long flights. It is interesting that some aspects/abnormalities of sleep have been linked with Dementia. The nature of that link is highly debatable as yet, but it is something to consider.

Another interesting observation is that the busier I am doing something meaningful, the better the quality of sleep. My most exhausting days are those days where I have nothing to do. Not only are they draining, but sleep

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quality is minimal. Contrast this to a day where I am busy, either carrying out a meaningful task at home, or traveling and speaking publicly about my experiences. I would be active for far more hours in the day, not feel exhausted and have better quality sleep.

The hard thing is that Dementia robs me of much of the choice of the type of day I can have.

To Make Sense, It's Not Just One Sense!

Most people when given the granular list of 20 or so senses are initially sceptical that we could have more than the 'traditional' 5 senses. Some research groups suggest that the number of individual senses could be near 30! What I was trying to do with this list, is reflect the increased knowledge about brain function and how brain anatomy relates to sensory interpretation.

We have evolved the 'most complex' organ in the known universe to enable us to better understand our environment and to interact with others of our species. To this end, our brain does not interpret sensory input in isolation. We work with all our senses together to better make sense of our environment. Imagine a 'caveman' peering into a dark forest. Are those stripes he can just make out a potential dinner in the form of a Zebra, or are they a Tiger that has him on the menu? Does it sound like a Zebra? Does it smell like a Zebra? (*If the Zebra was smart it might evolve an odour like a Tiger to confuse our caveman*). We rely on interpreting our senses together to help with our survival.

Now, let's take an example out of my experience, food. Take a humble chocolate biscuit and separate out our sensory interpretation of it.

How does it look? It has a chocolate colour and the right shape. Imagine if it was green? I think you would think twice before eating it.

Does it smell like chocolate? Not everything that has a chocolatey colour will taste like chocolate.

Now we take a bite. What is its temperature? Is it nice and cool or hot straight from the oven? Is it pleasant or will it burn us?

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What sound does it make? A nice crisp crunching sound or the sound of a soggy piece of bread? What texture do we feel in our mouths as we chew?

Now the flavour. Is it sweet? A sour 'chocy' biscuit would not be expected.

Now as we chew most of the flavour of our chocolate biscuit is coming from our sense of smell.

All these sensory inputs go toward us enjoying our chocolate biscuit. Now what happens if one aspect is out of synch or does process normally? For example, what if our brain doesn't synch the olfactory data as we chew with the taste? Our biscuit has lost most of its flavour!

Now to ask that 'Shakespearean' question "*Would a rose by any other name smell as sweet?*" I think not. Especially as we would have to taste it (thorns and all) to get the sweet sensation.

To summarise, our senses are interpreted together, and a 'corruption' with one may impact across others and impair our experience of the environment.

Conditions like Hyperacusis (*page 29*) exist and affect a significant part of our population, and presumably similar conditions exist across all our senses. The conditions seem to be more caused by neural degeneration, than physical sensory receptor damage. The implication being people with Dementia, and other degenerative conditions of the brain would likely develop these conditions. Yet this group of people would likely have their dismissed because they have Dementia. An idea contrary to logic and the UNCRPD (*page 4*).

Language and Communication.

Language and communication cover a wide area that both involves sensory inputs and interpretation, memory and a wide variety of cognitive skills and motor functions. All things that are affected by Dementia.

My abilities in this area are slowing becoming more of a challenge. This is very apparent to me, but it is often downplayed by other people. This is for two reasons, firstly (this is me being kind) they don't know me or have had enough experience with me to see the changes. Secondly (and this is me being

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honest), they don't see any problems with my language as I still have a deeper and wider vocabulary than them and can often better express myself.

I find it now better, but not necessarily easier to communicate through more than one medium, for example I often will produce small videos and animations to explain a point and am now trying to record some audio in the form of pod casts to record my ideas and to have them available when needed. Assuming I will remember them and be able to access them when I need them. I used this technique yesterday, having been engaged in several e-mail exchanges over a few days, I realized I was not able to get across a small but important point. That's when I remembered a video, I had prepared some time ago on a related subject, I e-mailed the links and received a replay in due course indicating that I was understood.

