Dementia: the future is now

Biennial Conference, Rotorua Convention Centre
14 November 2014
A stronger consumer voice

Kate Swaffer
MSc Dementia Care (2014), BPsych, BA, Grad Dip Counselling, RN
@KateSwaffer http://kateswaffer.com
• Living well with dementia
• Advocacy and speaking out
• Prescribed Disengagement™
• Dementia Working Groups
• Dementia friendly communities
• Language and stigma
Treat the symptoms of dementia as disabilities
DEMENTIA HAS A PROFOUND IMPACT ON THE SOCIAL WELFARE OF THE PERSON WITH DEMENTIA

“No one wants to spend time with me now that I have a diagnosis. It is like they think I no longer count and I am not a person anymore.”

“I have lost almost all of my friends and the few I have I see once a year or even once every 2 years. I have one friend who I see about every 4 months.”
Dementia Working Groups or Committees

Membership exclusive to people with dementia, supported by Associations
1. Scotland
2. Europe
3. Australia
4. Japan
5. Ireland
6. Ontario
Alzheimer’s Australia Dementia Advisory Group
Aims of dementia working groups

Work with their Association to:

- Determine the priorities of people with dementia
- Contribute to policy and advocacy work
- Promote dialogue between those with dementia and service providers with a view to promoting a better understanding of their social and care needs
- Assist in refining and evaluating national programs

“Being actively involved in shaping dementia policies and services, the very things that effect the daily lives of people with dementia.”
“I too thought the inaugural meeting was really worthwhile and it was so good to talk to other people in our situation (both those with dementia and those who stand by us) and how we will hopefully take a real part in the hat affects us.”

- Person with dementia

“It was an emotional and moving couple of days.”

- Alzheimer’s Australia staff member
“It will, I am sure, play a significant role now in mobilising our voice as people with dementia!”

- Person with dementia

“I thought this new group would be a waste of time and money, but am thrilled to see that people with dementia are still so capable of speaking up, and how productive it has been.”

- Carer, after Day 1

“Until this meeting, I feel I have not spoken for myself for over 5 years!”

- Person with dementia
Working to become Dementia Friendly
Dementia friendly… Or not?
Dementia friendly in Australia

- Include people with dementia at every step
- Set up a small Advisory group of people with dementia
- The environment, including signage, noise levels, and location is imperative
- Support for disabilities, in the same way as any other disabled person
- Be respectful with the language you use
Language is a powerful tool

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

(Sabat 2001; Parker 2001; Hoffert 2006)
Alzheimer’s Australia
Language Guidelines 2014

SEE THE PERSON
NOT THE DEMENTIA

Medical

Diagnosis

Prescribed Disengagement™

Referral to service provider e.g. Alzheimer’s Australia

Aged Care Services, inc respite, day and residential care

disAbility

Confirmation of diagnosis

Full assessment of disAbilities

Rehabilitation & strategies to manage disAbilities, including counselling

Focus on well-being and QoL

Continued meaningful, positive engagement, inc. employment

Aged care services, if required

Kate Swaffer © 2013
Person centred care
1. Don’t say, ‘but don’t look or sound like you have dementia’
2. Don’t tell us we are wrong
3. Don’t argue with us or correct trivial things
4. Don’t say ‘remember when...’
5. Don’t call us ‘sufferers’ or ‘victims’
6. Don’t refer to us as suffering, sufferers, demented, dementing illness, vacant dement, demented sufferer, an empty shell, fading away, disappearing, or that it is the longest goodbye, the saddest goodbye, stealing us away (we are always still here), afflicted
7. Don’t say you are ‘living with dementia’ unless you are diagnosed with dementia
8. Don’t remind us of the death of a loved one or pet
9. Don’t blame the person for the changes in behaviour or personality
10. We have a form or type of dementia, not an ‘affliction’
11. Don’t call me honey, love or anything other than my preferred name
13. Don’t assume because we can’t tell you, your words or actions don’t hurt our feelings
14. Don’t assume I can’t answer for myself
15. Don’t talk about me to someone else, in front of me
16. Don’t assume we can’t communicate even if I can’t speak
17. Don’t say, ‘but I’ve just told you that’ or ‘you’ve asked me that already’
18. Don’t think we can’t feel pain, or have emotions
19. Don’t assume we don’t understand just because we are silent
20. Don’t assume anything; it makes an ass out of u and me
Any questions?

Thank you.

@KateSwaffer
http://kateswaffer.com
http://dementiaallianceinternational.org

Kate Swaffer © 2014