

Start2Talk

PLANNING AHEAD COMMUNITY EDUCATION RESOURCE KIT

PLANNING AHEAD INCLUDING ADVANCE CARE PLANNING: A FACILITATOR'S GUIDE



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- NSCCH Carer Support Unit. *Advance Care Planning Facilitator's Additional Resources – Community* [internet] Newcastle, Australia; NSW Hunter New England Health; 2009 (cited 15 Dec 2016) Available from http://www.cclhd.health.nsw.gov.au/patientsandvisitors/CarerSupport/cpa/Documents/ACP_Facilitators_Resources.pdf
- Coalition of Compassionate Care of California. *Talking it Over: A Guide for Group Discussions on End-of-Life Decisions* [internet] Sacramento, USA: 2014 (cited 15 Dec 2016) Available from <http://www.amethystmed.com/uploads/1/7/7/9/17797177/talkingguide.pdf>

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Table of Contents

Introduction	3
Terminology	4
Role of the group facilitator	5
Facilitator ground work	5
Useful tips	6
Delivery	6
Content.....	7
Suggested Presentation Formats	9
Community Facilitator Presentation – 1 hour	9
Learning outcomes	9
Resources.....	9
Format	9
Community Facilitator Presentation – 2 hours	10
Learning outcomes	10
Resources.....	10
Format	10
Community Facilitator Workshop – 2 – 5 hours	11
Learning outcomes	11
Resources.....	11
Format	11
TAFE Educator Presentation – 1 hour	12
Learning outcomes	12
Resources.....	12
Format	12
TAFE Educator Presentation – 2 hours	12
Learning outcomes	12
Resources.....	12
Format	13
Home Care Staff Presentation	13
Learning outcomes	13
Resources.....	13
Format	13
APPENDIX A: Invitation template.....	14

Introduction

The Community Education Resources Kit, which includes this Facilitator's Guide as well as other resources, was developed to raise awareness and to encourage early financial, lifestyle and health planning including advance care planning (ACP) in the community. Planning ahead in the community is important for everyone. It is particularly important for people with dementia and other forms of cognitive decline as it is more certain that their capacity to actively participate, express their wishes and choices and make decisions in the future will decline over time. Planning ahead can reduce stress on individuals, their family and carers and allow for care in the future to match the wishes and choices of the person. The Guide and resources are intended for:

- Facilitators or co-ordinators of community groups e.g. seniors and veteran's groups;
- TAFE aged care, community and health courses
- Home Care staff

The Guide covers: the role of the facilitator; useful tips, suggested presentation formats and resources that can be used to support these presentations.

The Planning Ahead Community Education Resources Kit can be found at: www.start2talk.org.au

Comprising:

- Planning ahead including advance care planning: A facilitator's guide
- Case studies: Planning ahead including advance care planning and substitute decision making
- Scenarios: Planning ahead including advance care planning and substitute decision making
- Planning ahead including advance care planning video
- Planning ahead including advance care planning podcasts
- Planning ahead including advance care planning presentation template

Other resources at www.start2talk.org.au include:

- Brochures: Substitute Decision Making
- Planning Ahead Workbook: Start2Talk Information and Worksheet booklet
- Start2Talk Quick Guide to Planning Ahead

Terminology

Be aware that there is varying terminology used across the states and territories around substitute decision making (SDM) and ACP. There is currently no consistent terminology across Australia. Sometimes even experienced health and other professionals will use the terms advance care plans interchangeably with 'advance care directives' or 'health directions'. This can cause confusion as some documents are statutory (legal) documents and some are 'prescribed' or 'recommended' only. This is seen as problematic in the field of advance care planning and it is hoped in the future that this will change.

It is useful to use 'advance care planning' as a generic term for the 'process' of planning for health and personal care in the future. It is important that before facilitating a session you are familiar with the legal and government prescribed documents in the state or territory where the group session is being undertaken. For state and territory specific information, resources and documents follow the links on the national websites www.start2talk.com or <http://advancecareplanning.org.au>

Planning ahead is broader than ACP which often focuses just on health and sometimes personal care and appointing a substitute decision-maker for health and personal care. Planning ahead includes planning across a range of financial, health and personal care issues including preparation of wills, power of attorney (financial), nomination of substitute decision makers (SDM) for personal and health care , advance care planning (ACP) and lifestyle planning e.g. accommodation, support services, work and driving.

