

Supporting people with deMENTia to live well in the community

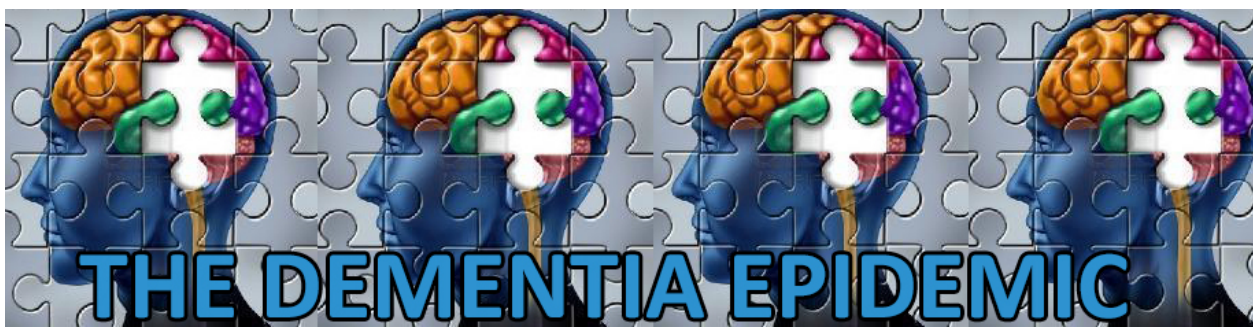
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DEMENTIA
ALLIANCE
INTERNATIONAL

Support and Advocacy: Of, by and for people with dementia



- >46.8 million people globally diagnosed with deMENTia (WHO, 2015)
- 342,800 people with deMENTia in Australia
 - including 25,100 under 65 (Younger Onset) (Alzheimer's Australia, 2015)
- 1 new diagnosis every 3.2 seconds (ADI, 2015)
- 1800 new diagnoses per week in Australia, therefore
 - 257 new diagnoses per day in Australia
- > 130 types or causes of deMENTia
- Alzheimer's Disease makes up 50-70% of all deMENTias
- DeMENTia is a terminal, progressive, chronic illness
- No cure, some treatment for some AD

Is it really possible to live **well** with dementia?

- Living well with dementia?
- Living better with dementia (than the public and health care perceptions of dementia)?
- Rarely are we at end stage when diagnosed, therefore enable people with dementia to

Live beyond the diagnosis

Loss and Grief... and dementia

- We are told to get our end of life affairs in order, **but not given the same support as any other terminal illness**; many people not even told dementia is a terminal illness
- Loss and grief is barely recognised as an issue for the person with dementia, therefore
- There is no appropriate loss and grief support
- Dementia loss and grief is very complicated
- It is constant, yet changing
- In the grief sector, we know that loss and grief symptoms make cognitive impairment worse

Prescribed Disengagement™



What is it?

- Dementia is the only illness I know where people are told to get acquainted with aged care, get their end of life affairs in order, and go home and 'live' for the time they have left.

What's the cost?

- Hopelessness for those diagnosed and our families
- Person with dementia assumes victimhood, and is further disabled and disempowered
- It promotes learned helplessness in the PWD
- Carer can assume the martyr role, with all the power and control

We have a **human right** to...

- A more ethical pathway of care, including our pre and post-diagnostic care, and on pre and postvention including rehabilitation.
- Being treated with the same human rights as everyone else, under the Disability Discrimination Acts and UN Convention on the Rights of Persons with Disabilities
- Not to be discriminated or stigmatised
- To full inclusion
- To employment, and
- To research that does not only focus on a cure, but on our care

Medical Model of care

Diagnosis

Prescribed Disengagement™

Referral to service provider

ACD's and Aged Care

Basic lifestyle support

disAbility/social model of care

Confirmation of diagnosis

Assessment of disAbilities

Authentic rehabilitation and grief & loss counseling

Strategies to support disAbilities

Focus on wellbeing & QoL

Continued meaningful engagement, including employment

ACD's

Aged care, if required



Current medical model of 'care'



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Diagnosis

Often lengthy process of misdiagnosis

Most feared disease >65 age group

Prescribed Disengagement™

Not supported to live pre diagnosis life

Lack of proactive pathway of care

Referral to service provider

Alzheimer's Australia

Aged Care provider

Advanced Care Directives

Aged care

Community

Respite

Residential)

Social/disAbility model of care



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Confirmation of Diagnosis

Letter from specialist or GP

Support for a terminal progressive chronic illness

Counseling for loss & grief & terminal illness

Assessment of disAbilities

Focus on QoL and well being

Support to remain employed

Rehabilitation

Speech pathology

Brain Injury Unit

Neuro Physiotherapist

Neuroplasticity, eg studying

OT

Strategies to manage and support disAbilities

IT/technology

Post it notes/
laminated sheets

Electronic reminders

Walking stick

Buddy/mentor

Webster packs

ETC!

