

Sean's decision

Decision-making support for
people with cognitive disability



Guidelines for families and carers

***“These people are
human beings and
deserve as much respect
and dignity as anybody.”***

– family member

Acknowledgments

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Bigby, C., Whiteside, M., & Douglas, J. (2015). *Supporting people with cognitive disability in decision making – Processes and dilemmas*. Melbourne: Living with Disability Research Centre, La Trobe University.

The quotes used in this resource are from the Latrobe research report. Other information and research has also been used to develop the content in this booklet and multimedia material.

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***“So you can’t just say well she can’t make decisions because she’s intellectually disabled, in actual fact she can make decisions and she makes some good decisions.”
-family member***

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About these guidelines

This booklet sets out guidelines for families and supporters - including siblings, friends and others - to help people with cognitive disability make decisions.



Often, people with cognitive disability want support to make decisions. Indeed *all* people often want or need support to make decisions. These guidelines are designed to help you support someone with cognitive disability make important decisions.

You can use these guidelines in several ways:

- To help a person make decisions about his or her life, whether big or small.
- To prepare yourself for a conversation about decision-making with a relative or friend with cognitive disability.
- As a resource to help someone prepare for a planning or decision-making meeting about services.

The term ‘cognitive disability’ is used in this booklet to refer to people with intellectual disability and those with acquired brain injury. It is important to note this booklet is designed to help support people with *mild* and *moderate* cognitive disability. It is not aimed at decision-making support for people with profound cognitive impairment, such as people who have extremely high support needs or are in a minimally conscious state.

This resource is part of a set of written and multimedia materials designed to promote decision-making support for people with cognitive disability. This is a Victorian resource which references specific Victorian law. The set also includes resources for service providers and legal professionals. The full set of resources can be accessed from www.scopevic.org.au.

The title of this document, Sean’s Decision, relates to a mock case study referenced throughout the document. In this example, Sean is a person with a cognitive disability. He sometimes needs help making decisions and consults both family members and carers when he is confronted with a decision he is not sure about.

Words of wisdom from family members

“So [my daughter] will tell [her friend] stuff that she won't tell us so it is helpful to have some insight from others, they won't breach her confidentiality.”

- parent

“You've got to let him do it, which has been our philosophy over the years because we've just brought him up as normal. He's got every chance that everybody else has got.”

- family member

“You have to have a philosophy, there is no point in having supported decision-making without having a very clear commitment to the model, this is the model I believe is appropriate ... I believe very strongly that everybody has the right to a meaningful life.”

- family member

“... there has to be a really big component in listening skills so it is really listening to as wide a range as possible ... but listening to the people - very often workers when they are on an initial assessment or something - have got the solutions before they start and they've got the outcomes and they will tick the boxes. They really need to listen and build up trust before major decisions are made.”

- family member

Introduction to decision-making support

Being able to direct decisions about our own lives helps define who we are. Making decisions, and having those decisions respected on an equal basis with others, gives us dignity, equality and control of our lives.

Decision-making support involves helping someone to express their will and preferences, have these understood, and acted upon. It is a way of supporting people with cognitive disability to make significant decisions and exercise their will and preference. It relies on the support of others (often a network of people) to gather and understand relevant information about the decision in question, think about different options, assist the person weigh up the benefits and risks and likely outcomes of a decision, and identify a plan for making the decision a reality.

Potential supporters may be family, friends, support staff, or community members, and are people known and trusted by the person who are willing to represent the person's will and preference. At times this process has been referred to as supported decision-making, but in this booklet, we will refer to it as decision-making support.

The intention of this model of support is to ensure that people have access to the support they need to make decisions that reflect their will and preference. It is different from times in the past when some people had the perception that “people with cognitive disability had not been perceived to have rights or the capacity to make or be involved with decision-making”¹. A decision-making support approach does not focus on the question of whether a person can or can't make decisions, rather it asks the question: “What types and levels of supports does a person need to fully make and enact decisions that reflect their will and preference?”

¹ Bigby, C., Whiteside, M., & Douglas, J. (2015). *Supporting people with cognitive disabilities in decision making – Processes and dilemmas*. Melbourne: Living with Disability Research Centre, La Trobe University.