I have been using a computer for my word processing needs since the late 1980's and am relatively adept at using Microsoft Office. What has made this easier is that since about the fourth version of MS Word (for DOS) the command structure, and menus etc have been consistent, that's not to say they haven't changed, but they have shown a remarkable consistence compared to what had gone before. For example, the **F1** (F1 key) is always associated with Help, compare this to what was the leading word processor of the late 1980's where **F3**+**F3** brought up help. I never had formal keyboarding skills training, but my skills are perfectly adequate to transcribe my thoughts to 'paper'. Lately I find I will spend a considerable amount of my time correcting 'typos'. Typos are literally what happens, as I will often type several words with each character offset by one 'die wzample' instead of for example.

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Communication is the meaningful exchange of information between two or more people. When it comes to interpersonal communication, I find speaking to someone face to face is far better than over the telephone. This reflects how we communicate (see **Figure 10: Communication** page 38). Despite

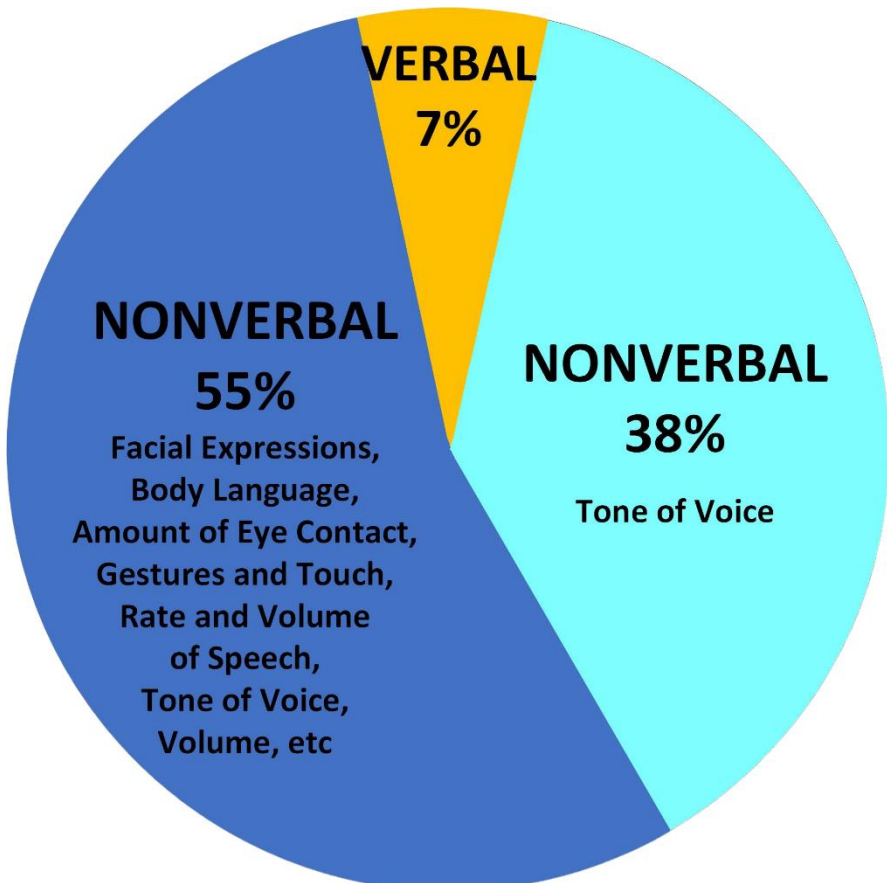


Figure 10: Communication

having very poor facial recognition I can recognise most genuine facial expressions.

