Facing the times
Denise Craig

Young Onset Dementia Support Group
Facing the times....

- Quick glimpse: Facebook support
- Identified needs
  - connect people
  - good information
  - platform
- Social Media health communication
- A private initiative

https://www.facebook.com/YoungOnsetDementiaSupportGroup
What is life about?

- With or without dementia
  - Keep active
  - Involved
  - Independent
  - Social identity
  - Sense of self-worth

(Sansoni et al., 2014, Swaffer, 2015, Westera et al., 2014)
YOD relative to late onset

- Extreme sense of loss
- Employment & financial pressures
- Family considerations
- Can be living alone
- Physically fitter, stronger, energetic
- Stigma & ‘aged care’

(Sansoni et al., 2014, Westera et al., 2014)

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Wants & needs

- Targeted advice & information = QoL
- Loss of one to one friendships
  - ↓ connections
  - ↓ fulfilment
  - ↓ identity
  (Sonsini et al., 2014, Moorhead et al., 2013, Westera et al., 2014)

- Social media is readily available

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Health Communication in Social Media

- Increased interaction
- Tailored information
- Accessibility of information
- Public health surveillance
- Influence health policy

(Moorhead et al., 2013)
The new frontier...

- 61% search online, 39% social media  
  (Fox & Jones, 2009)
- Use of video, music, pictures  
  (Moorhead et al, 2013)
- 75% single administrators  
  (Martinez-Perez, 2014)
- 864 million daily users in Sept 2014  
  (Facebook, 2014)
- Anonymity “Justin Case”

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The good news...

- Identification of others
- Targeted information
- Support
- The lived experience of dementia
- Carers learn vicariously

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And then one morning...
Final thoughts...

- People with dementia MUST be included in health decisions
- People with dementia have much to say
- Listen with your eyes

- Be creative – what can YOU do?

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References:


