

SUPPORTING DECISION-MAKING

A guide for people living
with dementia, family
members and carers

© 2018 the authors. You may copy, distribute, display, download or otherwise freely deal with this work for any purpose, provided that you attribute the authors as the owner. However, you must obtain permission if you wish to (a) include the work in advertising or a product sale, or (b) modify the work.

Sinclair C, Field S, Williams K, Blake M, Bucks R, Aret K, Clayton J, Kurrle S. Supporting decision-making: A guide for people living with dementia, family members and carers. Sydney: Cognitive Decline Partnership Centre, 2018.

With acknowledgement to Jean Low, www.jeanlowyy.com for graphic design work on this guidebook.

CONTENTS

Contents	1
Introduction	3
Using This Handbook	4
SECTION 1:	
KEY TERMS AND DECISION-MAKING APPROACHES	5
What Decisions?	6
Decision-Making	7
Supported Decision-Making	8
Key Values in Providing Support for Decision-Making	9
Decision-Making Ability	11
Substitute Decision-Making	12
What does Support for Decision-Making look like?	13
SECTION 2:	
SUPPORT FOR DECISION-MAKING - STEP BY STEP	16
Step 1: What Decision?	18
Step 2: Preparation	20
Step 3: Communication	23
Step 4: Choosing	26
Step 5: Putting It Into Practice	27
Step 6: Review & Follow Up	29

SECTION 3: LEGAL CONSIDERATIONS	31
Absence Of A Formal Legal Framework	32
Future Planning	33
Risk	33
If You Are Worried About Abuse Or Undue Influence	34
SECTION 4: FURTHER RESOURCES	35
Resources For Supported Decision-Making	36
Resources For Communicating With People Living With Dementia	37
Resources For Advance Care Planning	37
Resources On Assessing Decision-Making Capacity	38
Aged Rights Advocacy Services	38
State Administrative Tribunals	38
Reports And Policy Documents	39
REFERENCES	40
ACKNOWLEDGEMENTS	41
MY DECISION SUPPORT PLAN	43
NOTES	45

INTRODUCTION

This handbook focuses on how to support and help people living with dementia to make decisions about their lives. It is designed for people living with dementia, their family members, supporters and the broader community.



Over many years, people living with dementia have spoken and written about the importance of making decisions about their own lives, wherever possible. They have described the sense of purpose, inclusion, satisfaction and pride that comes with making decisions.¹

We all have times in our lives when we look for help and assistance in making decisions. Making decisions about our own lives, and having these respected, has been recognised as a human right, enjoyed by all.² While this can sometimes be more difficult when a person has a disability such as dementia, there are many things that can be done to help.

“ **...what we are faced with here [dementia] is a problem that you and I have and you and I have to deal with it. So, it's not just the individual. It's at least the individual and their carer. To take it further, it's the family, the friends, the associates... all those people are somehow affected.** ”

(Tony, person living with dementia)

We hope that you find this resource helpful in your journey.

Cognitive Decline Partnership Centre
'Supported Decision-Making in Dementia'
Research Team

USING THIS HANDBOOK

This handbook comes from a three-year research project, with personal experiences drawn from over 100 interviews with people living with dementia, their family members and professionals. The handbook has been reviewed by people living with dementia and their family members. It includes their practical tips and suggestions. While this advice may be helpful, also remember that the ideal approach will recognise each person's individual situation.

In **SECTION 1** the key terms are defined and the different approaches to decision-making are outlined.

In **SECTION 2** there is guidance on providing support for decision-making.

In **SECTION 3** you will find information on legal aspects of decision-making.

In **SECTION 4** there are a range of freely available resources, including websites, booklets and video materials.

Throughout this handbook, you will see icons which signal different types of information. These are described below.



Definitions of important terms, especially those which have legal or formal meanings



Suggested questions that you could ask yourself as you think through different aspects of supported decision-making



A person's story illustrates some of the concepts



**SECTION 1:
KEY TERMS AND
DECISION-MAKING
APPROACHES**

WHAT DECISIONS?

In this handbook, when we refer to decision-making we are referring to people making choices. This includes choices about 'healthcare', 'lifestyle' and 'finances', as well as 'everyday' activities of daily living. Some examples are listed below.



HEALTHCARE

- Getting a diagnosis
- Accessing (or refusing) care services
- Responding to crisis (e.g. falls or hospital admission)
- Agreeing to (or refusing) medical treatment/s
- Advance care planning (planning future health care)



LIFESTYLE

- Living arrangements (e.g. relocating, renovating or modifying the home, admission to residential care)
- Relationships
- Employment
- Civic participation (e.g. voting)
- Holidays and outings
- Pets and important possessions

HEALTHCARE



LIFESTYLE



FINANCIAL



EVERYDAY



FINANCIAL

- Investment decisions
- Sale or gifts of property or valuable possessions
- Use of money (e.g. savings, allowances or pensions)

