The unique challenges of living with younger onset dementia

Kate Swaffer
19 April 2013
Richard Taylor

‘Stand up speak out, do not become a victim of your own silence.’
Kate Swaffer

Wife, Mother, Daughter, Volunteer, Student; 
BPsych, BA, Grad Dip Counselling, RN; 
Author, Poet, Speaker, Volunteer; 
Advocate for Dementia and Aged care; 
Also a person living with a diagnosis of dementia.

My life is still interesting, busy and very fulfilling!
B.U.B
(Back Up Brain vs Carer!)
The unique challenges of YOD

- Disbelief
- Accreditation standards
- ACAT discriminates
- Lack of age appropriate services
- Loss of dreams
- Terminal illness without credentials
- Worry about who we will become
- Children/parents/partners
- Lost employment
- Reduced income
- Increased health and travel costs
- Lowered self esteem
- Intimacy and sex life
Prescribed Dis-engagement

• What is it?
  – Go home, give up work, give up our pre-diagnosis life, and live for the time left!

• What’s the cost?
  – Disempowers us, sets us up to become victims, and focuses on symptoms not the person
Stigma, isolation AND discrimination

- Impact of ‘coming out’ about diagnosis
- No assistance given to keep me employed
  - e.g. if I’d had an acquired brain injury I’d have been rehabilitated and helped back to work
- Resigning from paid employment
- Many PWD still actively involved
- Denied positions on boards and in organisations because of the symptoms of dementia
The Olympics of My Life
Dementia as a Disability

• Assistance to remain employed
• Increased social inclusion
• Increased social equality
• Decreased isolation
• Decreased stigma
• Decreased discrimination
• Decreased economic impact on person and society
Strategies for PWYOD

- Counselling to remain engaged with pre-diagnosis activities
- disAbility Access Plan
- Assisted technologies
- disAbility equipment
- Mentoring
- Note takers, memory loss reading logs, etc
- Treated with dignity as a whole person
Slowing the progression of dementia

- Non pharmacological interventions
- Positive psychosocial interventions
- Neuroplasticity training
- Exercise and cognitive fitness
- Authentic brain injury rehabilitation
- Focus on well being and QoL
Non-pharmacological Interventions for dementia

- Studying
- Phenomenology
- Neuroplasticity
- Exercise
- Authentic BIR
- Transcendental Meditation
- Blogging
- Poetry (haikus)
- Nutrition
- Supplements
- Music therapy
- Hydrotherapy
- Mind Mapping
Positive Psychosocial Interventions

- Studying
- Volunteering
- Laughter
- Love
- Poetry
- Reading
- Blogging

- Belief
- Holistic interventions
- Self Hypnosis
- Family time
- Nurturing friendships
- Spiritual
- Positive psychology
Thank you.

I am a person **living** with a diagnosis of dementia, with the emphasis on **LIVING**.

http://kateswaffer.com