2016

Final Report

LIVING WITH DEMENTIA IN THE COMMUNITY: PLANNING FOR MY FUTURE

ACTIVITY 8

UNIVERSITY OF NEWCASTLE | Professor Dimity Pond, Robin Scott,
Dr Jenny Day, Evelyn Mueller, Nigel Catzikiris, Gjyn O'Toole,
Elizabeth Cunningham and Deborah McKinney

THE UNIVERSITY OF NEWCASTLE AUSTRALIA

COGNITIVE DECLINE PARTNERSHIP CENTRE

Conducted by: Professor Dimity Pond
Discipline of General Practice
Faculty of Health and Medicine
The University of Newcastle, Australia.

Authors: Professor Dimity Pond, Robin Scott, Dr Jenny Day, Evelyn Mueller, Nigel Catzikiris, Gjyn O’Toole, Elizabeth Cunningham and Deborah McKinney.

Acknowledgements: This project has been funded by the Cognitive Decline Partnership Centre. We would also particularly like to acknowledge Danijela Hlis, Ian Gladstone, Joan Jackman & Ron Sinclair, who – as members of Alzheimer's Australia Consumer Dementia Research Network – provided consumer input through their Advisory Group membership.

Disclaimer: The views expressed in this work are the views of its author/s and do not necessarily represent those of the Cognitive Decline Partnership Centre or the University of Newcastle, Australia.

Contents

Executive Summary

Age and disease related physical and psychological changes can lead to changes in an older person's ability to carry out their activities of daily living (ADLs) and live in the community. People living with cognitive decline in the community are exposed to a number of additional risks associated with their ADLs, and difficult decisions may be made which negatively impact on the person's quality of life and independence. These include decisions about whether to restrict the person's ability to drive, to continue living alone, to independently shop or take medications, and when to move into residential aged care. Such important decisions require an assessment of the risks faced by the older person, a task that is often done in an informal or broad manner by family members, paid carers and professionals. Once risks are assessed, strategies need to be negotiated and put in place to ameliorate risks without adversely impacting on independence and quality of life. For this purpose a multi-faceted risk assessment tool has been designed for people living with cognitive decline in the community. This tool aims to help the individual themselves assess and manage current and future physical and psychosocial risks to independence and quality of life whilst living in the community; and to enable a person living with cognitive decline to live safely and independently for as long as possible in the community. In addition, the use of an advance care plan (ACP) tool was trialled to gain insight into the use of supported decision making and the ACP processes undertaken by older people with cognitive decline in the community. This included gaining an improved understanding of the issues/concerns that may impact on the completion of ACP with older people in the community by general practitioners (GPs) and practice nurses (PNs). A summary of recommendations from both aspects of the project are detailed below.

Summary of recommendations

1. Risk Assessment Tool

- The risk assessment tool should undergo further trial in general practice and community aged care settings to further refine its useability, applicability and adaptability across a number of clinical contexts and general practice working structures,
- Further evaluation of the risk assessment tool should be undertaken with older people in the community,
- Input from, and endorsement by, international experts in the field of aged care and cognitive decline should be sought,
- Once there is a final version of the tool, work with the Cognitive Decline Partnership Centre (CDPC) to develop an electronic version of the risk assessment tool available for download via the CDPC website,
- Promote and disseminate a final version of the tool to key stakeholders: Primary Health Networks (PHNs), Aged Care Providers, Dementia Study Training Centres, providers of culturally and linguistically diverse (CALD) services, General Practice Regional Training Organisations (RTOs), The Royal Australian College of General Practitioners (RACGP) and the Australian College of Rural and Remote Medicine (ACRRM),
- Promote the use of the risk assessment tool at relevant general practice, aged care and cognitive decline /dementia conferences,
- Educate GPs and PNs and community aged care service providers, including those who provide services to patients from CALD backgrounds, in the use of the risk assessment tool as an adjunct to the revised primary care dementia guidelines under development as part of CDPC Activity 14, and
- An economic evaluation of the tool should be undertaken.

2. Advance Care Planning

- Health professionals who introduce ACP to older people/their families should have sufficient knowledge of the process and be able to answer the questions that older people/their families may pose.
- ACP should be introduced to older people/their families and completion encouraged. However readiness to engage in this process needs to be considered and an individualised approach taken to plan completion.
- Health care professionals should not rush completion of ACP.

Background

Age and disease related physical and psychological changes can lead to changes in an older person's ability to carry out their activities of daily living (ADLs) and live in the community. People living with cognitive decline in the community are also exposed to a number of risks associated with safe completion of their ADLs, often necessitating difficult decisions about safely managing the person's ADLs. These include decisions which restrict the person's ability to drive, to continue living alone, to cook, to independently take medications, or when it is appropriate for the person to move into residential aged care. The decisions taken may negatively impact the person's future, quality of life, independence and ability to age-in-place at home.

Such important decisions require an assessment of the various risks involved in each ADL, a task that is often informally or broadly completed by family members, paid carers and health professionals. Most of these decision makers are not experienced at working through the ethical dilemmas, risk enablement and other issues involved in the process. Taking an overly risk-averse stance when assessing ADL risks and making decisions, perhaps out of fear of injury, can inadvertently have a negative impact on the person's autonomy, independence and quality of life.

A risk assessment framework with a checklist of ADL activities included in the assessment process would improve this situation by enabling people with cognitive decline in the community to identify and manage risks proactively and, if they are not able to do so, by assisting people who support them to collaboratively make decisions about their support and care. Such a tool exists in the United Kingdom but there is no equivalent in Australia for general practice or community aged care. The current project aimed to adapt the *UK Risk Assessment Framework* (Department of Health Older People and Dementia Branch, 2010) for use in Australia, exploring its applicability to the assessment of physical and psychosocial risks for people with cognitive decline who live in the community. By doing so a context relevant and practical risk assessment tool has been developed for people living with cognitive decline, their carers and professionals who work in the area of community aged care.

Research aims

The aims of this project were to:

- Adapt the existing *UK Risk Assessment Framework* as a tool for use with people with cognitive decline in primary health and community settings in Australia,
- Evaluate the tool from the perspective of consumers, their carer/s and care professionals, and
- Disseminate the evaluated tool through conferences and workshops.

In addition to these aims, the researchers, at the request of the funders, concomitantly aimed to:

- Better understand the advance care planning (ACP) process as undertaken by older people with cognitive decline in the community.

Method

The current project used a qualitative research design and was conducted as a follow-up to the *Dementia/Aged Care Nurse Practitioner (DACNP) research project.* Conduct of the project involved concurrent development of an ADL risk assessment tool (RAT) and trial of tool versions with older people living in the community/their carers. Concomitantly, completion of ACP processes was trialled with community based older people using an existing ACP tool: the Hunter New England Local Health District advance care plan tool (Hunter New England Local Health District, 2015) (See Appendix 1).

Ethics approval

The project was undertaken as a variation to the *DACNP research project*. The University of Newcastle Human Research Ethics Committee (HREC) approved the *DACNP research project* according to the study protocol (H 2012-0031) and subsequent variations relating to this project. All information from this project conformed to ethics guidelines for storage and use. The research was conducted within the scope of the HREC guidelines and the University of Newcastle health and safety policies.

Project oversight

- A steering committee made up of Australian and international experts in primary care and dementia research met regularly throughout the project to oversee the development and implementation of the 'Planning for My Future' risk assessment tool and 2 step process.
- An advisory group helped with the development of the risk assessments and provided general guidance for the project. Membership consisted of carer and consumer representatives.
- Two trained ethicists were engaged in order to analyse ethical issues using transcripts of the interviews.
- Project team meetings were conducted 2-4 weekly with the project nurse, chief investigator (Professor Dimity Pond), the project officer and an administrative assistant.

Staffing

- Throughout the project, the project nurse played a key role in the development of the risk assessment tool. The project nurse contacted potential participants/their carers and held initial discussions with consenting participants/their carers. Home-based risk and ACP interviews were also conducted.
- The project officer was responsible for meeting reporting requirements to the funders and the university, maintaining databases, monitoring the project budget and referrals and communicating with funding bodies, ethics committees and academic stakeholders.
- The administrative assistant was responsible for administrative tasks including data entry, collation of questionnaires and assisting to manage diaries in order to organise practice meetings.

Risk assessment tool development- 'Planning for my future' booklets

A two-step risk assessment tool, named the 'Planning for my future' booklets, were iteratively developed during the course of the project for people with cognitive decline living in the community. Later versions incorporated feedback provided by project participants, including their family and carers. The project nurse provided feedback as a result of tool administration. The steering committee, the advisory committee, senior occupational therapy (OT) students and a senior lecturer in OT were consulted and became instrumental to the tool's development. The resulting tool is a refined draft which addresses a diverse range of daily activities (e.g. shopping, driving, and cooking) at a task analysis level not previously available in Australia.

The developed RAT aims to:

- Help the individual themselves assess and manage current and future physical and psychosocial risks to independence and quality of life;
- Enable a person living with cognitive decline to live safely and independently for as long as possible in the community; and
- Promote the use of collaboration with family/health professionals about ADL risks, including the use of a risk enablement approach and supported decision-making.

Participant recruitment

During the *Dementia/Aged Care Nurse Practitioner (DACNP) research project* seventy-six participants were recruited and assessed for cognitive impairment and dementia. Of these, nineteen were diagnosed with dementia, and thirty-one were diagnosed with mild cognitive impairment. All participants consented to be followed up, and formed the pool of potential participants for the current project. The researchers for the current project contacted these potential participants by phone and provided project information, including consent forms (self and carer/support person), about ACP and/or ADL risk assessment.

Data collection

Participant interviews, based on the RAT developed during the project and the Hunter New England Local Health District advance care plan tool (Hunter New England Local Health District, 2015) (See Appendix 1), were conducted with consenting participants in their home by the project nurse. During each aspect of the project several participant interviews were digitally recorded and transcribed by the researchers. Transcripts were de-identified through the removal of identifying details and use of pseudonyms. In some cases the participants consulted with their families and sent the RAT back to the project officer by mail. In other cases, the participant completed the tool with the nurse.

Results

1. Risk assessment tool

In total, 6 older people, aged from 76 to 88 years, participated in the RAT trial (Male n=4, Female n=2). These 6 participants completed the various versions of the RAT with support from the project nurse (refer Table 1). Over the duration of the project two participants completed both an earlier and later version of the risk assessment tool: eight RAT completions in total. Overall, the first version was completed by 3 participants, the second by 3 participants and the final draft version by 2 participants. Completion of the second or final draft versions of the RAT occurred with the project nurse during a recorded interview with 5 participants (interviews n=4). Key outcomes of trialling later versions of the risk assessment tool are outlined in Table 2. (N.B. adherence to ethics guidelines precludes reporting of individual responses due to the more extensive and sensitive nature of data captured by this tool).

Table1: Risk Assessment Tool (RAT) Trials and Participant Characteristics

Participant ID #	Age	Gender	RAT Completions n=	RAT Version	Recorded Interviews n=
2248808	88	Female	1	2nd	1
2231461	78	Male	1	Final draft	1
2234524	79	Male	1	1st	*(mail only)*
2246433	84	Male	2	1st	*(mail only*
				2nd	1 (joint interview)
2249336	83	Female	2	1st	*(mail only)*
				2nd	1 (joint interview)
2244974	76	Male	1	Final draft	1
Participant n=6	**76-88yrs Average 81.3yrs**	**Male n=4 Female n=2**	**8**	**1st=3 2nd=3 Final draft=2**	**4 Participants n=5**

Table 2: Risk Assessment Tool (RAT) Trial Outcomes

Participant ID #	Age / Gender	Cognitive function	RAT Interview Completed	Topics Assessed	Evidence of functional areas that could be improved through risk management /further assessment	Insights from booklet completion
2244974	75 yrs Male	Mild/mod impairment of executive function. Early Alzheimer's diagnosis since assessment in project.	Yes - with carer present	• Sleeping • Physical and leisure activities • Medications • Driving and mobility • Grocery shopping • Chores at home	Yes • Emotional wellbeing • Driving • Physical activity • Leisure	Asking to start with a topic where the participant felt they had an issue worked well Using new initial open questions helped to establish what was important for the participant in terms of their quality of life. Person-centred rather than tool-centric assessment interview requires user to have a sound knowledge of the tool. Not all topics appropriate to discuss when spouse present. Recent ACAT and OT assessment created 'repetition' for the participant in assessment questions and impacted on discussion of risk/strategies. Changes in cognitive function since last contact can impact on tool use for research purposes.
2231461	78 yrs Male	Mild cognitive impairment	Yes	• Sleeping • Physical and leisure activities • Medications • Driving and mobility • Bathing and waterworks	Yes • Emotional wellbeing	Asking to start with a topic where the participant felt they had an issue worked well even though related to urinary function. More challenging to apply for a 'weller' participant. Some questions seem unnecessary based on responses in other topic areas. Not all topics appropriate to discuss when family nearby.
2248808	88 yrs Female	Mild cognitive impairment	Yes	• Shopping • Cooking • Eating and drinking • Physical activity • Emotional wellbeing • Continence and personal hygiene • Health management	Yes • Medications • Physical activity (use of furniture) • Eating and drinking (fluid intake)	Assessing risk frequency alone without asking how the participant currently manages the risk (if at all) provides the first step in planning for a safer independent life. Considering how participants manage risks and whether other strategies have been considered is important.

Participant ID #	Age / Gender	Cognitive function	RAT Interview Completed	Topics Assessed	Evidence of functional areas that could be improved through risk management /further assessment	Insights from booklet completion
2249336	83 yrs Female	Moderate Alzheimer's Dementia	Yes - with carer present	• Living at home • Eating and drinking • Physical activity • Emotional wellbeing • Continence and personal hygiene • Health management	Yes • Physical activity • Eating and drinking • Sleep	Focusing on the assessment tool and following each category throughout the booklet can limit depth of response about issues affecting daily life.
2246433	84 yrs Male	Cognitive impairment	Yes - with carer present	• Living at home • Eating and drinking • Physical activity • Emotional wellbeing • Continence and personal hygiene • Health management	Yes • Physical activity • Eating and drinking • Sleep	When cognitive impairment is more severe, responses from participants and their carers can contradict.

2. Advance care planning (ACP)

In total, 21 people, aged from 60 to 91 years (average 78.1yrs), participated in the ACP aspect of the project (Male n=9, Female n=12). All participants had initial project nurse contact to discuss ACP. Subsequently twelve participants completed an ACP (refer Table 3). Of these 12 participants, two completed one interview with the project nurse, eight completed two interviews and two participants completed three interviews.

Of the nine participants who did not complete an ACP, eight completed an initial interview with the project nurse, but did not participate in further ACP follow-up interviews, and one participant completed three ACP interviews with the project nurse. In total, four participant interviews were recorded by the project nurse with participant consent.

Key insights gained from undertaking the ACP process with participants are detailed in the discussion that follows.

Table 3: ACP Participant Overview

Participant ID #	Age	Gender	Date of initial ACP interview	Date of follow-up interview(s)	Recorded interview	ACP Completed
2249427	72	Male	23/10/2014	17/11/2014 & 27/08/15		No
2239519	79	Male	28/10/2014	ACP completed from interview 1		Yes
2243673	68	Male	23/10/2014	18/11/2014		Yes
2240282	60	Male	27/01/2015	No		No
1211621	84	Male	11/03/2015	No		No
2248808	85	Female	11/09/2013	3/09/2015 & 10/09/15		Yes
2234524	79	Male	14/04/2015	19/05/2015	Yes	Yes
2234704	79	Female	9/09/2014	22/10/2014 & 21/01/2015	Yes	Yes
2246433	83	Male	17/04/2015	1/05/2015		Yes
2249336	83	Female	16/03/2015	1/05/2015		Yes
2244974	73	Male	5/06/2013	No		No
2236148	68	Female	17/09/2014	22/10/2014		Yes
2241771	78	Female	23/09/2014	No		No
2242257	76	Female	3/02/2015	ACP completed from interview 1	Yes	Yes
1228808	85	Male	10/09/2014	No		No
2240770	86	Female	23/09/2014	No		No
2241238	91	Female	19/11/2014	15/12/2014		Yes
2249183	79	Female	27/04/2015	11/05/2015	Yes	Yes
2240410	65	Female	4/09/2014	No		No
1219369	90	Female	7/11/2013	18/03/2015		Yes
2239469	77	Female	28/11/2014	No		No
n= 21	**60-91 yrs Average 78.0 yrs**	**Male n=9 Female n=12**	**n=21**	**n=15**	**n=4**	**Yes n=12 No n=9**

Discussion

Risk Assessment Tool

A key focus of the project was development of an ADL risk assessment tool as a functional planning tool, i.e. that could be used to assist older people (particularly those with changes to their cognition) to reflect upon, and identify aspects of their everyday functioning that could be modified to enhance independent living and quality of life. Entitled '*Planning for my future'*, the two-part risk assessment tool developed during this project consists of two booklets that together enable older people/their carers to assess risks to their health and wellbeing, and facilitate supported decision-making conversations with their health care provider, e.g. general practitioner (GP), practice nurse, care co-ordinator, community nurse/carer). In the first booklet (Step 1), the older person works through topics themselves, possibly with their carer, and starts to think about how risks are or could be ameliorated to enhance autonomy and quality of life. In the second booklet (Step 2), the older person is supported by a health professional to develop strategies to enhance or maintain independence and quality of life at home in the short and longer term.

The risk assessment tool followed an iterative development process, incorporating feedback and advice from consumers and their family and carers, the project advisory committee and steering committee and project staff. The engagement of senior OT students and senior OT lecturer from the University of Newcastle served to ensure a current best practice approach to the tool, particularly regarding the breakdown of each ADL into key functional steps, as well as providing valuable professional development for the students involved.

The resultant two-step booklets have been designed with six key community care and chronic progressive disease management principles in mind, each of which has an ethical dimension:

1. Person-centred care
2. Consumer-directed care
3. Supported decision-making
4. Wellness/Healthy ageing
5. Risk enablement, and
6. Enablement/Wellness

Each of these cross-disciplinary care principles facilitates ageing-in-place through better management and self-management of chronic progressive conditions, such as dementia, enhancing independence, and assisting older people to maintain as much control over their health care decisions as possible.

The risk enablement approach embodied in the booklets considers both physical and psychological aspects of risk, e.g. the impact on wellbeing and identity of an older person from being unable to engage in regular social engagement with friends and leisure activities such as card playing. The process of risk enablement involves identifying the least restrictive actions/alternatives available through balancing both the positive benefits of taking risks with the negative effects of risk avoidance. In this way a practical ethical approach is taken. It also involves monitoring changes in an older person priorities and abilities over time.

The 'Planning for my future' RAT was well received by participants and their families/carers during the trial of each iteration of the tool. Key successes and insights from these trials included:

1. Establishing up-front the person's own values/goals with regard to quality of life was important,
2. Successful triggering of conversations during the visits which led to risks being addressed immediately (e.g. planning to install hand rails in the bathtub),
3. Documenting the person's existing risk management strategies (e.g. consulting with one's regular GP about medications received from another GP) acknowledges the person's problem solving; provides reinforcement; provides insight into the person's awareness of and experiences with available support services, enables reinforcement of appropriate strategies, and creates a basis upon which other strategies can be explored,

4. Discrepancies can occur between the person's responses and those of their carer (where cognitive impairment is more severe). These discrepancies create opportunities to explore risks further to establish shared concerns and strategies,
5. The appropriateness of particular topics needs to be considered when a carer is present, e.g. carer burden and mental health issues,
6. Person-centric assessment requires tool users to have a sound knowledge of the tool and to adopt a conversational assessment approach. Considering the RAT topics as a list detracts from the purpose of the tool, and
7. Healthcare professionals using the tool will require education/training in the underlying principles to ensure that a risk enablement and supported decision-making approach is adopted.

Whilst important insights about the tool's relevance and usefulness were gained during the project, further trial of the tool should be undertaken in general practice and other community-based health care contexts which focus on the health and care of older people with and without cognitive decline.

Advance care planning

With a focus on better understanding the ACP process undertaken by older people with cognitive decline, the Hunter New England Local Health District Advance Care Plan tool was undertaken with a small number of participants. The following insights and lessons were subsequently learned:

1. ACP takes time. For the majority of participants, completion of the ACP tool took over an hour, with most (n=10) needing more than one visit to complete. Time was also needed for considerable introspection and soul-searching by participants and their families (and in one case, the local priest) and could not be rushed. The ethical model of supported decision-making over time best fits this process.
2. Most participants were not able to complete the tool on their own. They had important questions that needed to be asked and answered before they were willing to complete the process or form/tool. For example, participants had questions about the meaning of various terms, modes of dying and when the plan would come into effect. As many had poor health literacy and were not familiar with modes of dying, terms such as "CPR" required considerable explanation. Most of these questions needed responses from a support person with a sound knowledge of ACP/ACDs and health issues/conditions for older people.
3. It was not always possible to include all members of the person's family in the process. Some family members found it too confronting and were not willing to participate. In other cases the participant held particular views about particular people and did not wish for them to be involved. Readiness to engage in the process, for older people and their family members, is a key aspect which needs to be considered. Issues related to family dynamics and conflict may need to be respected or addressed and family members/carers were concerned about influencing what participants wanted as part of their ACP.
4. Some older people did not want to undertake ACP and, though support was provided, some did not complete the process (n=9). The wishes of older people with capacity to decide about ACP arrangements should be respected.

Recommendations

Trialling of the RAT during the current project has indicated potential value to both older people with cognitive decline, and those managing their care, in developing and enhancing risk enablement strategies that promote improved quality of life and an extension of independent living within the community. The tool supports consumer-directed care, and this provides a strategy for those working with older consumers to engage with them, identify their care goals, and engage in collaborative decision making. Thus, its dissemination to key stakeholders, as a further formative process, is an important first step in its refinement before wider clinical adoption. Given the breadth of variability in the clinical settings of general practice and community health, further trialling of the tool is indicated to refine the tool’s useability, applicability and adaptability across a number of clinical scenarios and general practice / community health working contexts. An economic evaluation would also provide valuable further data.

The opportunity exists during the remainder of 2016 to continue both trialling the tool and educating/supervising health professionals in the tool’s clinical application as an adjunct to trialling the new primary care dementia guidelines currently being developed (as part of CDPC Activity 14 - *Development and implementation of a consensus guide on dementia in primary care*). The concurrent development of guidelines and assessment tool, designed to aid health professionals’ assistance of people with cognitive decline, provides a mutual value-adding opportunity that can optimise their adoption and better achieve a paradigm change in Australian primary health’s approach to aged care and cognitive decline.

Key recommendations stemming from each aspect of this project are:

1. Risk Assessment Tool

- The risk assessment tool should undergo further trial in general practice and community aged care settings to further refine its useability, applicability and adaptability across a number of clinical contexts and general practice working structures,
- Further evaluation of the risk assessment tool should be undertaken with older people in the community,
- Input from, and endorsement by, international experts in the field of aged care and cognitive decline should be sought,
- Once there is a final version of the tool, work with the Cognitive Decline Partnership Centre (CDPC) to develop an electronic version of the risk assessment tool available for download via the CDPC website,
- Promote and disseminate a final version of the tool to key stakeholders: Primary Health Networks (PHNs), Aged Care Providers, Dementia Study Training Centres, providers of culturally and linguistically diverse (CALD) services, General Practice Regional Training Organisations (RTOs), The Royal Australian College of General Practitioners (RACGP) and the Australian College of Rural and Remote Medicine (ACRRM),
- Promote the use of the risk assessment tool at relevant general practice, aged care and cognitive decline / dementia conferences,
- Educate GPs, practice nurses and community aged care service providers, including those who provide services to patients from CALD backgrounds, in the use of the risk assessment tool as an adjunct to the revised primary care dementia guidelines under development as part of CDPC Activity 14, and
- An economic evaluation of the tool should be undertaken.

2. Advance Care Planning

- Health professionals who introduce ACP to older people/their families should have sufficient knowledge of the process and be able to answer the questions that older people/their families may pose.
- ACP should be introduced to older people/their families and completion encouraged. However readiness to engage in this process needs to be considered and an individualised approach taken to plan completion.
- Health care professionals should not rush completion of ACP.

References

Department of Health Older People and Dementia Branch. (2010). *Nothing ventured, nothing gained: Risk guidance for dementia*. London, Department of Health Older People and Dementia Branch. Retrievd 7th September 2016 from https://www.gov.uk/government/publications/nothing-ventured-nothing-gained-risk-guidance-for-people-with-dementia

Hunter New England Local Health District. (2015). Advance Care Plan. Retrieved 7th September 2016 from http://advancecareplanning.org.au/library/uploads/documents/nsw/NSW_Advance_Care_Plan(1).pdf

Appendix 1: HNELHD ACP Tool

Advance Care Plan

NSW GOVERNMENT | Health
Hunter New England
Local Health District

Name: ___________________________________

Address: ___________________________________

Date of Birth: ______________________________

If I cannot speak for myself, I would like my doctor to talk about my health care and medical problems to the following person/s: (please write their name and contact number/s)

____

____

____

I have legally appointed the following:

	Yes/No	Name and contact number of person appointed
Enduring Guardian (*Health decisions*)		
Enduring Power of Attorney (*Money/finance decisions*)		

Who has copies of these legal documents? (please include contact number of person/s)

____

____

If I am very sick or badly injured, and others need to make medical decisions for me, please consider my following statements when making substitute decisions:

The following things are important to me, and I want them to be considered in any decisions that are made on my behalf:

____

____

Cardio Pulmonary Resuscitation (CPR) (*Initial the box that matches your choice*)

If my heart or breathing stops due to old age or irreversible (not curable) health problems my choice, if CPR is a treatment option, would be

☐ Please try to restart my heart or breathing (**Attempt CPR**)

☐ Please allow me to die a natural death. Do not try to restart my heart or breathing (**NO CPR**)

☐ I cannot answer this question. Let my doctor decide.

Signature: ________________________________ Date: ______________

Personal Values

Please consider my personal values for the following statements if I am unable to make my own decisions in the future. (Put your initials in the box that is your response to each statement)

I would find life to be *acceptable* **OR** *difficult but bearable* **OR** *unbearable* if, <u>for the rest of my life:</u>

	Acceptable	**Difficult but bearable**	**Unbearable**
I do not recognise my family and loved ones			
I do not have control over my bladder and bowels			
I cannot feed myself, and cannot wash myself, and cannot do my own personal grooming and dressing			
I cannot move myself around in or out of bed and rely on other people to reposition (shift or move) me			
I can no longer eat or drink and need to have food given to me through a tube in my stomach			
I cannot talk, read and write			
I can never have a conversation with others because I do not understand what people are saying			
I do not get enjoyment from many of the things that I have always enjoyed			

Talking about end of life:

Please initial the statement which is closest to your personal belief

I am frightened of dying and do not want to think about it happening to me or my loved ones. I do not discuss death or dying with others	
Dying is a fact of life. You just have to deal with it when it happens. I hope that I can talk about it with loved ones and others before my time comes	
Dying is a natural part of life. I am comfortable discussing death and dying with my loved ones and others. I want to be prepared for when my time comes	

When my time for natural dying comes, if possible, I would like to be cared for

☐ At home or in a home like environment
☐ In a hospital or hospital like environment

☐ I do not know. I am happy for my family / person responsible to decide

Signed:__________ Date: ___________

Review date/s:

Witness signature___________________________ Date:_____________

Additional optional page (not all people will want to include this page. Please staple to advance care plan if you wish this information to be included)

Name: ____

Date of Birth: _______________________________________

Specific requests with regard to medical care *(Please initial the box if you wish to identify specific treatment limitations. If you DO NOT have specific requests, please cross out this section)*

☐ I DO NOT WANT to have the following life prolonging medical treatments:

____

____

____

____

My personal, religious and spiritual care requests

If I am unable to communicate my wishes, please consider that I would want to receive the following care:

____

____

____

SPECIFIC REQUESTS FOR TISSUE, ORGAN AND / OR BODY DONATION *(PLEASE INITIAL THE SMALL BOX THAT IS NEXT TO THE STATEMENT YOU ARE COMPLETING. PLEASE CROSS OUT THIS SECTION IF YOU DO NOT WANT TO MAKE A REQUEST)*

☐ I have registered as an ORGAN AND TISSUE donor with the Australian Organ Donor register. My organ donor registration number is

____

I have discussed my organ and tissue donation wishes with my family and friends and they are aware of my decision **YES / NO**

I understand that my donation wishes may, in some situations, require the use of life sustaining treatment in an Intensive Care Unit. I understand and accept that I may receive this additional care so my donation wishes can be carried out.

BODY (CADAVER) AND OTHER DONATION

☐ I have registered as a cadaver / other donor. Please contact the following number to arrange collection ____

I understand that there may be specific instructions that need to be followed shortly after my death for cadaver and / or other body part donation to occur. I have discussed what needs to happen with my family / friends **YES / NO**

________________________________ ____________________________

Your Signature *Date document signed*

________________________________ ____________________________

Witness signature *Date witnessed*

Please use this page if you would like to provide additional specific direction or information regarding your choices for medical treatment or personal care if you are unable to speak for yourself.