

# Start2Talk

## PLANNING AHEAD COMMUNITY EDUCATION RESOURCE KIT

### **Case studies: Planning ahead including advance care planning and substitute decision making**

#### **Acknowledgements:**

This project was funded by the National Health and Medical Research Council's (NHMRC) Cognitive Decline Partnership Centre (CDPC). Generous support and contributions of time were made by the Stakeholder Advisory Committee and our project partners HammondCare, Alzheimer's Australia, Brightwater Care Group and KinCare. We would also like to thank our community partners Alzheimer's Australia ACT, National Seniors Illawarra and the representatives from the Alzheimer's Australia's National Dementia Consumer Network who so generously offered their time and energy in developing these resources.

## Who will speak for you if you can't: Choosing and appointing a substitute decision maker

Betty is an elderly widow who has been newly diagnosed with dementia. Betty has a son, John and a daughter Kathleen who live a few suburbs away and visit her regularly. Betty feels that John is good with money and could look after her financial affairs. Whilst Kathleen knows Betty's wishes to live at home as long as possible.

Betty decides to legally appoint John as her substitute decision maker for financial matters so that he can look after her pension, pay the bills and manage her assets when she can no longer do so. She decides to legally appoint Kathleen as her substitute decision maker for health and personal care, so that Kathleen can make decisions for health and personal care matters. Betty knows that the authority to make financial, health and personal care decisions for her will only come into effect when she loses capacity.

Both John and Kathleen understand the importance of these roles, have accepted their appointment as substitute decision makers and organise with Betty to complete the paperwork. Betty and Kathleen make an appointment with Betty's GP to talk about her illness and the types of health and personal care decisions that will need to be made in the future.

## How to start a conversation about your wishes with your substitute decision maker

Rosa has appointed both her husband Gino and her daughter Cara to be her substitute decision makers for personal and health care. Rosa and Gino share similar values and wishes about health care. Rosa suspects that Cara may not fully know her wishes and choices about personal and health care.

When Rosa is diagnosed with dementia she knows she needs to have a conversation with Cara sooner rather than later, as she knows that she will progressively lose the ability to talk about her wishes and make decisions for herself.

Rosa organises for her and Gino to meet with Cara for lunch at home, on a day they all have free time and there are few other distractions. Rosa has already decided that she needs to gently tell her daughter about her diagnosis before the lunch so her daughter has time to process the information and be prepared to listen to Rosa's wishes.

Rosa decides not to overwhelm their daughter with too much information at this time and just talk about the things she loves about her life and that have given her life meaning including gardening, reading, travel and family celebrations. She knows that Cara needs to understand this in order to better make decisions when needed. Rosa decides that she will have more conversations with Gino and Cara about her wishes and choices about health and medical treatment over the coming weeks.

## Sharing your values, wishes and preferences with your substitute decision maker

Brad has been newly diagnosed with younger onset dementia. Brad is estranged from his family, and knows that in the state of Australia in which he lives, his family may be identified as substitute decision makers when he loses capacity to make decision for himself. Brad decides to choose and to legally appoint his best friend Garry as his substitute decision maker for health and personal care, while he still has legal capacity to do so. Brad has had a consultation with his doctor about his illness and the sort of decisions he would need to make in the future as the illness progresses, including continuing to drive and work.

Brad decides that it is best to talk to Garry about his values and wishes, to make decision making easier for Garry when the time comes, when he can no longer express his wishes and make decisions for himself.

Brad tells Garry that he wants his dog Tasha to go to his cousin Melissa, who has agreed to look after him. Brad expresses his wishes to stay at home for as long as possible with some home help. However, when the time comes when he can no longer look after himself he tells Garry that he has put his name down in the dementia care facility in the next suburb. This facility has a homey environment in a garden setting and values residents' independence and dignity. Garry tells Brad that he will carry out his wishes and choices.

## **Substitute decisions makers supporting a person to make their own decisions**

Ada had been appointed as a substitute decision maker for health and personal care for her older sister Gita a number of years ago, just prior to her being diagnosed with dementia. Over time Ada notices that Gita is finding it more difficult to remember things and to make decisions.

Gita has been assessed by her GP as no longer being able to make legal decisions such as making a will or enduring power of attorney, however Ada knows that Gita can still express her wishes about personal and health care if she is supported to do so. Ada knows that to support her sister to make a decision that it is best to talk with her in the morning, as Gita is more alert at this time of day. When Ada asks Gita questions she uses simple language, speaks slowly, asks only one question at a time and waits for a response before proceeding. By supporting Gita in this way Ada finds that Gita can still make her own decisions on a range of things including household matters and where she likes to go on a holiday, even though she needs help to organise these things.

## **When you need to make a decision for someone as a substitute decision maker**

Frank knows that the best way to make a decision for his good friend Sam, as his appointed substitute decision maker, is to 'stand in his shoes'. Frank and Sam have had numerous conversations over many months about Sam's wishes and choices about his finances, personal and healthcare, starting soon after his diagnosis with dementia. Having had these conversations makes Frank feel confident that he would be able to 'stand in Sam's shoes' when making a decisions when Sam can no longer make decisions for himself.

When Sam can no longer communicate his wishes, Frank consults with Sam's doctors to make sure he has all the information he needs to make decisions about Sam's health care. Frank also reviews the copy of Sam's advance care plan. Frank feels an enormous relief that the important things about health care they had previously discussed had been recorded in this advance care plan. This forward planning now helps Frank to make the decisions on Sam's behalf, knowing these are the decisions that Sam would have made for himself.