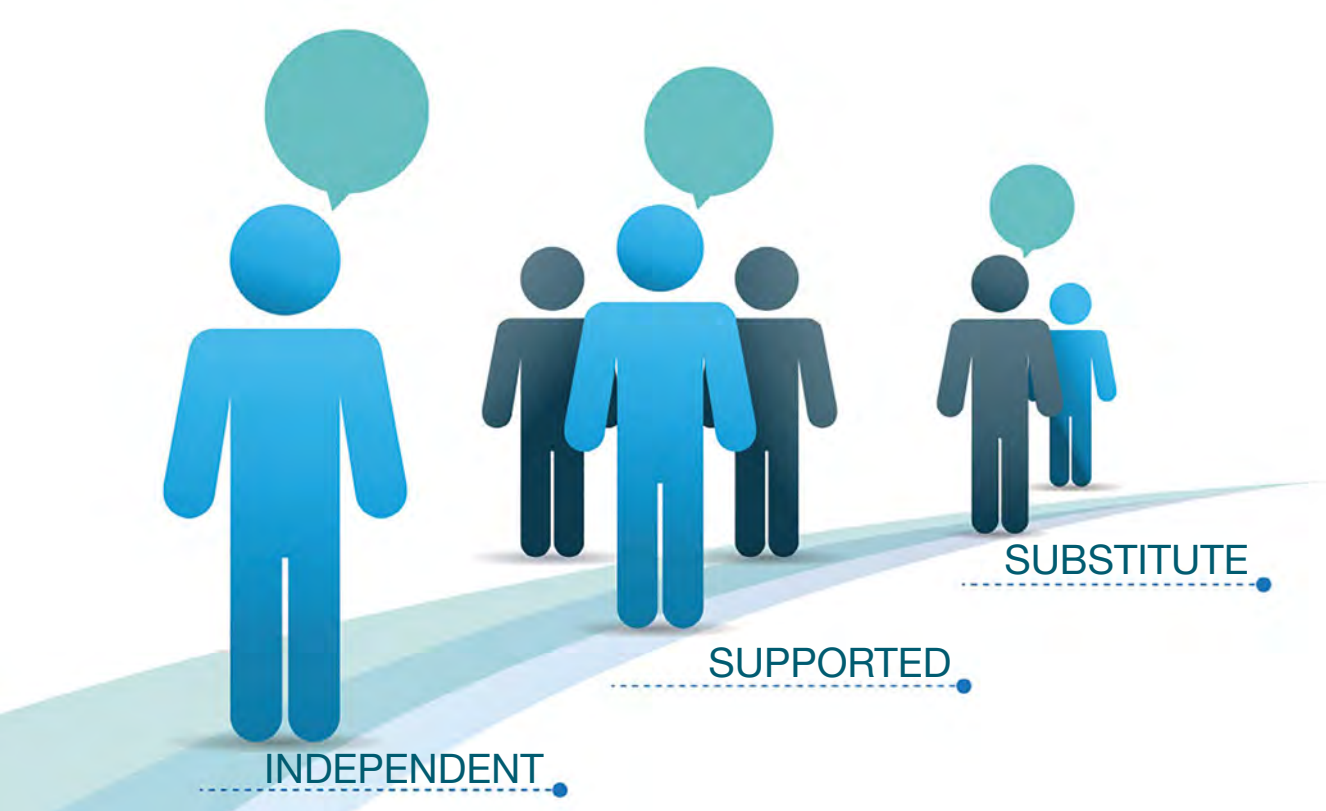


EVERYDAY

- Routine shopping
- Driving
- Household maintenance and chores
- Personal care (e.g. grooming, what to wear)

DECISION-MAKING

In making choices about our lives we sometimes decide on our own, with minimal input from other people. Sometimes we look for help and assistance from others, or make decisions together. Occasionally, we may want or need another person to step in and make a decision for us, representing our views. This is shown below as a spectrum of approaches to decision-making.



SUPPORTED DECISION-MAKING

Supported decision-making aims to provide help and assistance for people with disabilities, in making decisions about their lives. The United Nations Convention on the Rights of Persons with Disabilities promotes supported decision-making as a way of respecting a person's dignity and autonomy, and protecting their right to have help and assistance in making decisions.² The World Health Organisation has clearly identified that people living with dementia come within this Convention.³



WHAT IS 'SUPPORTED DECISION-MAKING'?

Supported decision-making has been defined as: “the process whereby a person with a disability is enabled to make or communicate decisions with respect to personal or legal matters”.² The term ‘supported decision-making’ also refers to the legal systems that protect the rights of people with impaired decision-making ability.⁴

What is ‘Support for decision-making’?

‘**Support for decision-making**’ or ‘**decision-making support**’ refers to the practical steps taken to assist a person in decision-making. As the laws in each state of Australia are different, this handbook focuses on the practice of providing **support for decision-making**. Support for decision-making can occur in a range of everyday contexts, and is not reliant on a specific set of laws.

Support for decision-making might look different for different people, or in different situations. The principles of support for decision-making can apply across the whole spectrum of decision-making (see p7).

KEY VALUES IN PROVIDING SUPPORT FOR DECISION-MAKING

In providing support for decision-making, there are a number of key values. These have been drawn from research with people living with dementia, and their family members.^{1,5}



KEY VALUES IN PROVIDING SUPPORT FOR DECISION-MAKING

INCLUSION:



“nothing about me without me”.

This value reflects the importance of including the person with dementia in all stages of a decision-making process, to the extent that they choose to be involved. It might mean that they have active participation in gathering information about a decision, or instead that they are kept informed through the process.

KNOWING AND UNDERSTANDING:



“knowing me and understanding the things that are important to me”.

Decision-making support is most effective when it is provided by someone who has a close, trusting relationship with the person. This helps in understanding the person’s values, likes and dislikes, and preferred approaches to decision-making.



RESPECT FOR RIGHTS:

“I have a right to be supported and safe in the key decisions about my life”.

This value reflects an understanding of the person’s rights in decision-making, including their rights to: have access to understandable information; have support in expressing their views; have advocates speak on their behalf where necessary; and be free from undue influence.



DIGNITY:

“walk alongside me, not in front of me”.

This value relates to the importance of taking the time needed to go through the process together. Importantly this enables the person who is receiving support to take initiative, or express concerns about how the process is unfolding.



ADAPTING TO CHANGE:

“things change over time or day-to-day, work with me”. This value reflects the understanding that the journey of living with dementia is a changing one. As the condition progresses, or as it fluctuates from day-to-day, different approaches may be required.

Support for decision-making can look different depending on the type of decision, or the situation. Applying these values will ensure that the process is followed in a supportive way, respecting the person’s rights, and their unique and changing needs.

DECISION-MAKING ABILITY

People vary in their ability to understand and make decisions, and these abilities can change over time. A person has a right to make decisions about their own life if they are considered able to understand the relevant information and express a choice in some way. The law refers to a person's 'decision-making capacity', and applies specific tests to determine this, asking:

- Can the person understand the nature and consequences of the decision?
- Can they weigh the relevant information in order to express a preference?
- Can they retain the relevant information long enough to make a decision?
- Can they communicate their decision in some way?

The concept of decision-making capacity, while necessary in legal activities (e.g. contracts and wills), has been criticised because it can exclude people with cognitive impairments from everyday decisions about their lives. The United Nations Convention emphasises that all individuals have the right to make their own decisions, in the context of relationships, and that a person's decision-making ability can be increased through support and education.² Support for decision-making aims to maximise a person's decision-making ability, enabling them to maintain involvement in decision-making.