Role of the group facilitator

As a facilitator it is your role to assist the group participants to get the most out of their attendance and participation. It is a good idea to clarify your role to the group. For instance as a facilitator you may not be an 'expert' in 'planning'. However you do need to feel comfortable with the content and understand the benefits of planning ahead. You will also need to know and be able to refer participants to other people, services and websites for assistance and further information.

The facilitator needs to be mindful that participants may have varying needs, and come from different backgrounds, have varying literacy and health literacy levels as well as communication skills. Participants may also have health issues including visual, hearing and mobility issues. The facilitator needs to be mindful of these factors. The facilitator also needs to be able to manage the group including keeping proceedings on track so that the session covers the information that it aims to cover and that the session meets the needs of the group as a whole.

Facilitator ground work

As a facilitator of a group where you are encouraging planning ahead, including advance care planning, you have to believe yourself that this is a worthwhile activity and that it has real and significant benefits for individuals and their families or carers. Planning ahead does in fact make life easier, not only in the short term, but also in the medium and long term when/as health declines and important health or other lifestyle decisions need to be made.

It is unfortunate that people often leave having discussions and making decisions on appointing a substitute decision maker and choices about healthcare too late. It is not a good idea to begin planning at a time of crisis in a hospital emergency room or intensive care unit. Nor when a person's health has declined and they have become incapacitated and unable to make decisions for themselves e.g. advanced dementia or other chronic conditions. At these times substitute decision makers, families and carers can find making decisions extremely difficult and can be distressed if they have to make decisions that they are not sure that their loved one would have wanted.

Be prepared yourself so you know what you are talking about. Do your own planning before you facilitate a group or in-service training.

Examples: Have you completed your will, appointed a SDM and undertaken advance care planning for yourself or assisted a loved one to undertake this planning? If you have not done this then what is stopping you? Remember that the same barriers may be preventing your participants from undertaking early planning and advance care planning as well. It is not unusual for adults to put off what is not seen as necessary until it becomes necessary, but then it may be too late!

Useful tips

Delivery

- **Preparation:** Be prepared – know the information and content of the presentation and have enough resources for the group i.e. brochures, planning booklets etc. compiled and at hand ready to give to participants.
- **Evaluation:** Develop an evaluation questionnaire to give to participants for feedback or rating of the presentation or group session. This provides useful information for improvements for the next group session.
- **Equipment** – Find out what equipment is provided and what you need to bring. Make sure all equipment is in good working order and you are able to use it.
- **Venue** – Ensure the venue is accessible especially for people with mobility issues and parking is available.
- **Seating:** If possible seating should be placed in a semi -circular rather than class room style rows. This is less formal and makes for greater participation of group members.
- **Ground rules:** Cover the ground rules upfront with the group as this is especially important if there is group discussion. Ground rules can include: being respectful of other's input by listening; allow everyone to have a say; what is said in the room stays in the room and to offer input into the group discussion in the 'spirit of sharing' not lecturing others.
- **Pace:** Keep the session moving and be mindful that in a discussion no one person should dominate and all participants have a chance to contribute. Invite quiet participants to share by asking what they may think, however don't insist if they seem reluctant to share.
- **Silence:** Be mindful that sometimes silence is ok and it may mean that the group members are thinking and reflecting before responding to a question you have asked.
- **Sensitivities:** Remember that the topics of discussion may bring up difficult experiences for people. They may have had difficulties in their own family in the past, or may be encountering their own challenges at the time of participating in the session. Always begin the session by acknowledging these difficulties and challenges and remind participants to be sensitive. You may also want to clarify with participants that if they would like some time to have a break from the session, then that is fine.
- **Clarification:** If you are confused by something a participant has said then chances are others may be as well, so it is best to simply ask them to clarify by using another question.

- **Winding up the session:** Towards the end of the session warn the group that there are a few minutes left of the session so you don't finish abruptly. The group has time also to ask any questions that have not been answered previously but are considered important.
- **Questions:** If asking questions of the group don't forget to ask open ended questions that encourage discussion versus closed question which require only a yes or no answer.

