Supporting people with dementia to live well in the community

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Board member, Alzheimer’s Disease International
Chair, Alzheimer’s Australia Dementia Advisory Committee
• >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

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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

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We have a human right to...

- A more ethical pathway of care, including our pre and post-diagnostic care, and on pre and post-vention 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

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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

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Continued meaningful engagement

• Positive and empowering
• Continue to live pre diagnosis lives
• Sense of identity in tact
• 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

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Physical and chemical restraint

...the top prescription is for your arthritis, but it may cause a heart attack. The second prescription should prevent a heart attack, but it could damage your liver. The third should prevent liver trouble, but it may destroy your spleen. The fourth protects the spleen but has been known to eat away the prostate. The fifth......
Not just a “Challenging Behaviour”

- Wanderer
- Aggressive
- Poor Feeder
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

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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 disAbilities
• Discrimination
• Isolation

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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

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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

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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

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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
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.joindai.org

The global voice of dementia
What the hell happened to my brain?: 
Living beyond deMEntia

My book, available for pre-ordering on Amazon:

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