## **Why is planning ahead including advance care planning important for everyone and especially someone with dementia**

Lee has just been diagnosed with Alzheimer's disease and he, and his partner Fai, decide that they both need to complete their will, appoint substitute decision makers for financial, health and personal care and do an advance care plan. Lee and Fai had delayed thinking about these things for a long time but know they can no longer delay this planning.

Lee and Fai's visit to Lee's GP provides them with information about Alzheimer's disease and how it will affect Lee's ability to make decisions in the future. Lee appoints Fai, as well as his brother Sun, as his substitute decision makers for health, personal care and financial matters. Lee wants to maintain control of his life for as long as possible, even into incapacity, and knows this is best done by telling his substitute decision makers his wishes about his health care, where and how he wants to live and what he wants done with his assets. Lee knows that his substitute decision makers needs to know these things in order to make the sort of decisions that he would want. Both Fai and Sun express relief and welcome these conversations as they now feel more confident to make decisions for Lee when he can no

longer make them for himself. Fai also decides to complete an advance care plan and appoint a substitute decision maker for herself to ensure she is prepared for the future.

## **How does a conversation about values, wishes and choices translate into an advance care plan**

Doug shared with his good friend and substitute decision maker Anne that he wanted to develop an advance care plan for himself. “It would be good”, he said to her, “to have a conversation about his wishes and choices first, before he wrote anything down in an advance care plan”. Doug printed off the documents from the Start2Talk website. Doug shared with Anne that he valued living a full and independent life for as long as possible, even though he had been diagnosed with dementia. Doug said that he valued a good quality of life, over quantity, as measured in years. A good quality of life for him meant that he could continue to attend sporting events for as long as possible and when this was no longer possible to be able to watch them on TV. He also expressed how he liked the company of friends. If the time came when he no longer knew who he was, where he was or who he was with, then he did not want to be kept alive by aggressive treatments in hospital. Doug said that he wanted to live and die in peace with pain relief. Anne agreed that when the time came that Doug could no longer make his own decisions that she would make decisions based on these wishes. Doug subsequently wrote these choices down in his advance care plan and gave Anne, his GP and his local hospital a copy.

## **The value of advance care planning and substitute decision making documentation when the time comes to make decisions**

Frieda is a seventy five year old woman who lives with her brother and sister in-law. She has advanced dementia and has just been hospitalised due to complications of recent hip replacement surgery. The doctors have asked to speak to Frieda’s nominated substitute decision maker for health care. Frieda had, many years ago, appointed her younger brother Klaus and sister-in law Meredith as her substitute decision makers for health and personal care. Klaus has now given a copy of the documentation to the doctors and has arranged for a family meeting to speak about Frieda’s treatment plan.

In the course of the conversation Klaus and Meredith indicate how they have been struggling with the increasing demands of Frieda’s care at home. The treating team including the doctor’s and social worker have asked if Frieda has an advance care plan. Frieda had completed one with Klaus and Meredith just after she had been diagnosed with dementia. The advance care plan is reviewed for Frieda’s wishes and choices about health and personal care.

The advance care plan clearly states that Frieda wished to stay at home for as long as possible but when her needs increased to a level where high care was needed then she wished to be admitted to a dementia specific facility. Frieda was clear that she did not want to be a burden to her family. She wished for her dog Missy to remain with Klaus and Meredith so that she could still see her dog on visits. She also stated that she had been a vegetarian all her life and wished to remain on a vegetarian diet when she entered the facility. Frieda had also chosen in her advance care plan that when she had advanced dementia she wished not to receive aggressive treatment and to be allowed to die naturally with dignity and in peace in the facility.

## Planning ahead for someone with early onset dementia

Mr and Mrs Li have made an appointment to see the community social worker Alice as Mr Li has been diagnosed with early onset dementia. The couple are concerned about the impact that this diagnosis of dementia will have on their life including Mr Li's continued employment.

Alice discusses with the couple the benefits of planning ahead especially as Mr Li will at some stage lose the ability to keep working and will need support in making decisions as his illness progresses.

Mr Li indicates that he feels that he is still able to work and that work has been an important part of what he regards as a good quality of life. Alice advises that Mr Li should consider speaking to his employer about his dementia and the possibility of continuing to work with possible reduced hours or workload. Alice also advises that the couple should approach Centrelink about possible government allowances once Mr Li is unable to work. Alice reassures Mr Li that even when he no longer is able to maintain paid employment it is still important for him to keep active and volunteer work may be an option for him to consider.

Alice advises that planning ahead also includes other aspects of financial planning including reviewing bank accounts, mortgage and insurance policies and Mr Li's Will. Alice also stresses that appointing a substitute decision maker for financial matters as well as health and personal care is also important. As legal appointment of a substitute decision maker needs to be completed whilst the person still has capacity to complete and sign the legal documents.

Alice provides contact information for Alzheimer's Australia for additional information and support services on financial and other matters. Alice also advises the couple to check the state government website for information on substitute decision making.

Mr and Mrs Li express their satisfaction with the assistance provided and make a subsequent appointment to speak to Alice about what they should do about their accommodation, carer supports for Mrs Li and health planning for Mr Li.