Key ideas in decision-making support

We all use decision-making support in our lives. Even people who are comfortable making their own decisions will sometimes rely on others to gather, understand and consider relevant information about key decisions. For example, we may seek the advice of family and friends when deciding to buy a new car, a hairdresser when deciding on a 'new do', an accountant for help with financial decisions, health professionals for medical decisions and lawyers for legal decisions. A person with cognitive disability is no different. They simply may need more support than people without cognitive disability to express their preference and to have this preference realised. But, some family members and people in paid supporting roles are not necessarily fully informed nor convinced by the philosophical underpinnings of decision-making support.

Informed by a human rights perspective, decision-making support is in many ways different from previous practices, and a break from philosophies of the past. In the past, people with cognitive disability were not always perceived to have rights or the capacity to make or be involved with decision-making. **The move to decision-making support is a fundamental shift away from decisions being made according to what is seen to be in the 'best interests' of the person.** Instead, just like how buildings now have ramps so they are accessible for people who use wheelchairs, decision-making support is about giving people with cognitive disability the supports they need to make decisions about their own lives.

Legislation currently reflects decision-making support for people with disability at a state, federal and international level. In Victoria, people are protected by the *Equal Opportunity Act 2010* (Vic),² the *Victorian Disability Act 2006* (Vic),³ the *Powers of Attorney Act 2014* (Vic),⁴ the *Guardianship and Administration Act 1986* (Vic)⁵ and the *Victorian Charter of Human Rights and Responsibilities Act 2006* (Vic).⁶ Federally, the *Disability Discrimination Act 1992* (Cth)⁷ provides protection from discrimination for all Australians and the *National Disability Insurance Scheme Act 2013* (Cth) established the National Disability Insurance Scheme.⁸ Internationally, the *United Nations Convention on the Rights of Persons with Disabilities 2013*⁹ affirms the rights of people with disability. More recent legislation and policies guiding decision-making support are discussed below.

² Australian Legal Information Institute. (2010). *The Equal Opportunity Act*. Retrieved February 20, 2016, from http://www.austlii.edu.au/au/legis/vic/consol_act/eoa2010250/.

³ Victorian Legislation and Parliamentary Documents. (2011). *The Disability Act*. Retrieved October 10, 2015, from <http://www.dhs.vic.gov.au/for-individuals/disability/your-rights/disability-act-2006>.

⁴ Victorian legislation and Parliamentary documents. (2014). *Powers of Attorney Act*. Retrieved October 10, 2015, from [http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/PubStatbook.nsf/f932b66241ecf1b7ca256e9200e23be/AF123F4F49B8FA2BCA257D40000EE0B2/\\$FILE/14-057aa%20authorised.pdf](http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/PubStatbook.nsf/f932b66241ecf1b7ca256e9200e23be/AF123F4F49B8FA2BCA257D40000EE0B2/$FILE/14-057aa%20authorised.pdf).

⁵ The Office of the Public Advocate. (1986). *The Guardianship and Administration Act (Version incorporating amendments as at 24 May 2005)*. Retrieved February 24, 2016, from [http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/LTOobject_Store/LTObjSt2.nsf/DDE300B846EED9C7CA257616000A3571/CBE1D00615581929CA25776100214AB3/\\$FILE/86-58a063.pdf](http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/LTOobject_Store/LTObjSt2.nsf/DDE300B846EED9C7CA257616000A3571/CBE1D00615581929CA25776100214AB3/$FILE/86-58a063.pdf).

⁶ Victorian Equal Opportunity and Human Rights Commission. (2006). *The Victorian Charter of Human Rights and Responsibilities Act*. Retrieved February 24, 2016, from http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/PubLawToday.nsf/e84a08860d8fa942ca25761700261a63/7379cff5e33da38dca257d0700051af8!OpenDocument&Highlight=0,Act.

⁷ Australian Government Commlaw. (1992). *The Disability Discrimination Act*. Retrieved October 10, 2015, from https://www.comlaw.gov.au/Details/C2015C00252/Html/Text#_Toc422301336.

⁸ Australian Government Commlaw. (2013). *National Disability Insurance Scheme Act*. Retrieved October 10, 2015, from <https://www.comlaw.gov.au/Details/C2013A00020/Html/Text>.

