Supporting advance care planning on the dementia journey – a new web resource from Alzheimer’s Australia

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Advance care planning

- Thinking about and communicating to others how you would want decisions made for you if you could not make your own decisions in the future
- This might because of an accident, acute illness or loss of capacity from illnesses such as dementia
ACP and dementia

- ACP has some relevance for everyone in the community
- Degree of relevance increases with chronic illness and cognitive impairment
- Particularly relevant in dementia because people will typically lose capacity to make their own decisions
- You need to plan before losing capacity
National group as part of Alzheimer’s Australia
Made up of people with dementia and family carers
Provide funding for projects that they identify as important
20012 funded six projects
Advance care planning project

Objective:
To improve promotion and uptake of ACP for people with dementia in primary and community care through development of a national website

Requirements:
- National reach and impact
- Consumer involvement and engagement
- Consortium approach
- Involvement of Alzheimer’s Australia organisation
National consultations

- Interviews and focus groups in all States/Territories (except NT)
- Those consulted included:
  - People with dementia
  - Family carers
  - Alzheimer’s Australia staff
  - Staff from Health and Guardianship depts
  - Academics and other interested people
Issues identified

- Low awareness of advance care planning
- Shock at time of diagnosis
- Information confusing and difficult to find
- GPs not always helpful
- Differences between States/Territories
- Special issues for younger onset
Low awareness of ACP

“We all think we are not going to need advance care planning – while you don’t have to deal with it you just put it to one side”

“Some people may have a mental checklist of what they need to do – but this will normally stop at Power of Attorney”
Shock at time of diagnosis

“I feel like I am heading into a dark tunnel and I am quite scared. My wife of 48 years is on a journey that is different from mine”

“The initial problem for carers – before they can even think about ACP – is understanding and accepting there is a problem and having some basic ideas about how to proceed”
“We are out in the desert on our own and don’t know where to go”

“People say there is information out there but we can never find what we want – it just feels overwhelming”
“Carers can be accused of trying to undermine their partner – rather than the GP acknowledging that the person has dementia”

“Biggest problem is when you fear something is wrong and you go to a GP – you can just get brushed off”
Differences between States/Territories

“My mother has just moved from Victoria and I have no ideas if her documents are valid here – everything is different”

“We should be lobbying the government to make all the processes and forms the same across Australia”
Special issues for younger onset

“It has been devastating going to so many doctors to try and find out what was wrong with my husband”

“We have a young family. Our life has been turned upside down and nobody accepts she really has dementia. We don’t know where to start in planning our future”
Scope of project

- Aimed at wider community - too late if just aimed at people with dementia
- Need to include wider approach to planning ahead – not just ACP for healthcare
- Need to include end-of-life issues
start2talk website

- Consumer-focused model
- Takes broad approach to planning ahead
- Promotes action through worksheets
- Includes ability to register with the website and store worksheets online
- Main target is general community
Further features

- Also targets persons with dementia & their families
- Comprehensive info & links for all States/Territories
- Section for health & community care professionals
- Section to ask questions and ‘Have your say’
Campaign approach

- Modest advertising campaign at time of launch
- Hope to recruit a range of consumer and professional organisation as campaign supporters who will promote the website to their membership
Launch of start2talk website in August/September

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“Well, when it’s my turn, I just hope I go quietly. ... You know—without a lot of running around.”