Continued meaningfully engaging activities

Usual pre-diagnosis hobbies

Sport, exercise, dancing

Clubs

Normal socialising

Advanced Care Directives

Everyone over 18 should get these done

Aged care, if required

Community

Respite

Residential

Manage the **symptoms** of dementia as

disAbilities



Dementia symptoms as **disAbilities**

- Assist us to remain engaged with our pre-diagnosis life, rather than Prescribe Disengagement™
- Provide authentic rehabilitation
- Focus on assets, abilities and interests of the person, not deficits
- Focus on dementia enabling environments
- Dementia accessible/inclusive communities
- Manage risk rather than eliminate it
- Promote community and social inclusion



Continued meaningful engagement

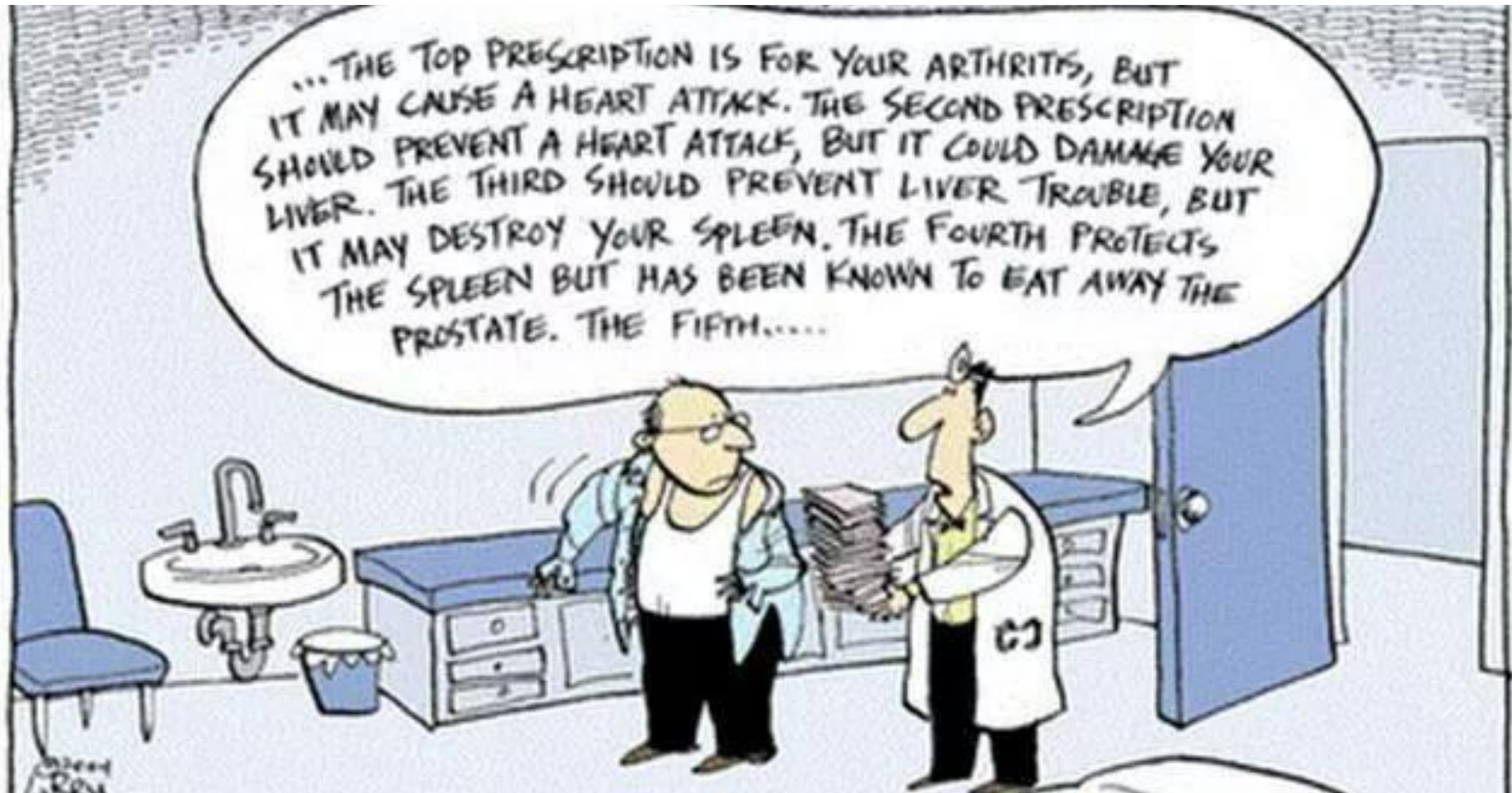
- **Positive and empowering**
- Continue to live pre diagnosis lives
- Sense of identity intact
- Reduces isolation, stigma, discrimination, depression, loneliness
- Person may remain employed, or become a volunteer
- Meaningful **positive** engagement, not things like Bingo!
- Self advocacy
- Enhances well-being and QoL



Meaningful engagement also needs meaningful roles

Meaningful lives need
meaningful roles, not just
'meaningful' activities

Physical and chemical restraint



Not just a “Challenging behaviour”



Rehabilitation

- Making use of the Neuroplasticity of the Brain
- Fortunately in recent times there appears to be some movement in the beliefs that people with dementia can still ‘learn things’
- Muscle Memory – Dancing, Choir, etc
- Speech pathology
- Authentic brain injury rehabilitation, as you would prescribe after a stroke



Is language important?

*'When your child is no longer a child,
you will have to find a new language'* (Fossum, K, 2003)

- It defines the way others see us
- It allows others to communicate with us
- It defines the way we view ourselves
- It allows us to communicate with others
- It can impact stigma and discrimination



Language is a powerful tool



*Our words do reflect our
thoughts and feelings, and can show
respect or disrespect;
they also show how others feel about us.*

(Sabat 2001; Parker 2001; Hoffert 2006)

Stigma

Why is stigma still such a common experience of dementia?

- Disrespectful language
- Lack of awareness and education of dementia
- Lack of **full** inclusion in society
- Campaigns such as *Dementia Friends* still ***About us without us***
- Minimal support for our dis**Abilities**
- Discrimination
- Isolation



Why fight for our lives?

- Dementia is the only disease I know of where the person is **Prescribed Disengagement™** from their pre-diagnosis lives, and told to go home and give up
- Living well or beyond the diagnosis (on our terms) is rarely suggested as an option, or that it is possible
- We need support to live as well as possible, and to ‘fight’ for our lives, in the same way as person does who is diagnosed with cancer

Non pharmacological Interventions for dementia

- Studying
- Speech pathology
- Exercise & Pilates
- Authentic brain injury rehabilitation
- Neuroplasticity brain and body training
- Occupational Therapy
- Hydrotherapy
- Blogging and journaling
- Poetry
- Creative writing
- Music therapy
- Supplements
- Spiritual health
- Phenomenology & Auto ethnography
- Grief counselling



Positive psychosocial interventions for dementia

- Advocacy
- Volunteering
- Laughter
- Spiritual
- Love & intimacy
- Nurturing friendships
- Reading
- Belief
- Transcendental Meditation
- Self Hypnosis
- Mindfulness
- Creative writing
- Poetry
- Motivation
- Humour



Dementia friendly communities

- Less about being friendly, more about
 - Respect, **including empowering and respectful language**
 - Human rights
 - Non discrimination
 - **Full inclusion**
 - Our right to full citizenship
 - Autonomy
 - Equality
 - Equity
 - Access
 - Dementia Enabling Environments
 - Support for disAbilities



Alzheimer's Australia Language Guidelines 2014

**SEE THE PERSON
NOT THE DEMENTIA**

Dignity in Care Principles



1. Zero tolerance of all forms of abuse
2. Support people with the same respect you would want for yourself or a member of your family
3. Treat each person as an individual by offering a personalised service
4. Enable people to maintain the maximum possible level of independence, choice, and control
5. Listen and support people to express their needs and wants
6. Respect people's privacy
7. Ensure people feel able to complain without fear of retribution
8. Engage with family members and carers as care partners
9. Assist people to maintain confidence and a positive self esteem
10. Act to alleviate people's loneliness and isolation.

Dementia Alliance International

- Exclusive membership to PWD
- Weekly online support groups
- Monthly online cafes
- Monthly webinars
- Master classes
- <http://www.infodai.org>
- <http://www.joinandai.org>



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The global voice of dementia



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What the hell happened to my brain?: Living beyond deMENTia

My book, available for pre-ordering on Amazon:

http://www.amazon.com/What-Hell-Happened-My-Brain/dp/1849056080/ref=sr_1_1?s=books&ie=UTF8&qid=1431378759&sr=1-1&keywords=kate+swaffer

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Thank you



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