⁹ United Nations. (2016). *The Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, A/RES/61/106 (entered into force 3 May 2008). Retrieved October 10, 2015, from <http://www.un.org/disabilities/convention/conventionfull.shtml>.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

Making decisions and having those decisions respected are principles that have been affirmed in international human rights law for people with disability, in particular, in the UNCRPD.¹⁰

Australia has now committed to following the UNCRPD, which came into force in 2008. The UNCRPD affirms that people with disability should be given support to make decisions on an equal basis with others. By ratifying the UNCRPD, the Australian Government must make sure that laws and administrative measures align with the principles set out in it. In turn, this means the principles of the UNCRPD should underlie how we support and work with people with disability.

The National Disability Insurance Scheme (NDIS)

Everyday life choice and control is a fundamental part of the NDIS. It is an expectation that participants of the scheme “will determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity”¹¹. This means participants will need to make more decisions about more things. The complexity of the participants’ decisions will increase as they take more responsibility for their own lives and the outcomes of the decisions they make. People with cognitive disability will need to develop skills and be provided with appropriate support to make their own decisions.

The Australian Law Reform Commission (ALRC)

The ALRC has recently undertaken a review of all Federal laws related to the equality and legal capacity of people with disability. Their world-leading review will inform the development of many laws and policies around Australia related to the rights of people with disability, including the NDIS. The ALRC has identified four key national decision-making principles that can be used to inform our work with people with cognitive disability:

Principle 1: The right to make decisions

All adults have an equal right to make decisions that affect their lives and to have those decisions respected.

Principle 2: Support

People who require decision-making support must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.

Principle 3: Will, preferences and rights

The will, preferences and rights of people who may require decision-making support must direct decisions that affect their lives.

Principle 4: Safeguards

Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for people who may require decision-making support, including prevention of abuse and undue influence.¹²

¹⁰ United Nations. (2016). *The Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, A/RES/61/106 (entered into force 3 May 2008). Retrieved October 10, 2015, from <http://www.un.org/disabilities/convention/conventionfull.shtml>.

¹¹ Australian Government Comlaw. (2013). *National Disability Insurance Scheme Act*. Retrieved February 24, 2016, from <https://www.comlaw.gov.au/Details/C2013A00020/Html/Text>.

¹² Australian Law Reform Commission. (2014). *Equality, capacity and disability in commonwealth laws* (Discussion Paper 124). Retrieved July 27, 2015, from http://www.alrc.gov.au/sites/default/files/pdfs/publications/alrc_124_whole_pdf_file.pdf.

A move away from substituted decision-making

Historically, families may have been encouraged to make decisions for people with cognitive disability. This is often described as ‘substituted decision-making’.

Substituted decision-making may occur formally under laws such as the *Guardianship and Administration Act 1986* (Vic),¹³ which authorises the making of decisions within certain areas of a person’s life using a ‘best interests’ standard to guide decisions. More often, however, substituted decision-making occurs informally, including within families and elsewhere in the community, including in disability services.

“There are still people out there, working in the field who ... have the same mentality as 20 or 50 years ago working in the institutions which is ‘you come over here and sit down here and don’t get that food on you, wipe that off your mouth, everyone get into your pyjamas now, it’s time for bed.’” - lawyer

There may be many reasons why others might make decisions FOR the person with disability, including:

- **Time constraints.** It may be seen as faster to make a decision “for” rather than “with” a person.
- **Protection.** It may be feared the person will make a decision that is harmful to him or herself, or to others.
- **Low expectations.** The role of people with cognitive disability in society is grossly devalued.
- **Abuse and discrimination.** People with cognitive disability face widespread discrimination, and their views are often not taken seriously.

Most of the time, people who are making substituted decisions are well-meaning people who consider the best interests of the person with cognitive disability when making decisions on their behalf. But despite their good intentions, the results can be negative for people with cognitive disability (for example, learned helplessness, discrimination, loss of confidence).



¹³ Victorian Legislation and Parliamentary documents. (1986). *The Guardianship and Administration Act (Version incorporating amendments as at 24 May 2005)*. Retrieved February 24, 2016, from [http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/LTObject_Store/LTObjSt2.nsf/DDE300B846EED9C7CA257616000A3571/CBE1D00615581929CA25776100214AB3/\\$FILE/86-58a063.pdf](http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/LTObject_Store/LTObjSt2.nsf/DDE300B846EED9C7CA257616000A3571/CBE1D00615581929CA25776100214AB3/$FILE/86-58a063.pdf).

General principles for decision-making support

Making decisions independently is an important part of anyone's sense of self-worth. It is integral to growth and development. People with cognitive disability have the right to make and take responsibility for decisions in their lives. But people make their best decisions when they have good information, consider the views of others and take time to think through what is most important to them.