Regardless of possible future changes to the law in this area, the following principles about decision-making ability are well established in common law (the law made from previous court decisions), and apply across Australia:

- A person is presumed to be capable of making decisions about their life, unless there is evidence to the contrary;
- A person's decision-making ability can fluctuate and change over time;
- An assessment of a person's decision-making ability is specific to a particular time and a particular decision;
- Assessments of a person's decision-making ability should occur in the context of the actual task or decision that is being undertaken.⁶

SUBSTITUTE DECISION-MAKING

Sometimes despite the best efforts at help and assistance, a person may feel unable to make their own decisions. They may want others to make a decision for them, or they may be unable to understand a decision or communicate their wishes. This may happen informally, with a partner, family member or friend taking on the role. The term 'substitute decision-making' is also used in a formal way, referring to the legal process of making decisions for another person. **Formal substitute decision-making is used when a substitute decision-maker is:**

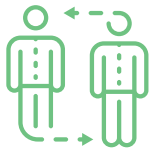
- i. **nominated** by the person themselves (e.g. with an 'Enduring Power of Guardianship or 'Enduring Power of Attorney' form);
- ii. **assigned** under law (e.g. as a 'person responsible' for healthcare decisions); or
- iii. **appointed** by a Court or Tribunal.⁷

While substitute decision-making can be important in some situations, it also removes the person from decision-making about their own life. **Formal substitute decision-making should only occur as a last resort.** A substitute decision-maker should still keep the person involved wherever possible, take their views into account and use what they know and understand of the person's wishes to guide their decision-making.



WHAT DOES **SUPPORT FOR DECISION-MAKING** LOOK LIKE?

We often think of decisions as belonging to a single person (e.g. “I made the decision” or “that was her decision”). In some cases this is true, but most of the time we make decisions with help from others. These other people might include professionals, family members or friends. Support means help that meets our needs, and is there when needed, without taking over or making us dependent. The help might be:

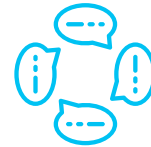


SHARING EXPERT KNOWLEDGE

e.g. a car mechanic, tradesman or doctor providing expert information or advice

INTERPRETING

help to translate unfamiliar words or complex ‘jargon’ into understandable language



PROMPTING

identifying an opportunity for decision-making, or providing reminders about decisions that need to be made

ENCOURAGING

help from other people to get motivated with making a decision



PROVIDING IDEAS

providing suggestions or giving examples of the sorts of decisions made by other people



LISTENING

a trusted person might listen to us talk through our ideas, ‘being a sounding board’ or just being with us and providing emotional support

QUESTIONING

asking questions about a planned decision, to raise potential problems or another point of view



AFFIRMING

providing reassurance about the decision and helping the person to see it through





Our decisions are almost always made with help and assistance from others. For people who have received a diagnosis of dementia, this can lead to an even greater appreciation of the value of having assistance and help from others.

“

...so I always take a friend with me [to the doctor]... because she understands exactly what the doctor's saying and the doctor will say something then she'll basically repeat what the doctor said but in my language, and then the doctor will say yes and then talk so I can understand what he's talking about.

(Susan, person living with dementia) ”



DEREK & JUNE'S STORY – STAYING INVOLVED AND PLANNING AHEAD

Derek is an engineer who has worked in shipping for most of his life. A few years ago he was diagnosed with dementia. He feels able to participate in conversations, but often forgets the details. Derek's wife June works part time as a personal carer, and provides support and assistance for Derek in day to day matters.

Due to the risks associated with Derek's work, he had to step down from his role. Some of his work colleagues were involved in this decision, and they talked with him about how he wanted to handle this:

“...Well his workmates noticed that he had been having problems when he was working... because they've known him for so long and they knew what he was really capable of... [they] came to see us one morning. (June)”

Together they discussed some options and Derek decided that he would take his remaining leave and then retire from work, but maintain social contact with his work colleagues.

Derek and June also sought advice and made decisions together about his finances (including his share portfolio and the decision to move to a smaller house).

“We both went into that meeting with the finance fellow, didn't we... which is good... it means I've had an input and received the unbiased data because I was there when it was being told. (Derek)”

They also talked together with his General Practitioner (GP) about Derek's decision to stop driving, and plans for his future healthcare. With help from his GP, Derek completed an advance care directive. June's involvement in the discussion left her satisfied that Derek was able to understand the issues and express his wishes.

“...so both of us were there, and [GP] sat down and had a good chat to him, and then [GP] produced the written document. (June)”

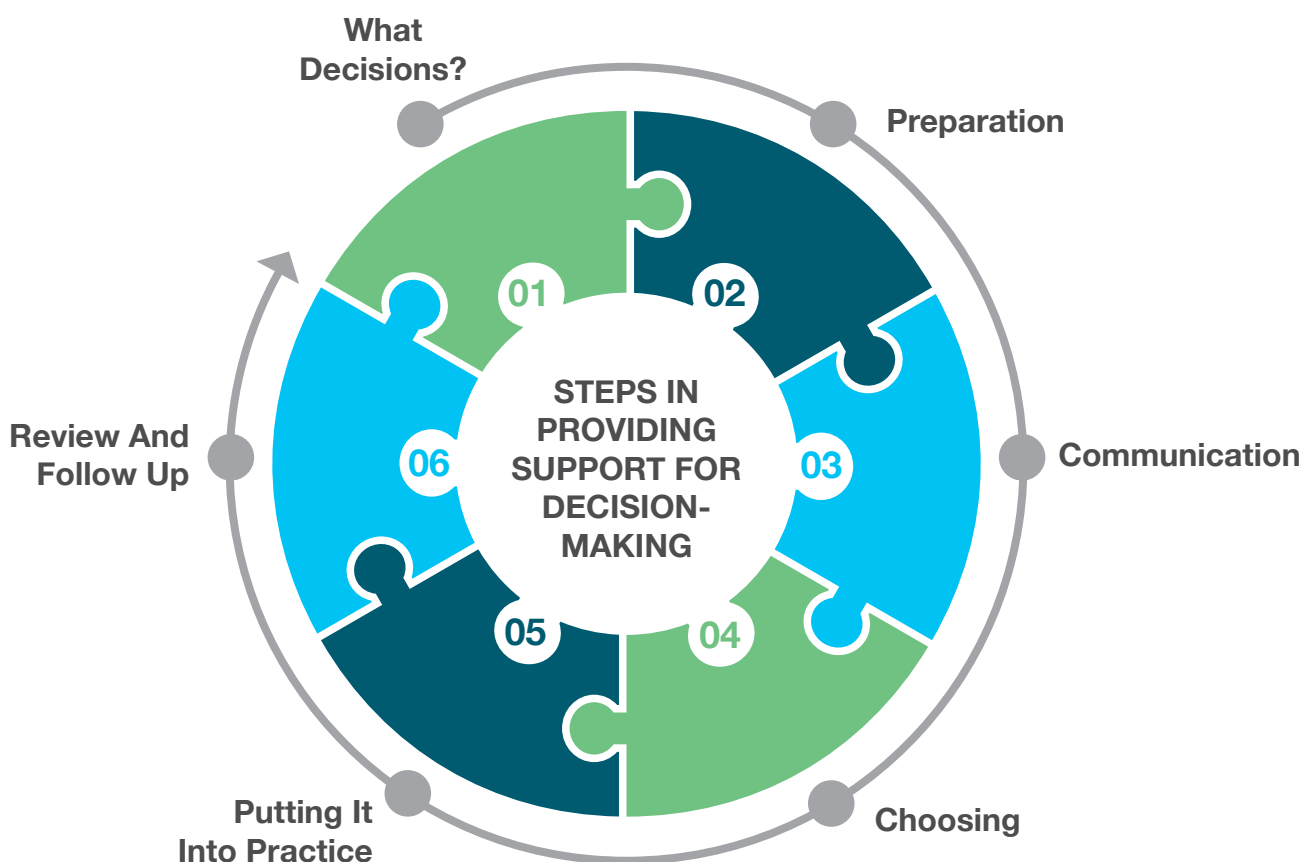
This story illustrates how discussing decisions with trusted people can enable a person with dementia to stay involved in important personal decisions.

