https://www.facebook.com/YoungOnsetDementiaSupportGroupQld
Facing the times...

Life isn't about waiting for the storm to pass. It's about learning to dance in the rain.

www.Daveswordsofwisdom.com
Facing the times...

- YOD in Australia
- Some of the issues
- Needs of people with YOD
- Purpose of the Facebook page
- Online support groups
- Who’s using this page?
- The good, the bad & the ugly

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A little background…

- YOD – dementia <65
- Also known as Early or Younger Onset
- 6-9% of all dementias (WHO)
- Only estimates
  - 2007 AIHW projected YOD 10000 in 2011
  - 2011 Access estimated 16329 that year
  - 2012 AIHW suggested 23900 in 2011
  - 2013 – AIHW estimate 24400 currently
- The INSPIRED Study – Australian first

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YOD relative to LOD

- Inverse ageism
- Extreme sense of loss
- Relationship complexity
- Employment pressures
- Family considerations
- Financial responsibilities
- Physically fitter

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YOD relative to LOD

- Lengthy diagnostic channels
- Incorrectly diagnosed
- Neuropsychologist
- Stigma
- ‘Aged care’
- Lack of common interests with aged
- More likely to access Facebook
  - Alzheimer’s Australia; Bakker et al, 2010; Chaston, 2010

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Relationship implications

- From my experience:
  - ↑ sense of guilt
  - ↑ stigma
  - Concern for partner
  - Fractured pre-diagnosis
- Partner may consider leaving

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Face it on Facebook

- Give YOD a voice
- Person with diagnosis often neglected
- Google “Dementia Support Group

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Support Groups give you an opportunity to meet with others in a similar situation to share experiences, learn new ideas for skills for living with dementia and engaging in mutual problem solving.

Who can attend?
There are over 200 Support Groups in New South Wales and many of them are dementia specific. All groups welcome anyone caring for a person with dementia or family members and friends of someone with dementia. In some areas there are specialist groups, for example, multicultural carers, male carers and adult children of people with dementia.

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REGIONAL GROUPS AND SUPPORT - QLD

Alzheimer’s Australia (Qld) operates a varied program of support groups and free activities for people living with Dementia, their carers and family.

INFORMATION ON ACTIVITIES OR GROUPS IN QUEENSLAND

GROUPS FOR FAMILY CARERS, FAMILY MEMBERS AND FRIENDS OF PEOPLE WITH DEMENTIA.

Our support group meetings are a way for carers, family members and friends of people with dementia to form friendships and to discuss common issues. The meetings run throughout the year and can include guest speakers who are local health and dementia experts.

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By now, I’m feeling even more alone…

Remember You are not alone
Alzheimer’s Australia can also put family and carers in touch with other family and carers of people with younger onset dementia, and provide links to support groups.

FURTHER HELP
Carers are not alone
Alzheimer’s Australia offers support, information and referral services and counselling. The National Dementia Helpline on 1800 100 500 can be contacted anywhere in Australia. Alzheimer’s Australia can put carers in touch with other carers of people with younger onset dementia or provide links to carer support groups.

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Face it on Facebook cont...

- Facebook provides another option
- Responses can be edited
- Diversity encouraged
- Anonymity an option
- Raises awareness
- 618 million daily users in Dec 2012

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Wants & needs of people with YOD

- Kutzleben et al 2012 - normality
  - Want to be heard
- Corbett et al 2011
  - Advice & information = QoL
- Roger 2008 – Alz or Huntington’s
  - Loss of connections & identity
- Ablitt et al 2009
  - Lack of attention to PWD’s perspective

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Katie Hildebrand: I am from America and have been diagnosed with Frontotemporal Lobe dementia. I am 47 years old. I have not been able to find a support group for patients, only for caregivers. It is very frustrating. It would be nice to find other people to share experiences with, to take comfort with, and to follow on this journey with.

Debra Bobbermein: Hi, I am the one with Dementia and my Husband is my carer but I also have the rest of my family they are all there for me and my husband can call on them at any time if he needs to talk, they are only a phone call away but we both also know that help from support groups are also just a phone call away. I believe that our families, friends and carers need so much more support then we the people with Dementia would ever need, we get confused and angry with what is happening to us but the people that love us also feel the pain and heart ache watching us fade into our own world where only we can be and I believe we are just fine we don't know what is happening and it is just a normal life that we believe we are living but our loved ones see the different life and the reality that they live every day not being able to help or even be apart of that place we are in would be worse than what is happening to us Dementia sufferers and yet without them we would be nothing. Thank you to all you carers and support groups out there that make it a much easier journey that we are on.

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Online support for others...

- **Chronic illnesses**
  - Cancer, diabetes, asthma, heart, IBS, carers (Coulson et al. 2007, Laakkonen et al. 2012)

- **Brain injury**
  - 60% relied on it for social support
  - 70% of those who didn’t, would like to (Tsaousides et al. 2011)

- **Beneficial for low life satisfaction, vulnerable, lonely** (Tsaousides et al. 2011)

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Reach by area

<table>
<thead>
<tr>
<th>Countries</th>
<th>Towns/cities</th>
<th>Languages</th>
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<tbody>
<tr>
<td>515 Australia</td>
<td>123 Brisbane, Queensland</td>
<td>430 English (US)</td>
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<tr>
<td>37 United States of America</td>
<td>99 Sydney, New South Wales</td>
<td>190 English (UK)</td>
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<td>92 Cairns, Queensland</td>
<td>11 German</td>
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<td>7 Auckland, Auckland</td>
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Reach by gender

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Hi Denise,

Brenda Sue commented on Young Onset Dementia Support Group Qld's status.

Brenda wrote: "Only here have I found anyone...I am in the U.S....I am 36...and am the only patient my nuro has with early PD and now beginning dementia...I am on the exlon patch... I also have 13 year old twins...it is terrifying... But I have to keep my chin up...support would be like life support... B"

Go to comments

Reply to this email to comment on this status.

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Most viewed

4th May 2013
> 616 clicks
545 Viral

Yes
I am a
strong
person,
but every
now and then
I also need
someone to
take my
hand and
say everything
will be okay

soul searchers

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The not so good side

- People need computer, and to read and write
- Sometimes attempts to use internet are thwarted
- Risk of bullying and spam
- Contribution judgement
- **Time consuming**
Sometimes we just need to change our perspective...

Comments, questions, bouquets or brick-bats?

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