Content

- **Include:** Introductions; icebreaker exercise(s); overview of session content; ground rules; housekeeping e.g. comfort breaks, emergency procedures; and learning outcomes.
- **Language:** Avoid jargon, acronyms and complex medical or legal terminology. Use language that is appropriate for the group.
- **Humour:** The use of humour is very useful to engage participants and to relax the mood of the group. However be mindful that humour is also quite individual and what is humorous to one person may not be to another, so use humour e.g. cartoon, joke or funny story judiciously.
- **Group interaction and sharing:** Avoid 'talking at' the group for extended periods. Invite interaction by posing questions to the group and seeking their input or sharing. This changes the pace and makes the session more engaging and stimulating. People are the 'experts of their own lives' and the sharing of their stories and insights can be of benefit to others going through similar life experiences. Videos and podcasts can also be used for a change of pace and for other voices to be heard and to stimulate discussion.
- **Further information and assistance:** This can be done during the session or at the end. It is important to ensure that if you don't know an answer that you say so and that you will follow up with the relevant service/agency for advice i.e. a government body e.g. Public Advocate or Public Guardianship and will get back to the participant in a timely manner.

If the issues are complex and require more than a simple straight forward response or you are not sure, then a referral may be best. You can suggest that the person contact the agency themselves. To be helpful and professional provide the contact details to the participant either at the session or take the contact details of the participant and contact them at a later time with the agency's contact details. It is preferable to give the agency a heads up or confirm that they are able to provide an answer or give assistance.

- **Use of stories, anecdotes, case studies and scenarios:** Stories, anecdotes and case studies are useful to illustrate a point or process e.g. appointing a SDM or why ACP is important. Scenarios with questions are a useful tool for learning and to generate discussion. Be sure to remove identifying information such as names, age or ethnicity to maintain confidentiality and privacy. It is also recommended not to have stories or anecdotes that are too lengthy or complex.

- **Guest speakers** can also be used to provide specialist information and answer questions from the group. Speakers may be sourced from local health services e.g. community dementia nurse; Alzheimer's Australia state or regional office; state or territory Public Advocate or Guardianship Office; Respecting Patient Choices or other advance care planning program; non-government financial planner or local law firm. Just be aware that if asking for a speaker from a commercial entity there will always be a commercial imperative to seek 'business', however sometimes this may work in a panel format in a 'community forum'.

Suggested Presentation Formats

You can use the method that best suits the group considering the size, needs and interests of the group.

A more formal lecture style/presentation may be used for larger groups. An informal 'chat' with printed information may work best for a smaller informal group who generally meet over a morning tea etc. An appropriate DVD with discussion points around the issues raised can also be useful in a small group. See national websites for links to state and territory resources including videos at www.start2talk.org.au or <http://advancecareplanning.org.au/>

A panel forum approach can be very effective for very large group gatherings in a club or town hall. Invite a lawyer from a local law firm to speak on wills and appointing a financial substitute decision maker in your state or territory, a financial planner from the community sector and a health professional to talk on advance care planning and appointing a substitute decision maker for health and personal care.

When working in or with a church or spiritual group you can adapt the presentation to include relevant content from scriptures or teachings.

If the group has a particular interest in any aspect of the presentation e.g. advance care planning or financial planning or lifestyle issues you could consider a separate session that focuses on just this subject and consider a guest speaker or use a suitable video for the content. Detailed information on financial, lifestyle and health planning can be found at the www.start2talk.org website.

Community Facilitator Presentation – 1 hour

Learning outcomes

Participants will:

1. Understand what planning ahead is including financial, lifestyle and health
2. Understand why planning ahead including ACP is important
3. Know the key principles of choosing a substitute decision maker (SDM)
4. Identify their state or territory specific information, documents and resources and where to go for more information and assistance

Resources

- Community Education Resource Kit at www.start2talk.org.au
- Planning Ahead Workbooks: Start2Talk Information and Worksheet booklet and the Quick Guide to Planning Ahead at www.start2talk.org.au
- Brochures: Substitute decision making at www.start2talk.org.au

Format

- Introductions, ground rules, house keeping
- Overview
- Presentation on Planning Ahead including ACP: either use PowerPoint; laminated cue cards with key messages or verbal informal chat
- Include a short video if time permits

- Distribute and explain the resources e.g. Start2Talk workbooks, SDM pamphlets or state or territory specific materials and/or documents. For links see the national websites as below.
- Where can people go for more information e.g. websites www.start2talk.org.au (for broader planning issues) or <http://advancecareplanning.org.au> (for ACP only).

