

# Advance care planning and end of life: Informing and empowering older people

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# Advance care planning

- Advance care planning (ACP) involves a person thinking about and communicating to others how they would like decisions to be made for them if they have a condition in the future where they can no longer speak for themselves
- For example after a stroke, progressive dementia, or becoming unconscious from some form of accident or illness
- ACP may also include planning on behalf of someone who has lost capacity

# Why is ACP important?

- Future decisions about your care are more likely to reflect your wishes
- Helps you raise sensitive issues about the future with those close to you that might otherwise be avoided
- Reduces the chance of confusion, conflict and guilt if others have to make decisions about your care at some time in the future

# Barriers to ACP

- Low awareness of ACP processes
- Information confusing and difficult to find
- Death-denying within health system and the community
- Over-specialisation of medical care
- Lack of systems to promote and document ACP
- Cultural barriers

# Requirements for information

- Available in different formats
- Includes overview as well as more detail
- Contains practical advice that helps facilitate action
- Disseminated through range of community settings
- Images and information relevant for various cultural communities

# Why empowerment?

- Health system does not always promote informed choice
- Particular pressure can fall on substitute decision-makers
- Health and community staff can play a stronger role as patient/client/family advocates

# Start2Talk website

- Project funded by the Consumer Dementia Research Network within Alzheimer's Australia
- One of six projects funded in 2012
- Objective:
  - To improve promotion and uptake of ACP for people with dementia in primary and community care through development of a national website

# 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



# Project consortium members

- Colleen Cartwright
- Anne Meller
- Lisa Shaw
- Jenny Henderson
- Kylie Sait
- Dimity Pond
- Deidre Fetherstonhaugh
- Chris Hatherly
- Andrew Robinson
- Elizabeth Beattie
- Brendan Moore
- Peter Saul
- Gideon Caplan

# 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
- Also targets persons with dementia and their families

# Further features

- Comprehensive info & links for all States/Territories
- Section for health & community care professionals
- Section to ask questions and 'Have your say'

# Campaign approach

- Advertising campaign at time of launch
  - Online ad on The Senior website
  - Print ad in The Senior paper
  - Facebook campaign
  - Print ad in Go 55
  - Radio ad
  - Stalls at Seniors Week events
- Website has a number of “Supporting Organisations” – national consumer and industry organisations that will promote the website to their membership

# Supporting organisations

- Carers Australia
- Council on the Ageing Australia
- Health Consumers' Forum of Australia
- Federation of Ethnic Communities' Councils of Australia
- Aged and Community Services Australia
- Palliative Care Australia
- Leading Age Services Australia
- Australian Association of Gerontology
- National Seniors Australia
- Royal Australian College of GPs
- Australian Medicare Local Alliance



## WELCOME TO START2TALK



### What is planning ahead?\*

Planning ahead is thinking about your future, and putting things in place so that your choices will be known and acted on if you cannot express these choices yourself later in life.

This may happen if you have a sudden accident, become very ill or develop a condition such as dementia that affects your memory and your planning ability. Planning ahead can include issues related to your finances, lifestyle or health care.

This website will help you to plan ahead for your future. It is a practical and comprehensive resource for people across Australia just like you. It gives you the information you need to make decisions and helps you to put your decisions into action.



*"Start2Talk would give families the chance to think about becoming unwell or developing dementia, but it is important to have plans in place in case we do. Start2Talk has been developed by Alzheimer's Australia and our partners to help all Australians start the conversations involved in planning ahead."*

—The Honourable A.O. OBE  
Australian of the Year 2013  
National President, Alzheimer's Australia

### Planning online

This website offers a number of practical planning worksheets that you can print out or complete and save online. To plan online, you must register here.

[LOGIN](#) > [REGISTER](#) >

### Multilingual Resources



Information about planning ahead and this website is available in 30 languages. Please choose from the list of available languages to download the separate brochures. You will need pdf reader software like Adobe Acrobat.

ENGLISH

start2talk > Early Planning >

START2TALK



# Other resources to know about

- Planningahead tools from NSW Govt  
([www.planningaheadtools.com.au](http://www.planningaheadtools.com.au))  
Rebadged as “Get it in Black and White”
- GroundSwell Project  
([www.thegroundswellproject.com](http://www.thegroundswellproject.com))

**Be aware of  
Dying to Know Day – 8 August**