Prescribed Disengagement, Models of care and QoL

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NO CONFLICT OF INTEREST
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Prescribed Dis-engagement

• What is it?
  People with dementia are told to go home, give up work, give up our pre-diagnosis life, and live for the time they have left
Prescribed Dis-engagement

• What’s the cost?

Prescribed disengagement disempowers people with dementia and their family care giver.

It focuses on symptoms, not the person.
Two models of care

Medical
- Diagnosis
- **Prescribed disengagement** from pre diagnosis life
- Referral (if lucky) to service provider

disAbility
- Diagnosis accepted
- Full assessment
- Rehabilitation
- **Continued engagement** with pre diagnosis life
- QoL and well-being
Medical model: prescribes disengagement

- Referral to Service provider to provide support with home, community, respite and aged care
- Alzheimer’s Society or Association
- Link or key worker – if funding available
- Memory Loss course and support group
- Activities, e.g. Bingo, art, coffee groups, music therapy, hair brushing, smelling fresh flowers or pot pourri, stroking an animal, a visit to a herb farm or a flower show
- Assisted technology – very basic
- Safe Return bracelet

- Support offered:
  - Planning for the future
  - Coping with “Behaviour “change
  - Preparing your home
  - Community & respite care
  - Residential care

- No referral to disability or employment advisor
- Increased stigma, discrimination, isolation, loneliness & social inequality
- High risk of depression
- Negative impact on progression of dementia
Impact is negative

- It disempowers
- Sets up the martyr and victims roles
- Increases isolation
- Increases stigma and discrimination
- Loss of identity
- Ensures financial burden
- It steals our ‘voice’
- Ignores the real experts
disAbility model: continued engagement

• Referral to Disability Adviser to provide support to continue with studies
• Non discriminatory acceptance & description of illness/disAbility
• Mentor and buddy
• Disability Access Plan
• Alternative assessments and exams
• Counselling
• Note taker and/or podcasts
• Strategies for students, e.g.
  – Planning for completion of degree
  – Time management
  – Managing reading & writing
  – Study skills & library assistance
• Supportive aids, as required
• Disability equipment & Assisted technology
• Referral to careers and employment, or referral to Disability Career sector on how to stay in employment if still employed
• Reduced stigma, discrimination, isolation and loneliness
• Reduced social inequality
• Meaningful positive engagement, sense of achievement and chance of decreased progression of dementia
• Well-being & QoL enhanced
Impact is positive

- Empowering
- Enhances well-being and QoL
- Person may remain employed
- Continue to live pre diagnosis lives
- Meaningful engagement
- Self advocacy
- Reduces isolation, stigma, discrimination, depression etc
- Sense of identity in tact
Side by Side

A workplace engagement Programme enhancing QoL
Thank you

Live every day as if it’s your last, just in case it is.

http://kateswaffer.com/daily-blog