Likewise, a person's tone of voice and gestures are an important part of my communications. Hence, I often find it easier to travel to meet with someone face to face rather than hold a telephone conversation.

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I, like many people I know with Dementia, find it much easier to read text printed on paper, rather than text presented in electronic format. My comprehension is much better that way. Recently I came across a study in a reputable scientific journal, that suggested this would be true for most people. My personal experience, and the experience of many of my friends suggests that this is compounded for people with Dementia.

Three years ago, I purchased a paperback to read on a long international flight. Needless to say, I didn't finish the book on the flight, but I continue to take it with me on any long flight (or when I know I am going to have a long wait in a Doctors surgery). I can pick the book up now, open it to the last page I was reading, and begin to read. After about one paragraph I can remember the story line, characters etc and have very good comprehensions of what is happening in the book.

Now contrast this to my E-reader. I have had a Kindle for many years (from pre-dementia days). About the same time as I purchased the book, I downloaded a book to my Kindle. The book was very interesting, but I found if I put the Kindle down for ten minutes, then resumed reading, the only way I could comprehend the story line was going back a relatively long way and re-read what I had already read. Since then, my Kindle died, and I don't mourn its loss.

Being Semantic About Semantics.

My form of Dementia suggests that the ability to assign meaning to words is gradually being lost. My reading, spelling, comprehension and expression are gradually declining. The meanings of words, objects and concepts may become confused. I experience impaired understanding of single words, when taken out of context, especially when they are used incorrectly. I experience difficulty in finding people's names or assigning someone to a name. For example, if you asked me, "Do you remember Fred?" I would likely identify a dozen or so 'Fred's' some of whom I would never have met e.g. 'Fred Flintstone'. This is because it may not be likely that I can easily connect your references to the particular 'Fred' you have in mind.

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I now often say that I have Pedantic Semantic Frontotemporal Dementia. My background in the sciences has trained me to avoid ambiguous language or terminology that is confusing or imprecise. I understand that language is evolving (some might say de-evolving), but that does not excuse using words inappropriately or contrary to their meaning. Words should mean what they mean, not what people would like them to mean.

I think I speak for all with Dementia when I say we need language that is clear and concise, with simple and clear explanations when we require more.

Emotional Changes.

Another significant change that has a variety of impacts are the emotional changes that come with many forms of Dementia. Some significant things for people to be aware of include the following;

- Neural degeneration is the cause. We don't decide to express ourselves this way. Our Dementia has eroded many of our learned social controls. As such we may be more emotionally honest than 'normal' people and react in ways that can be confronting.
- Not all emotional changes are bad. I find I now readily shed tears of joy. When I listen to good music⁵ I sometimes will cry. This is especially so if I can enhance the experience by viewing the written lyrics.
- If I seem angry when you talk to me, it is most likely your fault, because it is definitely not my fault!

When you come to accept these changes, you can see some of the benefits.

⁵ I only like good music, that is music from the 60's and 70's with very rare exceptions. 1984 represents the year that music died.

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A Doctor once told me that he liked people with Dementia because they don't lie. There is much truth in his statement, because the effort to construct and maintain a lie is often beyond us. I have found being honest, both with the truth and with my emotions pays better dividends.

There seems to be a bit of space left on this page

So, a walk on the light side.

A few years ago, I took my boys out for a meal.

I asked them a hard question.

"Can you remember the registration of your first car?"

Now they were in their mid-twenties so I thought should be able to remember something as significant as that.

They couldn't remember.

I said I can remember mine "A grey Morris Major with a rego number of DBU 484".

This surprised them a little, but I then forgot my PIN number for my card, and they had to pay!

See Dementia does have its advantages!

Some Solutions.

In this section I will elaborate more on what I think can help, and both address some questions about what helps as well as raising some more questions that should be asked by all.

The Role of People.