Community Facilitator Presentation – 2 hours

Learning outcomes

Participants will:

1. Understand early planning is including financial, lifestyle and health aspects
2. Understand why early planning is important
3. Understand what ACP is and why it is important
4. Know the key principles of choosing a substitute decision maker (SDM)
5. Identify their state or territory specific information, documents and resources and where to go for more information and assistance

Resources

- Community Education Resources Kit at www.start2talk.org.au
- Planning Ahead Workbooks: Start2Talk Information and Worksheet booklet and the Quick Guide to Planning Ahead at www.start2talk.org.au
- Brochures: Substitute decision making at www.start2talk.org.au

Format

- Introductions, ground rules, house keeping
- Overview
- Presentation on Planning Ahead: either use PowerPoint; laminated cue cards with key messages or verbal informal chat
- Include a short video if time permits
- Break e.g. morning tea
- Distribute and explain the resources e.g. Start2talk workbooks, SDM pamphlets or state or territory specific materials and/or documents. For links see the national websites as below.
- Where can people go for more information e.g. websites <http://advancecareplanning.org.au/> (for ACP only) or www.start2talk.org.au (for broader future planning).

Community Facilitator Workshop – 2–5 hours

Learning outcomes

Participants will:

1. Identify their values and understand how these values influence life decisions past present and future
2. Understand the benefits of planning across financial, lifestyle and health
3. Understand what ACP is and why it is important
4. Understand how to have a values based advance care planning (ACP) conversation
5. Understand how to choose and appoint a SDM
6. Understand how best to support a loved one with making a decision if they have dementia or other form of cognitive decline
7. Understand what helps when you need to make decision for someone as a substitute decision maker
8. Identify their state or territory specific information, documents and resources and where to go for more information and assistance

Resources

- Community Education Resource Kit at www.start2talk.org.au
- Planning Ahead Workbooks: *Start2Talk Information and Worksheet Booklet* available at www.start2talk.org.au
- Brochures: Substitute Decision Making at www.start2talk.org.au

Format

- Introductions, workshop overview and icebreaker
- Looking back on life exploration: What values have been consistent over time.
- **Exercise** for individual reflection and completion: *Start2Talk Information and Worksheet Booklet. Worksheet 4a: Values, wishes and preferences Life Values* (5 questions). Allow 5-10 minutes for this exercise.
- How have these influenced the decisions we make?
- 'Where am I now' exploration: What is important to me in life now, what do I regard as 'quality of life'
- **Exercise** for individual reflection and completion: *Start2Talk Information and Worksheet Booklet. Worksheet 4a: Quality of Life* (3 questions). Allow 5 minutes for this exercise.
- The future and life transitions exploration: How planning helps
- Break
- Substitute decision making (SDM): Keeping your voice: The what, why and how of SDM
- **Exercise** for individual reflection and completion: *Start2Talk Information and Worksheet Booklet. Worksheet 3: Who will be my spokesperson on healthcare issues* (9 questions) Allow 10-15 minutes)
- Advance Care Planning (ACP): Keeping control: The what, why and how of ACP including the 'values based conversation'.
- **Exercise** for individual reflection and completion: *Start2Talk Information and Worksheet Booklet. Worksheet 5: Communicating my wishes to others* (3 questions and additional first 2 questions under Overcoming barriers). Allow 10 minutes for this exercise)

- Identify state specific information, documents and resources and where to go for more information and assistance.

A follow up session with potential guest speakers can be given as an option for any document assistance/completion and where and to whom to give copies.