As a family member, friend or other supporter, there are many ways you can help others make informed and thoughtful decisions.

- **Will, preferences and rights:** Focusing on what the person wants and on their rights rather than what others might judge to be in their best interests.
- **Believe:** Having positive attitudes/expectations of the person and creation of opportunities to make decisions.
- **Help only where needed:** People with cognitive disability often face the over-involvement of others. Not everyone needs help with the whole decision-making process. A person may only need help on one or two steps.
- **Stay neutral:** Being neutral means staying impartial and not influencing the person in their decision. By helping the person consider options objectively, you show your respect for them. You also help them develop their decision-making skills. This may mean you don't necessarily agree with their choice.
- **Take your time:** It's OK to stop and re-start decision-making. Consider ways to ensure the person does not feel pressured, while helping them focus on deadlines. For example, before a conversation you may need to research options for the person to explore. This can take time, but doing so could help prevent a person feeling confused.
- **Work with other supporters:** The person may have others in his/her life (e.g. paid workers, friends) who could provide decision-making support. Having more than one person providing this support makes for more equal power dynamics in which a person can consider different options, views and influences. Speak to the person about who else might be approached to be involved in providing support. You might encourage the person to approach someone else to be a supporter.



Staying neutral

Staying neutral or impartial may be more challenging for family members than for disability workers. This is because family members tend to have a greater stake in the decisions being made. Family members cannot simply “clock off” and go home as disability workers do. But being neutral in your support can be essential for the person to form his or her own opinions and decision-making skills.

Staying neutral does not mean withholding advice about what you believe to be the best course of action. It simply means that such advice is offered in a non-dominating and respectful way. For example, it may be useful to differentiate between your opinions and assisting to clarify information. When you do offer your opinion, be clear that you are offering an opinion rather than a fact: “Can I offer my opinion?”

Staying neutral may involve becoming aware of and reflecting on your own values and opinions as a supporter, and the potential impact of these on the support process. It may be useful to write these reflections down before a conversation that involves the person making a decision. This written record can serve as a reminder of any potential personal biases that may impact on neutrality.

Staying neutral is not straightforward. It is easy to influence the direction of a person’s decision by inserting your own values into the process of support. Influencing someone can happen by the nature of the options that are presented to the person, the way the pros and cons of each option are discussed, your reactions to proposed decisions, or even because of the nature of your relationship with the person.

For families, an important part of decision-making support is to understand the overarching vision the person with cognitive disability has for their own life. Having an overarching vision for a good life is important and valuable. Goal setting is often used so that smaller decisions can be aligned to this overarching vision.

Working with other supporters

To work well together, supporters need an understanding and respect for the different roles, contexts and challenges of supporters in the person's life. An understanding of the unique and sometimes challenging role of others can reduce tension and conflict, making collaboration easier. For example, a support worker who predominately works with a person during the day may lack an understanding of the role of a family member who has spent the last thirty years with them.

Working with other supporters may mean helping them to get to know the person better. Share your deep knowledge of the person, such as their history and background, how he/she communicates, what helps them understand information, their likes and dislikes, and their unique support needs.

A supporter:

- Has a trusting relationship with the person being supported.
- Has a relationship which respects the person's autonomy and dignity.
- Has a relationship which respects the person's decision-making style.
- Knows the person and is committed to keep learning about the person—that is, knows the person's background and history, goals, values and preferences, and has an understanding of how support for that person can be offered.
- Can call on others to support the decision, if that is what the decision maker wants.
- Is able to spend as much time as is required to support decision-making.¹⁴

Having relationships of trust and understanding is essential to good decision-making support.

¹⁴ Office of the Public Advocate (2011). *Developing a model of supported decision making: Background information to assist the facilitation of agreements*. Collinswood, SA: Office of the Public Advocate.

Steps for decision-making support

It is important the person's will, preferences and rights drives the decision-making process. This means that, throughout the process and while you are providing support, you will need to focus on what the person intends and wants, and not what others might judge to be in their best interests. If you know the person well you may assume they want something a particular way, but often people can surprise us with unexpected wishes and preferences.

It is also important your communication is pitched at a level that is right for the person. Most family members will understand the communication needs of their relative, and how to communicate in a way that he/she can understand. There are many resources you can use to help you with communication (refer to the Additional selected resources section).