Many things I find difficult or are very hesitant to do can be made much easier if people are understanding and willing to help. For example, many retail businesses are staffed by people who are unwilling or unable to act outside a very narrow script. This often makes dealing with them very difficult and elicits confrontational behaviour. Two minutes of flexibility can make the process much more pleasant and easier for all concerned.

People are the key part of any solutions, therapies, and care when it comes to Dementia.

We are People with Dementia, NOT Consumers.

We are constantly referred to as consumers, but consumers of what? As for most of the services promoted, they appear without real substance and are not things I would engage with. I may be a 'potential' client (highly unlikely in any voluntary capacity) so to refer to me as a consumer of these services is highly fanciful. Also, the term consumer implies making an informed choice. I have yet to see meaningful information to base a choice on, let alone a choice.

The Role of Technology.

If we take the term technology in a broad sense i.e. the application of scientific knowledge for practical purposes, used to solve problems or invent useful tools that interact with us, society as a whole and the environment, and separate it from the concept of consumerism or consumption for consumptions sake, then we can progress. The overarching goal of technology should be to improve the quality of life, not the size of profits.

Any assistive technology should be designed with the realisation and understanding of the complexities of Dementia. For example, our ability to learn and remember new complex tasks is a diminishing skill. Our fine motor

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skills are deteriorating, this can make the most familiar of tasks more difficult and frustrating.

Let's take Robots as a potential solution to some of our problems. Most people would be familiar with 'I Robot'. What comes to mind when you see that title? Most people think of the movie 'I Robot' released in 2004 which is a portrayal of the story 'I Robot' written by Dr Isaac Asimov in 1950 (compiled from short stories he published in the 1940's). In 1942, Asimov postulated his **Three Laws of Robotics**⁶ quoted as being from the "Handbook of Robotics, 56th Edition, 2058 A.D.", are:

- First Law – A robot may not injure a human being or, through inaction, allow a human being to come to harm.
- Second Law – A robot must obey the orders given it by human beings except where such orders would conflict with the First Law.
- Third Law – A robot must protect its own existence as long as such protection does not conflict with the First or Second Laws.

These 'Laws' would be good guidelines for the development of any form of autonomous assistive technology.

The 'robotic' technology emerging today has many design issues. Firstly, let's discuss appearance. There is a great deal of effort going into making robots look 'human like'. In most cases they leave a lot to be desired. Because they are readily identified as not human, they portray themselves as a lie and false.

Recently, I had an opportunity to see some robots in action in Japan. The group of people I was with, from Europe, the USA and Australia, all found the design to be uncomfortable and false. They suggested if they found one of these 'Asimo' style robots assigned to assist them, they would feel obliged to teach it a lesson using a cricket or baseball bat (depending on their nationality). It was also interesting to note that many people were of the

⁶ 1942 in his short story "Runaround" (also included in the 1950 collection I, Robot also by Isaac Asimov).

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contrary opinion and would be able to engage easily and meaningfully with Asimo. This I think is partly cultural, but ultimately individual.

If they were designed for their function i.e. ‘form follows function’⁷, and not to mimic humans, they would be more useful, and I suggest much cheaper.

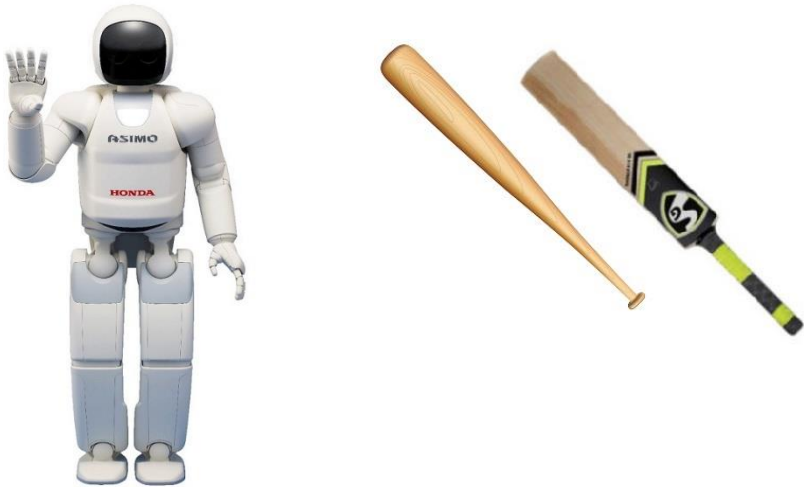


Figure 11: Asimo Learns Cricket

Were robots will be acceptable, is in doing specific functions such as lifting or food preparation.