SECTION 2:
**SUPPORT FOR
DECISION-MAKING
- STEP BY STEP**



SUPPORT FOR DECISION-MAKING - STEP BY STEP

In this section we introduce a series of steps that might be helpful for you when thinking about how to go about support for decision-making in your situation. Decisions come in many types, and some are quite urgent. You may not always be able to go through all the steps.



As you work through each of the steps and answer the questions, refer to 'My Decision Support Plan' on page 43. As you answer the questions you may be able to use this information to fill in the form. It is important that both the 'decision-maker' and any 'supporters' communicate about what goes into this form.

STEP 1: WHAT DECISIONS?



Often the first step is to identify the actual decision to be made. Sometimes we learn about something, or see what other people are doing, and this motivates us to make a decision about our own lives.

Some decisions contain a number of smaller decisions, or steps. Some decisions present themselves, due to a change in our life situation. While certain decisions can be urgent, it is useful to give some time to thinking about ‘what is the decision that needs to be made here?’ It is crucial that the person who is being supported has input into identifying the decision that needs to be made. Start from the point of view of knowing the person well and understanding what is most important to them.

“ **The first step to that process is finding out what is important to [the person living with dementia] and then fitting everything else that we do around that**

(Consultant Geriatrician) ”

Understanding the person's wishes: The person's wishes are often the most important factor in determining what decision needs to be made. This requires knowing the person well, and working with them to draw out what they want to achieve. In other cases you may need to prompt the person about a decision, or explain why a certain decision is required.

In some cases, the nature of dementia can also make certain types of decisions harder. It's not always the 'big' or 'important' decisions that feel difficult! Chris, the husband of a person living with dementia, talks about the challenge of making decisions about everyday activities:

“ **Her activities are restricted ... [activities] that form a very powerful and fulfilling part of her life aren't available anymore, so although it seems trivial it's the little decisions ... that causes the most consternation. Big decisions, that's something we talk about and we make and have always done it the same and they're done in the blur of an eye you know, but the little decisions, they're the buggers.** ”


Depending on a person's situation or the nature of their dementia, some decisions will require more time or support. Understanding what is most important for the person you are supporting, and clarifying 'what decision?' can help in this process.



STEP 2: PREPARATION

All great things require preparation! This section contains some questions on different things you can do to prepare for your role in supporting a person's decision-making.

Understanding the person's needs in decision-making: We all have good days and bad days, and respond better to information when it is presented in certain ways. Consider what is required, in order to enable the person's involvement in the decision. It might help to ask yourself some questions:

- 
- How does this person typically approach decision-making?
 - What are some examples of previous decisions that were successfully made? Think about the context for these decisions (e.g. time of day, setting, who was involved, the person's mood etc.)
 - How familiar is the person with the information relating to this decision?
 - Could the person experience strong emotions relating to this decision? If so, what can be done to help? (e.g. familiar soothing music, or having trusted, familiar people on hand)
 - Does the person like to discuss ideas and talk about their values, or do they prefer to be presented with simple choices and options?
 - Is this an urgent decision? Or can it be approached gradually over time?




Once you have thought about these questions, refer to 'My Decision Support Plan' on page 43. You may be able to use some of your answers to fill in parts of the form.

Identifying support networks: Some people with dementia talk about losing contact with friends and family, and find it difficult to stay involved in the community and meet new people. Some lack variety in their social relationships. Because social networks are a key source of support for decision-making, some of our participants talked about the value of getting involved in dementia advocacy, joining peer support networks, or using ‘circles of support’,⁸ to broaden their access to social networks and supporters.

“ **... Richard [person living with dementia] has a circle of friends that help him make decisions. They have a sort of conference type of situation, or he’ll go to one of them and ask.**

(Barbara, supporter of person living with dementia) ”

Assisting a person to maintain social networks and stay involved in their community can be an important way of providing support for decision-making. In identifying relevant support networks, it might help to ask:

- 
- Who would the person living with dementia want to support them?
 - Do I have sufficient time and knowledge of the person, to support them in this decision?
 - Can I put my preferences aside in order to support the person?
 - Does the person have access to other potential supporters?



Once you have thought about these questions, refer to ‘My Decision Support Plan’ on page 43. You may be able to use some of your answers to fill in parts of the form.

Being objective: When decisions are made within relationships, the supporter often has their own values and preferences. When providing support for someone, we need to think about our current relationship with the person, and also whether our own views might lead us to prefer a particular decision. It is important to be objective and remember that the supporter role is about putting aside our own views, and helping another person to express their wishes, and enact the decisions that are important to them.

Gathering information: Not all decisions are straight-forward, and some will require you to do your own research or get advice from professionals. This might be something that is done in advance of discussing the decision. Alternatively, it might present an opportunity to collaborate in the decision-making, by gathering information together. It may depend on the type of decision, and the person's own preferences for being involved in the 'details'. Think about how the person with dementia might want to be involved in this process of gathering information.



Preparing emotionally: Part of the challenge in providing support is that it might not always turn out the way that we had hoped for. This can be difficult for supporters, particularly if it brings up feelings of grief or loss associated with changes in a person's memory or cognitive abilities. If the person we are supporting does not respond the way we expect, it could lead to a feeling of shock, frustration, or maybe a sense of rejection. Preparing emotionally might be about having some quiet time alone, writing in a journal, or talking with a trusted friend or professional person about your own feelings relating to the decision.

STEP 3: COMMUNICATION

“ The fact that someone can’t easily express what they want or what they think should not be a barrier to their inclusion or participation, so it’s about reasonable adjustment.

(Liesel, partner of person living with dementia) ”

Communication is a very important part of decision-making. Using appropriate communication will give the person the best chance of participating, understanding and retaining information, and being heard. However there are also a number of principles that will apply for many people living with dementia.

These include:

- being at eye-level and in eye contact (where this is appropriate);
- using positive body language that signals your curiosity and interest in understanding the person’s wishes
- speaking with a relaxed tone of voice (slower if needed but without ‘talking down’ or patronising the person)
- building or ‘scaffolding’ new information onto familiar concepts that the person already understands
- using short sentences and addressing one idea at a time
- pausing between sentences to give the person time to process your information
- waiting for acknowledgement to ensure the person has understood
- taking breaks as needed
- revisiting key ideas and taking reminder notes to support the person’s recall

These principles should be considered in the context of relevant cultural factors that apply to communication and decision-making for certain groups.



Once you have thought about these points, refer to ‘My Decision Support Plan’ on page 43. You may be able to use some of these points, or your own ideas, to fill in parts of the form.

In some cases it is important to establish points of shared understanding or agreement. This can be particularly helpful if there are words that mean different things to different people. Consider the situation encountered by Liesel and her partner in considering decisions about her care:

**“ ... she had banned [the word ‘respite’] from our house...
By the word respite she understood the thin end of the
wedge of admission ended for her in residential aged
care. And for me respite was time out, totally different.**

(Liesel, partner of person living with dementia) ”

Importantly, when the term ‘respite’ was clarified through discussion to a point of shared understanding, this enabled the decision-making process to continue.

For people who experience difficulties with understanding speech or forming sentences, it may help to word questions in ways that give a small number of alternatives or allow a simple ‘yes’ or ‘no’ response. Providing visual cues can also help (e.g. holding up two different coloured shirts as part of a decision on what the person would like to wear).

There are a number of resources that can assist in communication, and the use of these may depend on the specific nature of a person’s impairment. For those with specific communication impairments it may be helpful to incorporate tools such as ‘talking mats’.⁹ It might help to prepare an album of photographs of significant people in the person’s life, and pictures of valued activities or possessions. These may enable conversation and trigger memories.





Communication can be challenging, and we have all experienced situations where other people have misunderstood us, or where we have misunderstood others. In the context of important decisions, this can lead to strong feelings, and potentially add further tension. As far as possible, we suggest that being patient, responsive and relaxed will assist in the process. Remember that for a person with dementia, being faced with decisions, even in the context of help and support, can be confronting, and can be a reminder of their own struggles to understand and communicate.

“ ... you feel as though you’re being bombarded. If somebody’s trying to tell you something like [husband]’s been trying to tell me something sometimes and he says, ‘but I mean this, this is what I’m meaning,’ and I’m not catching on and then I lose it because it’s just not working.

(Josie, person living with dementia)

”

STEP 4: CHOOSING

Having real choice requires meaningful options. Sometimes decisions are limited or constrained (e.g. due to distance, financial barriers or a lack of choice in service providers). However, wherever possible we want to provide meaningful options and assist the person to weigh the positives and negatives of these options, in order to come to a decision.

Research has shown that we are more able to choose, and more satisfied with our choice, when the number of options is not too large.¹⁰ For people with cognitive impairments, presenting too many options can be confusing. Having a relationship and knowing the person's preferences is helpful in strategically presenting options that are more meaningful for the person:

“...[my] partner's very good at knowing what my preferences are to start with and for example going out to dinner... She made the decision to narrow it down to two or three venues that I would function with. Offered a narrow choice which fitted in with what I would have gone with anyway. But it saved the problems of having to dismiss other options.

(David, person living with dementia)

However it is also very important to think about our own assumptions, and ensure that we are not introducing bias, or limiting the options that we choose to present. If the person you are supporting suggests other options, these should be explored as fully as possible.

Continue to use the communication strategies above (Step 3), and creatively try to find ways that will enable the person to understand and express their wishes. Focusing on one option at a time can be helpful. You might also be able to build on a person's existing experience and interests, by 'scaffolding' the options onto their existing knowledge. It may be helpful to work with the person on a list of reasons as to why a certain option is 'important to me', and also why it is 'important for me'.

STEP 5: PUTTING IT INTO PRACTICE

At the point at which there is agreement about a choice, and an understanding of the person's wishes, we might move towards putting the decision into practice. This may well look different for different decisions. In the case of a healthcare decision it might be about giving or refusing consent for a certain treatment. For a financial decision it might involve signing paperwork to formalise an agreement or sale. In some cases putting a decision into practice begins a series of events that cannot be reversed. In other cases 'putting it into practice' really means starting a new behaviour (e.g. a physical fitness program) or entering an agreement (e.g. accepting a home care package) which can be reversed later.

In some cases putting a decision into practice may require you, along with other people in the person's support network, to take specific actions that 'carry the decision through'. In some cases this can lead to tensions, particularly if it is someone from the person's support network who has to take ongoing responsibility for carrying out, or maintaining a decision.

“ ...if you're going to make a decision there's always got to be someone who's got to carry out that decision. Even if you're in a group, you've still got to have one person to carry out that decision.

(Simon, son of person living with dementia) ”

In some cases, it may have become clear through the 'communication' and 'choosing' stages of the decision that the options available do not match well with the person's wishes. In such cases, this may require creativity, or direct advocacy with service providers or professionals, to enable the person's decision to be carried out.

Finally, it is important to remember that a person's wishes can be associated with some level of risk, and putting the decision into practice will include some 'risk-management'. While it is important to responsibly manage risks in the interest of maintaining safety, it is also important that risk-management does not unreasonably impinge on the person's liberty or autonomy.

“ I think you have to let people do it and perhaps take away as many of the risks as possible and let them still do it. And you're dancing around the edges trying to keep him safe... ”

(Barbara, supporter for person living with dementia)


The Australian Law Reform Commission have suggested that any restrictive measures aimed at keeping a person safe from harm should be applied only as a last resort, in ways that are tailored (individually matched to the person's needs) and proportionate to the risk (only just enough to serve their purpose of managing the risk, and no more).



