

Developing an education program for children about dementia - what do consumers want children to know?

Jess Baker, UNSW

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A DEMENTIA-FRIENDLY SOCIETY



To increase awareness and understanding of dementia



To successfully deliver a message that de-stigmatises and raises awareness and understanding of dementia in youth

Four Reasons why it Starts with Educating Children

1. Children want to know
2. Increased contact
3. Stigma exists
4. Consumers rate it as top priority



Education Program Development Protocol

1. Focus Groups/Interviews
2. Design
3. Review and refine – advisory groups
4. Pilot in a school, for future roll-out



Focus Groups and Interviews

Children

- Scouts aged 9 – 12 years
(n=13 boys and 9 girls)
Videos / role-plays



Consumers

- People living with early stage dementia (n=5)
- Family members in a primary support role (n=12)
- Family members in a non-primary support role (n=5)
- 9-12 year olds with grandparent with dementia (n=4)

Scout Theme – Affective Thoughts /Behaviour



1. Help

2. Keep away

Scout Theme – Causes of Behaviour / Unawares

- Recognition something not quite right
 - Sensory impairment
 - Putting it on
-
- Behaviour extent
 - Age
 - Cure?
 - Will I get it?



Consumer Themes

- **The whole truth about dementia**



“when you see somebody who’s physically disabled, they get that instant sympathy and patience...when it’s a mental disability, they don’t see it...”

- **Personhood**



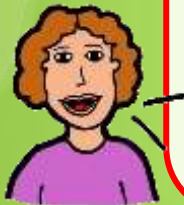
“It’s important to know that there is actually a person underneath.... they’re not just some random now they’ve got a disease ... they’re still special to us.”



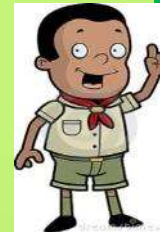
“It's like Albert Einstein, if when he gets older maybe he could start to act a bit strange.... He’s still the smartest person on earth.”

Consumer Themes

- **Stigma**



“Before we knew the diagnosis she was treated like an idiot ...there’s just no need for that.”



“they’re cool in a way because they are quirky ...I liked that they were different”

- **How best to relate to the person with dementia**



“I felt pretty angry but I didn’t really feel that angry because I know it’s not her fault... it’s probably the sickness.”

Key Messages for the Education Program (1)

Tell the whole truth about dementia

- It is diverse
- It is unpredictable
- Not everyone who forgets has dementia
- It is progressive, and there is no cure yet
- You cannot “see” it
- Activity suggestions for care facility visits
- How to keep your brain healthy
- Look for positives



Key Messages for the Education Program (2)

Address Stigma

- People with dementia are not “weird” or “crazy”
- Not just “old” people develop dementia
- It is okay to talk about it/seek help

Raise empathy for the person and their family

- A person with dementia is “still” a Person
- It’s not the person’s fault
- It’s life-changing for the people living alongside them

Teach how to relate to the person with dementia

- Don’t be afraid



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THANK YOU

Jessica.baker@unsw.edu.au

The Draft Program – a Sneak Preview!

Module	Education Format	Activity	Messages conveyed	School subject	School Outcomes
What is dementia?	Story Animation	Discussion	- Differs for everyone - Unpredictable -	- PDHPE - English - Science	- Communicating - Interacting - Problem-solving

- WHAT IS DEMENTIA?
- What causes dementia?
- How does it feel to have dementia?
- What is it like for the family?
- What can I do at home?
- What can I do in the community?
- What happens in nursing homes?
- How can I keep my brain healthy?





<http://www.dementiadaily.org.au/courageous-conversations-2/>

<http://www.abc.net.au/dustechoes/default.htm>