In providing decision-making support, be aware the person's preferences can change over time and with different people. This is important as it respects the person's right to change with experience, or to choose to take on different roles with different friends or acquaintances.

Communication tips

As a family member, you are perhaps the most skilled at communicating with your loved one. Some tips that could be part of your approach may include the following:

- Accessible information: Visual aids may be useful, such as diagrams, pictures or pictographs.
- It may be useful to meet in a calm place where there are minimal distractions, and a place in which the person feels comfortable. Meet in a place of their choosing, if possible.
- Short bursts of conversation with breaks can be effective for some people.
- It may be necessary to repeat information.
- Watch for non-verbal communication such as body language, facial expression or gesture to see if the person is comfortable, stressed, and so on.
- It can be useful to ask open-ended questions such as: "What do you think of living in a retirement home?" But it is important to acknowledge that some people with cognitive disability struggle with open-ended questions. A useful strategy can be to offer the person two carefully selected alternatives, while gradually narrowing the choice. For example: "Do you feel sad about work sometimes or all of the time?"
- It is important to confirm that a person has understood. People with cognitive disability may have learned to agree or nod in a gesture of understanding as a means of 'getting by' when in fact they have not understood. Checking back can be useful to improve communication and to identify what is and is not working.

Case study:

Sean is a person with cognitive disability. He sometimes needs help making decisions and consults both family members and staff when he is confronted with a decision he is not sure about.

Sean's decision

Sean has recently picked up a paid job folding towels. He is 30 and for various reasons has never had a job that has lasted more than a few weeks. He doesn't like being paid \$2.20 per hour and wants to find a better paying job. But he enjoys having the company of his workmates and having something to do on Friday's.

Sean tells you he has to quit his job because he wants to be paid more. He likes the work itself and his workmates and is sad to leave it. You suggest that before he makes a decision to quit he should spend some time seeing if he has other options.

Identify the decision

The first step is to clearly define the particular decision that needs to be made. This may not always be straightforward as big decisions – such as moving out of the family home or making the decision to go into a nursing home – might give rise to many smaller decisions that need to be made.

Questions

The following questions may help the person (and yourself) identify the decision that must be made:

What do you see as the main issue?

What do you want to stay the same?

What do you want to change?

What decision(s) do you feel have to be made?

What order do the decisions go in?

Which decision do you tackle first?



Sean's decision

You talk to Sean and ask him what the decision is that needs to be made. He feels that it's time to make a decision about whether to stay at the job. He has to decide whether it's worth his time. If he was to leave, he'd have to make decisions about whether or not to seek another job. But you both agree the key decision to be made is whether to stay in the job.

Involve other people in the decision-making process

Very few people make decisions in isolation. Decisions about our lives also affect others, including family members, friends and workmates. Sometimes others need or want to be involved in making big decisions. This involvement might be welcomed by the person — though it may not. You might help a person consider who is implicated by a decision. Or you may help them choose others to be involved and to discuss how best they can help: as a history giver, gatherer of information, as an advisor, as someone who will assist with weighing pros and cons or the outcomes and consequences, or as a person with whom a decision is being made together.

Questions

Is this a decision just for the person?

*Are other people affected by this decision?
How?*

Should other people be involved?

How would these other people help?

Researching – support the person to gather, understand and consider relevant information

We all benefit from knowing the facts around a particular decision. Research might include gathering information from different sources, such as from relevant people and agencies, or doing your own research online. Help the person understand the relevant information by presenting it in ways they will understand.

Questions

Do you have all the facts?

Do you know the options that are possible?

Do you need more information?

What information might be helpful?

Where might you find this information?

Sean's decision

You encourage Sean to make sure he has all the facts about his situation. Sean double-checks with his boss that his pay is \$2.20 per hour. He finds out that if he stays for three months, it will increase to \$5 an hour and he will be back-paid for the three months at the increased rate. He doesn't understand what 'back-paid' means and you explain it for him. You set out the numbers clearly so he knows how much money is at stake. Despite the increased rate – about \$28 per day in total – he still doesn't feel that this is worth it.

Work out what the options are

Using the facts, support the person to work out a range of different options that are possibilities in this decision. Set out the different options so they are easy for the person to see and understand. Remember to build an awareness of what is involved in making things happen for each of the options. Remember also to present options the person may not have previously considered.