Now take the current generation of ‘digital personal assistants’ such as Siri, Cortana, Google and Alexa. All are relying on voice recognition to provide assistance. In all cases they require an internet connection to do two things, firstly to transmit our voice to one or more ‘clouds’ so that it can be converted into text and digital instructions, then secondly to retrieve what ever information was requested. Many people find the lag as information is shuffled around the clouds to be a problem, but most people overlook such things as privacy. Our voice and instructions are there to be spread around

⁷ Form follows function is a principle associated with 20th-century modernist architecture and industrial design which says that the shape of a building or object should primarily relate to its intended function or purpose.

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and sold (or stolen) by the highest bidder. An old proverb says 'The devil is in the detail', but perhaps he just lives in the 'cloud'.

I find these ethical concerns to be a bigger problem than the functionality of the technology. Also, again let us consider how Dementia is affecting us. We are most likely slowly losing the fluidity of our speech, as well as in many cases having semantic problems. As yet, issues like these have not been addressed in the design of these 'digital assistants. I feel that when we would most need their assistance, we would not be capable of addressing them in a manner they would understand, and hence may have a false sense of security with them. They provide some novelty value but may be best suited for cricket practice.⁸

Most people I have seen promoting these technologies (and similar electronic/digital devices), have very little understanding of how they function and more importantly the limitations they have.

The problems in applying digital technologies to our needs, can be summarised in these areas;

- Initial Design. There is very little understanding of Dementia as a disability by people involving in the design process. Not only must designers increase their understanding of Dementia, but people with Dementia should be involved not only in the design, but in the testing and evaluation of these products.
- Implementation. Here there are two concerns, again the awareness and understanding of Dementia in selecting appropriate featured technologies and secondly the hidden technologies that lie behind the scenes, that may expose us and our personal data to abuse.
- Robust design. I was recently looking at a wearable GPS device. It was water resistant, but when viewing the specs in a little detail, would have to be removed for showering etc. I doubt it would have survived a week of my 'normal' use. (I doubt it was hammer resistant!).

⁸ I have no interest in Cricket, but I do have a good collection of hammers that are suitable for fine tuning these devices!

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- Flexible application and modification. Devices – digital and ‘real’ need the ability to be easily reconfigured and adapted for individuals. Our ability to learn complex new tasks and to adapt is diminishing. This should be the domain of the device.
- *We don't need new ways to do old things, we need old ways to do new things!*

The Answer to Who's Problem?

Each person with Dementia is not only unique, but their form of Dementia is probable unique to. A sub-type of dementia is often characterised by a small number of symptoms and their impact. There may be many other symptoms or related problems that effects that individual. I often liken a diagnosis of Dementia to a meal in in a large suburban supermarket's food court. Pick your cuisine, Thai, Mexican, Chinese, Italian etc. This is analogous to the type of Dementia, FTD, Lewy Bodies, Alzheimer's etc. Now pick your combination food from the large smorgasbord from your favourite cuisine. This is analogous to your symptoms. One symptom may and does occur across differing forms, while some may be unique to a single form. The severity of each symptom will vary across forms, differ between individuals and vary over time for everyone.

Now when offered a solution to our problems, say a reminder clock, some people even call them Dementia Clocks – I suppose that's because they can't tell the time, the clock that is, not the person! (See Being Semantic About Semantics. page 39).Who is it designed for? I may have difficulty in drawing an analogue clock, but I can still read one.

One Size Fits No-One!

The concept of universal design is good, but invariably can never be universal. There will always be people and situations where it fails. If a broad approach is adopted it needs to be easily customised and adapted for each individual as required. Consider also the variations of each home.

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Recently I heard of some ‘wonderful’ assistive technology implemented to enable a person with very limited mobility control his home via a variety of wireless remotes and an array of sensors. The whole system failed when someone (a paid carer) placed an empty cardboard box on a shelf that blocked an infrared sensor. The best laid plans of mice and men.

Simple is best, but a good understanding of both the problems (and challenges) and the potential solutions, by all parties is better.

Timing

In order for any solution to work well, we must be familiar with it and be comfortable using it. The nature of our diseases are that they are degenerative and our conditions will worsen over time. As such our ability to learn new things and to adapt to the new is decreasing. Despite the best of intentions and great efforts in learning how to use something new, our efforts may be in vain. The new ‘solution’ may be very short lived, and everyone’s level of frustration may be raised. I would suggest that new aids, procedures etc. be introduced well before their need is critical. That way they will be familiar and more likely to be engaged with.

Solutions need to be implemented proactively in advance of the point when they will be necessary.

An example of this approach I’m taking is with my balance. I’m aware of some issues with my balance, but nothing that has caused a fall. This is due largely to me being very much self-aware and avoiding situations where it could cause a fall or worse. I’m currently in the process of getting some small structural changes i.e. some purpose-built hand rails sourced and installed. This is so that I can adapt to them and have them useable when I need them.

An annoying downside to this approach that comes with self-awareness, can be that because you know your ability to sustain something new that is outside your normal experience is limited, you refuse to waste your time doing something that will quickly show to be not sustainable and hence a waste of your ever-diminishing time. Those making these suggestions often refuse to believe this. They need to better understand Dementia.

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A simplistic example is the idea of making lists. Many well-intentioned people have suggested I make a list of things that I need to do etc, to aid my memory. This works well for people who have made lists all their lives, but I need to make a list of the lists I've made that are a waste of time and effort. If I could remember to look at the list (assuming I could find where I had 'filed' it), I wouldn't need the list because I could remember the thing in the first place.

Also, we need to consider how long will this solution work for. Two things are important considerations here.

The functional life of the product. How long will it last before it begins to fail? Many devices with internal batteries will become expensive door stops (or hammer buffers) because their lithium battery is ageing and requires recharging at increasingly more frequent intervals. The batteries may not be easily replaceable, without a significant cost.

Secondly, we need to consider the opposite- will it outlast its usefulness because your situation/abilities have deteriorated. Hopefully, this won't be the issue.

Try Before You Buy.

An obvious and necessary adjunct to the idea of pre-emptive implementation of potential solutions, is try them out in advance of committing to them. A try before you buy approach. To really test them they need to be trialled in a realistic environment, i.e. your home, for a reasonable amount of time, possibly weeks. This way you can be sure that they will work as intended, and more importantly that they will work for you.

A Novel Idea!

We (us lucky enough to be diagnosed with Dementia) need to be involved in the whole process. Not only do we need to be consulted and listened too⁹, about possible solutions to our problems, but we need to be involved from the very beginning of the design process, though product development, and

⁹ Failing to do this could lead to a violation of our basic human rights (Dementia and Human Rights. page 5)

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more importantly with product testing and evaluation. After all, *'Nihil de nobis, sine nobis'*¹⁰.

This now brings me to my final point.

Warning: You've Met One Person with Dementia! You Need to Meet Us All!

As stated by Prof Tom Kitwood in 1997 *"If you've met one person with Dementia, then you've only met one person with Dementia."* This is as true today as it was then, perhaps more so. Remember, what I detail here is my experience, and is applicable to me. Don't assume what works for one will work for others, even with the same or similar diagnosis.

We are all unique individuals, whether we have a Dementia or not. So please treat us as such and remember us for who we are, not our disease.

If you wish to work with people with a Dementia diagnosis, you must be flexible and open to learning new things and to see the world from differing perspectives.

¹⁰ Nothing About Us Without Us!

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Twilights Journey

Figure 12: The View from 'The Grand High Tops', The Warrumbungle Mountains

It's dark and I find myself walking, the road is dusty.

It has never seen bitumen.

The road is grey path in a dark landscape.

*The sky is shrouded in cloud and only the dimly filtered light of a fading moon
lights my way.*

*I remember rising early as I do normally, breaking my nights fast and setting
out to walk.*

*Walking with a purpose only dimly viewed. It's not clear but it burns bright in
my mind.*

*My feet hurt, my body's way of asking, why am I walking? Where am I going?
The road is gravel and dust, long corrugated with mounds of dust lining the dry
gutter.*

*Low and dry scrub stretch away, occasionally dotted with the silhouette of a
low tree.*

Dry grass and clay pans, silence to the dim horizon.

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The air is neither warm nor cool but stirring slowly with a gentle predawn breeze.

I don't know where I am, only that I am my journeys path. I walk slowly on, my pain melts into the dust.

Before me another road crosses my path.

A dim sign swings in the breeze. Its direction long bleached by the sun and the elements.

It offers no direction, no guidance.

I am lost to the direction I should take, confused by the seemingly identical choices, my path is only one of the ways.

There is no help on this road. I am confused.

Then I become aware of a presence beside me.

Darkly cloaked and blending into the darkness.

Was he there when I came to this crossroad? Does he follow me? Do I follow him? Who is he?

He speaks, and I know him.

Like me he has no name only a purpose.

Mine is as a Journeyman, his is as a guide.

I speak with him every day.

People often call him Death, but he is only its guide.

He holds no fear for me and knows it, for when the time is right, I will follow without fear, curious to continue my journey.

As he speaks the clouds begin to thin, and the stars begin to show though the darkness.

The Crux shows clearly, and I have a way.

Turning, I can see the constellation of the Emu – dark amount the stars.

A dim red glow forms on the horizon and I can hear a Kookaburra announcing a new day.

My friend waves and slowly walks away and I turn into the rising Sun and continue my journey.

As the horizon glows.

I can see Burra the eastern grey grazing the dew-covered morning grass.

She raises her head to acknowledge my journey.

All is well with the world and I have direction.

Where my journey ends, I don't know –

I am a journeyman not a destination.



Figure 13: The Constellation of the EMU

The Constellation of the EMU is known to Indigenous Astronomy. Its head is formed from the Southern Cross



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About the Author:

At the time of diagnosis like most people I knew very little about Dementia. Since that time, it has been a steep learning curve, but the journey has not been all bad. It has woken the sleeper within and inspired me to Advocate for others with Dementia who have been less fortunate, and to help make the rest of the community more aware of what living with Dementia is really like.

I was elected as chair of the Dementia Advisory Group to the Dementia Friendly Kiama Project in 2014. The position of Chief DAG is one I hold dear and am most proud of. This has introduced me to many people worldwide who are living well with Dementia and to such groups as the Dementia Alliance International.

This has also introduced me to many research projects and public forums, that enable me to share my Lived Experience and the experiences of my friends with Dementia.



Dennis Frost pictured here at the 32nd International Conference of Alzheimer's Disease International in Kyoto, Japan 2017, was diagnosed with Semantic Frontotemporal Dementia at age 59.

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Live Well and Prosper



I challenge you!

I challenge you all.

For all that you know.

For all that you say you are.

For all that you beg borrow or steal.

Confront your doubts!

Confront your ignorance!

Confront your fears!

Take the time to understand us.

To share our journeys.

To be our friends.

*This resource has been developed as part of the ongoing Dementia Friendly
Kiama Project.*