STEP 6: REVIEW & FOLLOW UP

Support for decision-making, like everything else, takes practice and reflection in order to achieve the best results for all involved. In order to learn from each decision made using this approach, we encourage you to reflect on both the process and outcome of each decision you are involved in, thinking about what went well and what could have gone better.

During the review stage, we suggest asking the following questions:

- 
- Was this the 'right' or most important decision, to address?
 - Has addressing this decision raised other issues or decisions?
 - Would I prepare differently next time?
 - How did the process of communication go? Would I do anything differently next time?
 - Was the person able to effectively choose? Did their choice reflect what I saw as being their own wishes'?
 - Was the decision put into practice?
 - Was the person living with dementia happy with the decision-making process and outcome?
 - Was I comfortable with the decision-making process and outcome?

It is worth remembering that decision-making is a process. Addressing one decision may bring up other issues or decisions. It may be that as a person is supported to exercise greater choice and decision-making in their life, they will in fact respond by taking more control and addressing things they are dissatisfied with. This review process, when it works well, can lead to learning, and improvements in your future approach to support for decision-making. If possible, include the person you are supporting in the review, to gain insights into how they experienced the decision-making process as well.



Each time you review a decision, record some of your thoughts about the process in the 'Notes' section of this booklet (page 45). Over time you may notice patterns that help you work out what is working well, as well as areas for improvement.



MARIA'S STORY

Maria is an older woman who has lived most of her life in Australia, having immigrated from Italy in her late teens. Since her husband's death five years ago, she has lived alone in a small apartment. Maria has two daughters and two sons, and her youngest daughter Sofia lives nearby and visits regularly.

Three years ago, Maria was diagnosed with a form of dementia called primary progressive aphasia. While she can follow conversations, she finds it difficult to speak, particularly in English. When she is at the shops or bank she prefers to speak in Italian and have Sofia, or one of her other children, speak on her behalf. She mostly prefers to stay at home, but continues to attend her church and occasionally visits other family friends.

Maria's children want to support their mother. They find that Maria does not want to talk about her condition, but appreciates their help and company. They communicate with Maria about everyday things in Italian, using short sentences with 'yes' or 'no' answers. With the help of a speech pathologist, they also start combining speech with gesture and pictures. They create some photograph albums of family, friends, places and everyday objects, to assist in communication.

Following advice from the speech pathologist, Maria's children ask her to think about nominating someone to make decisions about her finances, in case she is unable to in the future. Maria agrees, and wants her children to talk with the lawyer and 'sort it all out'. However the lawyer wants to meet with Maria at least once without her children present, to ensure that she is 'making her own decision'. As the lawyer does not speak Italian, the children arrange for one of Maria's family friends to help at the meeting, and Maria's speech pathologist advises using photographs of family members, so that Maria can point to people in her family. Sofia advises the lawyer about the most effective ways of phrasing questions before the meeting.

At the meeting, the lawyer explains the role of an attorney, and is able to establish that Maria understands this, and that she wants to nominate Sofia to undertake this role. The lawyer sees that Maria understands the consequences of her decision, and later follows up by explaining to Sofia that she should continue to help her mother make decisions, as long as Maria can understand and communicate her wishes.



SECTION 3:
**LEGAL
CONSIDERATIONS**

It is important to be aware of the legal issues associated with supported decision-making.

Absence of a formal legal framework

Supported decision-making is endorsed by the United Nations Convention on the Rights of Persons with Disabilities, and in a high-level report from the Australian Law Reform Commission. However, while some states have laws in place to formalise support arrangements (e.g. Victoria), this is not consistent across Australia. So while ‘support for decision-making’ is considered good practice, and ‘supported decision-making’ may be legislated for in the future, it currently does not have a consistent legal framework across Australia. This may become an issue in certain situations, such as:

- **Accessing information:** In some cases supporters may need to gain access to a person’s private information, in order to assist them in making decisions (e.g. healthcare, financial etc.). Organisations have obligations under the *Privacy Act 1988*, and will typically require the consent of the person (or their legal substitute decision-maker) in order to release information. Some organisations may have their own additional processes for the release of information. Future laws may however provide some rights for ‘supporters’ to access a person’s information, or be notified about certain events.
- **Impaired decision-making ability:** If a person’s decision-making ability is in question, and you have provided support for them to make a decision that could be seen as advantaging you (e.g. a gift of property or a decision to forego a medical treatment), this might be challenged by others. Such situations are always complex, regardless of whether there are laws in place for supported decision-making. You may be able to pre-empt such concerns by being open and transparent about your role in providing support with other family members and friends. Including other family members, friends or professionals in the process of supporting the person, and clearly documenting decision-making processes and outcomes, is another means of protecting yourself in the case of disputes.

Future planning

While there is much that can be done to help and assist a person in making decisions, there are some situations in which this will not be possible. In these situations it is helpful if a person has documented their wishes regarding decision-making, particularly relating to their healthcare and financial arrangements. Support for decision-making can be helpful in assisting a person to document their wishes for future healthcare, or appoint another person as a substitute decision-maker (see 'Derek and June's story' on p15 'Maria's story' on p30). There are a range of resources for Future Planning that are specific to each state (see 'Further Resources').

Risk

When a person makes decisions, this can be associated with risk. Risk comes in a number of forms, including physical, financial, legal, psychological and emotional. In providing support for decision-making, it is important to be aware of potential risks, and to explore these with the person in ways that they can understand. It is also important to realise that risk is a normal part of life. There may be risks associated with supporting a person to make their own decisions, however there are also risks associated with overriding a person's wishes.

Striking a balance means taking an approach that **manages risk**, rather than avoiding it altogether. This means assessing the potential risks involved, and developing plans and actions that can be taken to maximise safety, while minimising restrictions. It is important that the risk is defined and assessed in terms of what is important to the person living with dementia. Involving other support networks, consulting with professionals, using advocacy services and documenting discussions and plans that are put in place can all assist in this process.

If you are worried about abuse or undue influence

Elder abuse is a growing issue, and it is important for everyone to be vigilant with respect to the treatment and care of people with cognitive impairments, who might be particularly vulnerable. As someone who is in a close relationship with the person who you provide support for, you may become concerned about possible elder abuse. In the context of decision-making, this might be associated with 'undue influence' over a decision.

WHAT IS UNDUE INFLUENCE?



Undue Influence: This term comes from the law, and is particularly used in the context of gifts or contracts. Where an agreement is made in the context of an 'unequal relationship', which allows one person to unfairly influence the other, this can be considered an example of undue influence. In rare cases, this influence is deemed to be so strong that 'undue influence' is presumed, and requires specific protections.¹¹ The important thing to remember is that undue influence in decision-making can be considered to be a type of abuse, and can lead Courts to rule that decisions made under undue influence can be reversed or overturned.

Aged rights advocacy services in your state or territory can offer further assistance in these areas. However some advocacy services will only act under the instructions of the person living with dementia, and only when they are deemed to have 'decision-making capacity'. In other cases the relevant administrative tribunal in your state or territory may need to be involved. Some states have options for mediation prior to taking matters to the tribunal (see Further Resources section).



SECTION 4:
**FURTHER
RESOURCES**

Resources for **Supported Decision-Making**

Alzheimer Scotland. (2012). **Dementia: Making Decisions. A practical guide for family members, partners and friends with powers of attorney, guardianship or deputyship.** https://www.alzscot.org/information_and_resources/information_sheet/2413_dementia_making_decisions_-_a_practical_guide [WEBSITE AND DOWNLOADABLE BOOKLET, Scotland]

Cognitive Decline Partnership Centre. (2018). **Supported Decision-Making in Dementia Project Resources.** <http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php> [WEBSITE AND ONLINE VIDEOS, Australia]

Fulton, K., & Pearman, L. (2014). **Supported Decision-Making.** Perth: WA Individualised Services. <http://waindividualisedservices.org.au/wp-content/uploads/2014/11/Supported-Decision-Making-all-4-Booklets-in-One.pdf> [DOWNLOADABLE DOCUMENT, Australia]

National Resource Center for Supported Decision-Making. (2016). **Supported decision-making: Your support, my decisions.** <http://supporteddecisionmaking.org/impact-stories/supported-decision-making-your-support-my-decisions-video> [ONLINE VIDEO, United States of America]

Victorian Office of the Public Advocate. (2018). **Side by Side: A guide for people wanting support to make decisions.** Melbourne: Victorian Office of the Public Advocate. <http://www.publicadvocate.vic.gov.au/our-services/publications-forms/supported-decision-making-1/side-by-side-a-guide-to-appointing-supportive-attorneys> [WEBSITE AND DOWNLOADABLE BOOKLET, Australia]

Victorian Office of the Public Advocate. (2018). **Supported decision-making in Victoria: A guide for families and carers.** Melbourne: Victorian Office of the Public Advocate. <http://www.publicadvocate.vic.gov.au/our-services/publications-forms/supported-decision-making-1/supported-decision-making-guide-for-families-and-cares> [WEBSITE AND DOWNLOADABLE BOOKLET, Australia]

WA Individualised Services. (2014). **Supporting Decisions.** Perth: WA Individualised Services. https://www.youtube.com/watch?v=Zqv7_J3SAAQ&t=18s [ONLINE VIDEO, Australia]

Resources for **communicating with people living with dementia**

Alzheimer's Association. **Communication: Tips for successful communication at all stages of Alzheimer's disease.**

https://www.alz.org/national/documents/brochure_communication.pdf [WEBSITE AND DOWNLOADABLE BOOKLET, United States of America]

Dementia Australia. **Dementia Language Guidelines.** Canberra: Dementia Australia.

<https://www.dementia.org.au/resources/dementia-language-guidelines> [DOWNLOADABLE DOCUMENT, Australia]

Mental Health First Aid International. **Guidelines for helping the confused older person.**

<https://mhfa.com.au/sites/default/files/MHFA-helping-the-confused-older-person.pdf> [WEBSITE, United Kingdom]

Social Care Institute for Excellence. **Having a conversation with someone with dementia.**

<https://www.scie.org.uk/dementia/after-diagnosis/communication/conversation.asp> [WEBSITE, United Kingdom]

Talking Mats Australia.

<https://talkingmatsaustralia.com.au> [WEBSITE, Australia]

Resources for **Advance Care Planning**

Cognitive Decline Partnership Centre. (2016). **Future Planning and Advance Care Planning: Why it needs to be different for people with dementia and other forms of cognitive decline.**

<http://sydney.edu.au/medicine/cdpc/resources/advance-planning.php> [DOWNLOADABLE BOOKLET, Australia]

Advance Care Planning Australia. **Advance care planning in dementia.**

<https://www.advancecareplanning.org.au/for-health-and-care-workers/in-various-settings/advance-care-planning-in-dementia> [WEBSITE, Australia]

Cartwright, C. **Planning for End of Life for People with Dementia.**

<https://www.dementia.org.au/about-dementia/i-have-dementia/advance-care-planning> [WEBSITE AND ONLINE VIDEOS, Australia]

Resources on **assessing decision-making capacity**

NSW Government Attorney General's Department. (2008). **Capacity Toolkit**. Sydney: NSW Government.

http://www.publicguardian.justice.nsw.gov.au/Documents/capacity_toolkit0609.pdf
[DOWNLOADABLE BOOKLET, Australia]

Aged Rights Advocacy Services

Older Persons Advocacy Network (OPAN). **Links to advocacy organisation relevant to your state or territory.**

<http://www.opan.com.au>

Phone: 1800 700 600 across Australia.

State Administrative Tribunals

New South Wales (NCAT): <http://www.ncat.nsw.gov.au>

Victoria (VCAT): <https://www.vcat.vic.gov.au>

Australian Capital Territory (ACAT): <https://www.acat.act.gov.au>

Queensland (QCAT): <http://www.qcat.qld.gov.au>

South Australia (SACAT): <http://www.sacat.sa.gov.au>

Western Australia (WASAT): <http://www.sat.justice.wa.gov.au>

Northern Territory (NTCAT): <https://nt.gov.au/law/courts-and-tribunals/northern-territory-civil-and-administrative-tribunal-ntcat>

Tasmania: <http://www.guardianship.tas.gov.au>

Reports and Policy Documents

Australian Law Reform Commission. (2014). **Equality, Capacity and Disability in Commonwealth Laws.**

<https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>

[DOWNLOADABLE REPORT, Australia]

Sinclair, C., Field, S., & Blake, M. (2018). **Supported decision-making for aged care providers.** Sydney: Cognitive Decline Partnership Centre.

<http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php>

[DOWNLOADABLE BOOKLET, Australia]

United Nations Enable. (2008). **Convention on the Rights of Persons with Disabilities, Article 12.**

Retrieved from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> [WEBSITE, United Nations]

REFERENCES

1. Fetherstonhaugh D, Tarzia L and Nay R. Being central to decision making means I am still here!: The essence of decision making for people with dementia. *Journal of Aging Studies*. 2013; 27: 143-50.
2. United Nations. Convention on the Rights of Persons with Disabilities (CRPD). New York: United Nations, 2006. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
3. World Health Organisation. Global Action Against Dementia: Meeting Report. Geneva, 2015. http://www.who.int/mental_health/neurology/dementia/ministerial_conference_2015_report/en/
4. Bigby C, Douglas J, Carney T, Then SN, Wiesel I and Smith E. Delivering decision making support to people with cognitive disability - What has been learned from pilot programs in Australia from 2010 to 2015. *Australian Journal of Social Issues*. 2017; 52: 222-40.
5. Sinclair C, Gersbach K, Hogan M, Bucks RS, Auret KA, Clayton JM, Agar M, Kurrle S. How couples with dementia experience healthcare, lifestyle, and everyday decision-making. *International Psychogeriatrics*. (online first) 2018: 1-9. <https://www.cambridge.org/core/journals/international-psychogeriatrics/article/how-couples-with-dementia-experience-healthcare-lifestyle-and-everyday-decisionmaking/C91F4A51900E7CC6A1453B5A12803D64>
6. NSW Government. Capacity Toolkit. Sydney: NSW Government (Attorney General's Department), 2008. https://www.justice.nsw.gov.au/diversityservices/Documents/capacity_toolkit0609.pdf
7. Australian Health Ministers Advisory Council. A National Framework for Advance Care Directives. Australian Health Minister's Advisory Council, 2011. http://www.coaghealthcouncil.gov.au/Portals/0/A%20National%20Framework%20for%20Advance%20Care%20Directives_September%202011.pdf
8. Macadam A and Savitch N. Staying connected, with circles of support. *The Journal of Dementia Care*. 2015; 23: 32-4.
9. Murphy J and Oliver T. The use of Talking Mats to support people with dementia and their carers to make decisions together. *Health & Social Care in the Community*. 2013; 21: 171-80.
10. Iyengar SS. *The Art of Choosing*. New York: Twelve, 2010.
11. Ridge P. The equitable doctrine of undue influence considered in the context of spiritual influence and religious faith: Allcard v Skinner Revisited in Australia. *University of New South Wales Law Journal*. 2003; 26: 66-89.

ACKNOWLEDGEMENTS

The authors wish to thank the participants involved, and to acknowledge Dementia Australia, Brightwater Care Group, Helping Hand Aged Care and HammondCare for facilitating the process of recruitment to the study. The authors would also like to acknowledge the contribution of organisations and individuals who have contributed to advisory groups associated with this project.

Cognitive Decline Partnership Centre ‘Supported Decision-Making in Dementia’ Research Team:

- Dr Craig Sinclair (University of Western Australia)
- Sue Field (University of Western Australia)
- Professor Sue Kurrle (University of Sydney)
- Professor Meera Agar (University of Technology Sydney)
- Kathy Williams (Dementia Australia)
- Associate Professor Meredith Blake (University of Western Australia)
- Professor Romola Bucks (University of Western Australia)
- Associate Professor Kirsten Auret (University of Western Australia)
- Professor Cameron Stewart (University of Sydney)
- Associate Professor Josephine Clayton (University of Sydney, HammondCare)
- Meredith Gresham (HammondCare)
- Helen Radoslovich (Helping Hand Aged Care)
- Dr Angelita Martini (Brightwater)

Advisory Group Consumer Representatives:

Kathy Williams, Ann Pietsch, Theresa Flavin, Mike Barry, Vicki Barry, Dr Ron Sinclair, Cate McCullough, Karine Shellshear, Darcelle Wu

Advisory Group Organisations:

- NSW Office of the Public Guardian
- SA Office of the Public Advocate
- SA Government Department of Communities and Social Inclusion
- Dementia Australia
- Alzheimers WA
- Carers Australia (NSW, SA)
- Leading Aged Services Australia NSW

- Australian Aged Care Quality Agency
- Council on the Ageing (SA)
- NSW Elder Abuse Helpline & Resource Unit
- Seniors Rights Services NSW
- Advocare
- MCCI / PICAC (Partners in Culturally Appropriate Care NSW & ACT)
- Multicultural Aged Care (SA)
- University of South Australia - Margaret Brown
- Dr Suzanne Jarrad - Independent Consultant

Advisory group members did not determine the study design, or have access to identifiable raw data. Participation in advisory groups does not imply endorsement of the study findings by these individuals or organisations. The authors also acknowledge the contribution of Funding Bodies (National Health & Medical Research Council) and Funding Partners (Dementia Australia, HammondCare, Helping Hand Aged Care, Brightwater Group). The contents of these materials are solely the responsibility of the individual authors identified, and do not reflect the views of the Funding Bodies or the Funding Partners.



This plan is to inform others about the things that help me to be involved in decisions about my life. It identifies my key support people and the agreements we have made about how they can help me in decision-making.

MY DECISION SUPPORT PLAN

DECISION-MAKER

My name:

MY SUPPORTERS

Name: _____ ph: _____

Name: _____ ph: _____

Name: _____ ph: _____

MY GOALS AND VALUES

My Most Important Goal:

The things that are important to me, for my lifestyle, healthcare, financial and everyday decisions.

LIFESTYLE
where &
how I live

HEALTHCARE
medications &
treatment

FINANCIAL
my money &
possessions

EVERYDAY
daily routines
& activities

Continued on page 44



WHAT'S HELPFUL TO ME

Things that help in making decisions (tick those that fit you best, cross out those you disagree with):

- Extra time to think is helpful
- I like professionals to talk in 'plain speak'
- Photos / pictures help me understand
- Notes help me remember what was discussed
- I would like to have my supporter/s with me when making decisions
- I would like access to an interpreter: _____ (preferred language)
- I like to know all the options OR I prefer a smaller number of choices
- Other: _____
- Other: _____

My supporter/s [name] _____ may access information about my healthcare / finances / other matters to help me make decisions (cross out those that do not apply).

My supporter/s [name] _____ may access information about my healthcare / finances / other matters to help me make decisions (cross out those that do not apply).

Completed by _____,

with help from _____, on [date]: _____

Signed: _____

Make copies of this form for those who provide support for you in decision-making.

This form is not legally binding, but provides information for those who are supporting your decision-making.



COGNITIVE
DECLINE
PARTNERSHIP
CENTRE



THE UNIVERSITY OF
**WESTERN
AUSTRALIA**



THE UNIVERSITY OF
SYDNEY