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Questions

What are some ways to go about it?

Can you think of what the options might be?

Have you also thought about doing A, or B or C?

What has and has not worked in the past?

If the person chooses to do A, would that involve doing X, Y, and Z to make it happen?

.....

In working with the person to determine the options, consider what is possible in terms of resources. For example, most of us would love to go to Paris tomorrow, however, life has a funny way of placing limits on us. Sometimes our preferences are unachievable because we may not have the money or time to execute them.

Sean's decision

You suggest to Sean he consider how difficult it has been in the past to find work.

You help him to set up a time to talk with someone from an employment agency. You ask if he knows other people with jobs he is interested in and who he might get in touch with to ask for advice. You ask him to think about what skills he might need to do those jobs. Sean decides his options are:

- Quit the job
- Do nothing: keep working
- Stay for the short-term until something else is found

Identify and weigh the pros and cons of the different options

Get the information together and work with the person to identify the pros and cons of each option - what are the advantages and disadvantages of each option?

Questions

Will this option be easy or hard?

Will it be fun or serious?

Will it work immediately or take a long time to work?

Will it affect other people in a good or a bad way?

Sean's decision

Sean says the decision is his, although the choice would affect his workmates, his boss and his family. He thinks getting paid more is more important than his time spent with workmates. He acknowledges the risk he may become bored and lonely, spending time without a job, but is willing to take that risk.

You are concerned that without the job, Sean will stay at home more and become increasingly isolated. This may cause you increased stress. You ask Sean if you can share your opinion. When he says yes, you explain - making clear that this is your opinion - that you are concerned that he is worse off and that it will also mean more pressure for you.

You let him know that ultimately it's his decision and you want to support him. You list the outcomes of each decision. A table can help Sean see the pros and cons of each decision.

	Pros	Cons
Option A: Quit	<ul style="list-style-type: none"> • More free time • No longer doing work he doesn't like 	<ul style="list-style-type: none"> • Less money • Lose contact with workmates
Option B: Stay, do nothing. Keep working	<ul style="list-style-type: none"> • Receive \$28 per day in pay • Keep contact with workmates • Has something to do 	<ul style="list-style-type: none"> • May continue feeling underpaid • May continue wondering if there is something better
Option C: Stay for three months until something else is found	<ul style="list-style-type: none"> • Keep earning money • Something to do • Continues contact with workmates • Has an end to unsatisfactory work in sight 	<ul style="list-style-type: none"> • May continue feeling underpaid • May not find alternative



Prioritise the different options

It can be useful for a person to more clearly identify priorities related to a decision. You might help them identify their priorities. If the final decision matches a person's priorities, it is more likely the decision will be more fully followed through. The person will feel a greater sense of ownership and control. Encourage the person to list or consider things that are important. The person might even rate which priorities are more important.

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Questions

What are the top three priorities?

What are the lowest three priorities?

What would be the perfect outcome in the face of the current problem?

.....

Sean's decision

You acknowledge all the thinking and research Sean has done so far. He is doing a great job and is sticking with the process.

You and Sean talk together about his perspective on the situation and the pressure he is feeling. With such little pay – about \$28 a day – Sean feels it is not worth his time. But he also feels pressured to have a job. He is leaning toward quitting but is willing to explore other ideas.

You talk about whether there are other ways to develop meaningful relationships with people, similar to what he has with his workmates, if he quit his job. Following this discussion, you suggest he lists the most important things related to the decisions. He comes up with:

- Income
- Company/friendships that he has developed over the years
- Something to do
- Work experience

Explain the potential consequences of the options

Providing people with a clear sense of the consequences and practicalities of a decision is important. Outline as clearly as possible the consequences of option A compared to option B or C, including both positive and negative outcomes. Many people with cognitive disability may find it difficult to predict outcomes and consequences and will benefit from support to evaluate the available options. They may also benefit from having time to weigh up these options. Consider imagining or reimagining the future to simulate testing the options.



Questions

*How might that look? What might happen?
What would you have to do if you decide to go ahead with that decision?*

Have you thought that if you do A it is possible that X or Y might happen?

If you choose to do B would you have to do Z to make it happen?



Make the decision and follow it through

Once the decision has been made, it is important that there is appropriate support to ensure the person with cognitive disability can actually get the outcomes of the decision happening within a reasonable timeframe. Consider what supports the person will need to be able to participate in the actions that flow from the decision - who might be involved, what environments are suitable, is special equipment needed? At this point you may provide opportunities to assist the person to follow through.



Questions

How are you feeling about getting started?

Do you want some help to do this?

Is this going well for you?



Sean's decision

Sean considered all three options. You supported him to clearly identify the pros and cons of each decision and to compare them with his priorities. He hadn't considered just how important the relationships he'd developed at his workplace were. He was surprised to see they were a key reason he'd stayed in the job. Although he'd resolved to leave his work, he thought it would be worth staying for a few months while he looked for work elsewhere. You help Sean communicate this to his boss.

The priority Sean placed on having workmates and others to see on a day-to-day basis was a surprise even to you, and made Sean himself ask how he could maintain such relationships or find other meaningful relationships when he leaves the job. You assist Sean by helping him seek employment elsewhere. You encourage him to take annual leave to attend job interviews or to visit other potential employers to enquire about work. You and Sean and other supporters in his life consider ways he can establish meaningful relationships with others.

Not all decisions will require heavy involvement or structured decision-making. Sometimes, supporting someone is just about letting him or her decide without fuss!

Check in after to see how the decision went in practice

Check in with the person as the decision is being implemented to be sure their expectations are being met and that they are feeling emotionally supported and confident. Keep in mind that supporting a person with cognitive disability to build experience will broaden their understanding of what is possible, and help them practice making decisions.



Questions

How did that go - what did you like about it, what did you not like about it?

Would you do that the same way next time?

What could you have done differently so it will be better next time?



Keeping the big picture in mind throughout

Remember that lots of small decisions can together have a big impact on a person's life. It is important to have a good understanding of what the person's overall goals are and their vision of a good life, so that decisions can be made in line with those goals and vision, if that is what the person wants to do. Sometimes people may choose to ignore longer term goals, but this should be an active choice, based on knowledge and understanding that the decision might lead away from the bigger outcome. Some people may need support to remember what their goals and vision of a good life are.



Questions

Remember that you set yourself the goal of ... - will this decision help you reach that goal?

Do you still want to (big goal)? Doing this might make it harder for you to achieve that.

You told me (significant person) had more information about that - do you want to go ahead before you get that information anyway?



Building opportunities for decision-making

All too often, people with cognitive disability are denied the opportunity to learn decision-making skills (and equally, families are not necessarily supported to help their relative in this way). This can cause a damaging cycle in which others assume a person can't make decisions, including sometimes the person with cognitive disability! As such, it is important to build opportunities for decision-making. Every decision counts, even small ones!

- **Building confidence:** Consider ideas for building the person's confidence in decision-making. Is there an area of family life or the home where the person can make decisions and take responsibility?
- **Seek opportunities for decision-making:** This might include the smallest of decisions. If a person is living in a retirement home or supported accommodation, identify opportunities for the person to make decisions about the space. A person might decide on what food should be prepared for dinner, then follow through with shopping and cooking.
- **Encourage the person to take risks:** Stepping outside of one's comfort zone can be the key to building confidence. This is true for all people, but people with cognitive disability, often they don't get the chance because of protectionist models of care. It should go without saying that any risks should be taken within reason and after weighing up the costs and benefits.

As the person gains confidence, the level of support may be drawn back or even faded out.

Dignity of risk.

We all make mistakes and this is an important part of making decisions and being your own person. Consider the times when you have made a mistake, or a risky decision, which helped you grow. Any assumptions you have about a person's decision-making skills should be reflected upon with a view to respecting his or her wishes and preferences. Remember, almost all people make decisions that we sometimes disagree with (especially those closest to us). People with disability deserve that chance too.

 *"...everybody has the right to make a bad decision, people should be supported to make their own decisions ... they can make the wrong decision, it's their decision, doesn't matter if you disagree with it." (lawyer)*

“Everybody is different and every technique is different so you have to sit there and kind of work out where you are pitching it.” - lawyer



Dilemmas and tensions in providing decision-making support

Providing decision-making support can be challenging at times - it is not always straightforward. Here are some things you will need to keep in mind.

Remaining neutral

Being neutral means not influencing the person to make one decision over another because of your own beliefs, or because it is the decision you would make if you were in their shoes. It also means that you work with the person to identify the full range of options and avoid a situation where only those options you consider acceptable are considered. In order to remain neutral, you need to be aware of how your own background, knowledge, experience, values and opinions might affect the support you provide. This can be challenging at times.