TAFE Educator Presentation – 1 hour

E.g. aged care, community and mental health and enrolled nurses

Learning outcomes

Participants will:

1. Understand what the fundamentals of early planning
2. Understand why early planning and ACP is important for people with conditions like dementia (visit <https://www.fightdementia.org.au>)
3. Understand the what why and how of SDM
4. Understand the what, why and how of ACP
5. Explore how ACP relates to potential work in the aged, community or health sectors
6. Identify where to go for state or territory specific information, resources and documents

Resources

- Community Education Resources Kit at www.start2talk.org.au
- Planning Ahead Workbook: Start2Talk Information and Worksheet booklet and the Quick Guide to Planning Ahead at www.start2talk.org.au
- Brochures: Substitute decision making at www.start2talk.org.au

Format

- Presentation on early planning (visit www.start2talk.org.au and <http://advancecareplanning.org.au>)
- Video
- Potential roles and application in the workplace
- Where to go for more information, resources and document

TAFE Educator Presentation – 2 hours

Learning outcomes

Participants will:

1. Understand the fundamentals of early planning
2. Understand why early planning including advance care planning is important for people with conditions like dementia (visit <https://www.fightdementia.org.au>)
3. Understand the what, why and how of SDM
4. Understand the what, why and how of ACP
5. Explore how ACP relates to potential work on the aged, community or health sectors
6. Identify where to go for state or territory specific information, resources and documents.

Resources

- Community Education Resources Kit at www.start2talk.org.au

- Planning Ahead Workbook: Start2Talk Information and Worksheet booklet and the Quick Guide to Planning Ahead at www.start2talk.org.au
- Brochures: Substitute decision making at www.start2talk.org.au

Format

- Presentation on early planning (visit www.start2talk.org.au and <http://advancecareplanning.org.au>)
- Video
- Break
- Scenarios: Break class up into small groups for discussion of scenarios.
- Reconvene in the larger group so that a representative for each group can report on the responses to the questions
- Potential roles and application in the workplace
- Where to go for more information, resources and document

Home Care Staff Presentation

Learning outcomes

Participants will:

1. Understand dementia care principles (visit <https://www.fightdementia.org.au>)
2. Understand the what, why and how of SDM
3. Know the what, why and how of ACP
4. Know what their role is to support ACP in Home Care service delivery

Resources

- Community Education Resources Kit at www.start2talk.org.au
- Planning Ahead Workbooks: Start2Talk Information and Worksheet booklet and the Quick Guide to Planning Ahead at www.start2talk.org.au
- Brochures: Substitute decision making at www.start2talk.org.au

Format

- Dementia Care Principles
 - Person centred care for people with dementia (visit <https://www.fightdementia.org.au>; Useful reference: Brooker, D. Person centred dementia care: Making services better. London: Jessica Kingsley, 2007)
 - What is supported decision making (visit www.capacityaustralia.org.au)
 - Understand a person's values and what is important to them if their life (ACP)
- The what, why and how of SDM
- The what, why and how of ACP (visit www.advancecareplanning.org.au or www.start2talk.org.au)
 - The ACP conversation (visit <http://www.swslhd.nsw.gov.au/mywishes>)
 - How decision making is based on values and these ACP conversations
- Home Care staff role in ACP

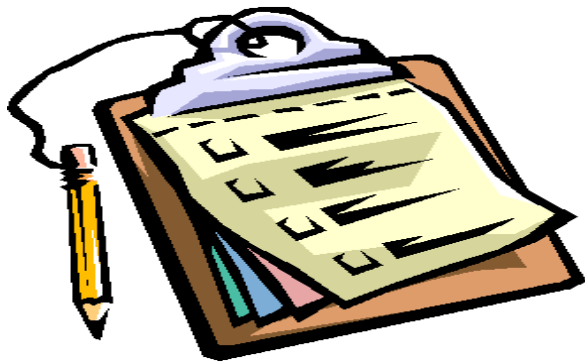
APPENDIX A: Invitation template

Planning Ahead

Are you facing a life transition? Downsizing or seeking a sea change? Requiring aged care services for assistance at home? Retiring from full time work? Just been diagnosed with a chronic health condition e.g. dementia?

Are there decisions that you have to make or think about making?

This information session on **planning ahead** will help you get started.



Why attend the session?

It will assist you to:

- Know what is planning ahead, including advance care planning for healthcare, and choosing a substitute decision maker
- Know why it is important
- Know where to go for more information
- Start the process of planning ahead

Where:

When:

Time:

Cost:

For further information and rsvp please contact: