WORLD ALZHEIMER REPORT 2012
Overcoming the stigma of dementia

http://www.alz.co.uk/research/world-report-2012
WATCH THE SHORT FILM
Overcoming the stigma of dementia

http://youtu.be/-TC-KDUhBB0
Stigma & Dementia Survey

1. Individual level
   - Questions about experiences of stigma and discrimination

2. Country level
   - Opinions of country level awareness of dementia of general population, political leaders and media
Individual Key Findings

Treated as Human

Being Marginalised
Social Exclusion
Focus on My Abilities

Not Respected
Treated Like a Child
Mocked
Being Marginalised

• “I don’t know if it is a different way but what I feel [sad about] is that they call me ‘Monchito’ [ito is a diminutive so this would be like ‘little Moncho’ in English] instead of Moncho as they used to call me before. They are all really good people but I feel that they treat me like a child.” Person with dementia, Spanish survey

• “I am afraid to tell others that I have dementia. Therefore, other people are always impatient toward me, and sometimes make fun of me”. Person with dementia, Chinese survey
Social Exclusion

“Friends, family are uncomfortable and say they don’t know how to behave ‘normally’ around me anymore – they didn’t really give our relationship a chance to move forward.”

Person with dementia, USA

“Some of my friends have moved on as I can no longer be a part of what I used to do.”

Person with dementia, UK

“Came out straight after diagnosis, writing or contacting over 150 friends, and received less than 5 responses.”

Person with dementia, Australia
Focus on Abilities, not Disabilities

“Showing more positive media stories of living well with dementia. Showing people with dementia using their strategies to live life to the best, coping with the physical and emotional social impacts of this disease.”

Person with dementia, UK
Want to be treated as human

“Recognition that someone with dementia is still a human being and should be treated with dignity and respect and included in everyday activities wherever possible when desired.”

Person with dementia, UK

“To reduce the fear, to have more of an understanding of dementia that I am still a person with feelings and that because I have this diagnosis I am still a human being that just needs a little more attention but not to be condemned to a nursing home.”

Person with dementia, Australia
Country-level Key Findings

*English survey*

**Do people/political leaders/media understand dementia in your country?**

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<th>People in general</th>
<th>Political leaders</th>
<th>Media</th>
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<tbody>
<tr>
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<td>60%</td>
<td>40%</td>
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<tr>
<td>Don't know</td>
<td>10%</td>
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**Do you think there are negative associations (i.e., stigma) about people who have dementia or carers in the country where you live?**

<table>
<thead>
<tr>
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<th>Negative association about people with dementia</th>
<th>Negative association about carers</th>
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<tbody>
<tr>
<td>Yes</td>
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What did we learn from people with dementia

1. Other people (friends, neighbours, etc.) must initiate maintaining the relationship
2. Include people with dementia in conversations; ask the person what is helpful for him/her to be successful
3. Some people with dementia would like to be asked about their condition
4. Accommodate to the new level of abilities of the person
What did we learn from caregivers

1. Social exclusion happens to caregivers too
2. Caregivers also feel marginalised
3. There is a tremendous lack of understanding of what it is like caring for someone with dementia
4. A lot is expected of caregivers from family, community and society as a whole with little support available
There is hope

- 40% of people with dementia reported not being avoided or treated differently
- 59% of people with dementia report having skills and abilities to cope with stigma
- What’s currently working?
Ten key recommendations to overcome stigma

Ten key recommendations to overcome the stigma of dementia

1. Educate the public
2. Reduce isolation of people with dementia
3. Give people with dementia a voice
4. Recognise the rights of people with dementia and their carers
5. Involve people with dementia in their local communities
6. Support and educate informal and paid carers
7. Improve the quality of care at home and in care homes
8. Improve dementia training of primary healthcare physicians
9. Call on governments to create national Alzheimer’s disease plans
10. Increase research into how to address stigma
Recommendation 3: Give people with dementia a voice

- Roles and opportunities
- Abilities and desires of the person with dementia
- Challenges for the person with dementia
- Care partner considerations
- Cultural differences
- Ethical issues
Recommendation 7: Improve the quality of care at home and in nursing homes

• The Challenges
  – In home
    • Family caregivers being criticized for the care they provide by other family members
    • Assumption by other people that a nursing home is inevitable
  – In nursing homes
    • “I’m never going to place my mother in one of those places.”
    • Why???? What can we do about it?
Be part of the solution

Things to think about

- Our own bias towards caring for people with dementia
- Our workforce and what attitudes need to change
  - Staffing ratios
  - Task-oriented versus people oriented
  - Activities
- How our organisation, agency or nursing home fits into our local community
Thank You!

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