Think about:

- Your own values and consider how these might influence your actions, including what you present to the person.
- Distinguish your opinion from facts. Offering opinions is not bad but it can be important to ask if the person would like to hear your opinion. Clearly state that something is your opinion rather than fact.
- Present a range of ideas impartially.
- Consider the dignity of taking risks.
- Hold onto a vision of the good life. At the same time, be mindful of not shaping the person's decisions based on your values rather than theirs.

Managing conflicting perspectives amongst supporters

Different supporters have different roles in a person's life. Families might have the bigger picture in mind and may advocate for what they feel is in the person's best interest, or support decisions that move the person towards that bigger picture.

Workers may have a different view of the person and may not be aware of the bigger picture that families are working towards. There may be varying perspectives about the person's right to choose or to take risks. These differing roles and views mean that, at times, supporters may disagree about a decision and there may be conflict or tension. Where conflicts between supporters escalate, or where there is some ambiguity about balancing risks and rights, advocacy organisations may provide useful resources.

 *“Too often people think they're being kind to let her have ... an iced coffee which is full of ice cream and sugar ... I don't want to be critical of staff because they want to have happy people around them ... [She] will gravitate to choices which are not going to help her from a health and weight point of view.”*

Think about:

- Working together and understanding each other's roles, motivations and strengths.
- Being respectful of each others views and opinions.
- Committing to being open and honest with each other.
- Talking about conflict openly and how you will resolve conflict, if it arises.

Managing risks and best interests

Supporting a person to take risks on an equal basis with others, while also acknowledging the difficulties and disadvantages caused by disability, is not a straightforward task. For people with cognitive disability, decision-making can be fraught where issues of risk are involved. It is, however, important to understand there are inherent risks in making decisions, and that everyone has a right to make poor decisions, or badly-timed decisions. It is part of the learning process.

Think about:

- What is the risk?
- What is the nature of the harm that could occur and what is its impact?
- What is the likelihood of harm arising?
- Are there strategies that could be implemented to reduce the risk of the harm occurring?
- How important is the decision weighed up against the possibility of harm?
- Is the person fully informed at their level of understanding about the potential consequences of a decision, and do they understand the risks (to themselves and others)?

Limits in resources to make a decision happen

Although good support may have been provided to make a decision, in practice, it might not be possible to follow up on that decision because of limits in funding or services that are available to the person. It is important to be aware of the resources that are available to the person, and manage his/her expectations about what is and isn't possible throughout the decision-making process.

Think about:

- What is a realistic option now, and what is a dream for the future?
- What resources are available to the person?
- What are the person's priorities and which should we dedicate resources to?
- What are creative ways in spreading resources – such as pooling resources with others who have similar interests, or looking for alternative resources?



Questions for family members supporting decision-making

1). Think of a time when YOU made a big decision. What kinds of advice and help did you get with your decision? How is this similar and different to the support needed by your family member when making decisions?

2). Think about your assumptions and beliefs about your family member's capacity to make decisions. To what extent do you believe they are able to make decisions about their life?

3). How important are the following ideas and values?

Everyone having the right to make decisions that affect their lives and to have those decisions respected.

Not very important - - - - - very important

My family member being provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.

Not very important - - - - - very important

Decisions being led by their will, preferences and rights.

Not very important - - - - - very important

Ensuring the prevention of abuse and undue influence.

Not very important - - - - - very important

4). What types of things help your family member to express choice? What types of things are a hindrance to them making choices?

.....
.....
.....

5). How do I make sure I stay neutral, so that decisions are led by my family member and their viewpoint?

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.....
.....

6). How can supporters (including unpaid and paid supporters) work more closely and collaboratively in supporting the person make decisions?

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.....
.....

7). Considering the person's communication and the way information is gathered and presented, list three ideas you can put in place to better support your family member's decision-making.

.....
.....
.....

Concluding remarks

The guidelines contained in this booklet do not provide a 'magic bullet' for solving the complex dilemmas that may arise when supporting a person with cognitive disability to make decisions. Decision-making is complicated, emotional and messy. It may be necessary in some situations to seek advice, legal or otherwise, as to how best to support a particular person with cognitive disability. In such cases, support can be sought from a number of organisations. For a list of additional resources that may be useful, refer to the following section.

Additional selected resources

Victoria

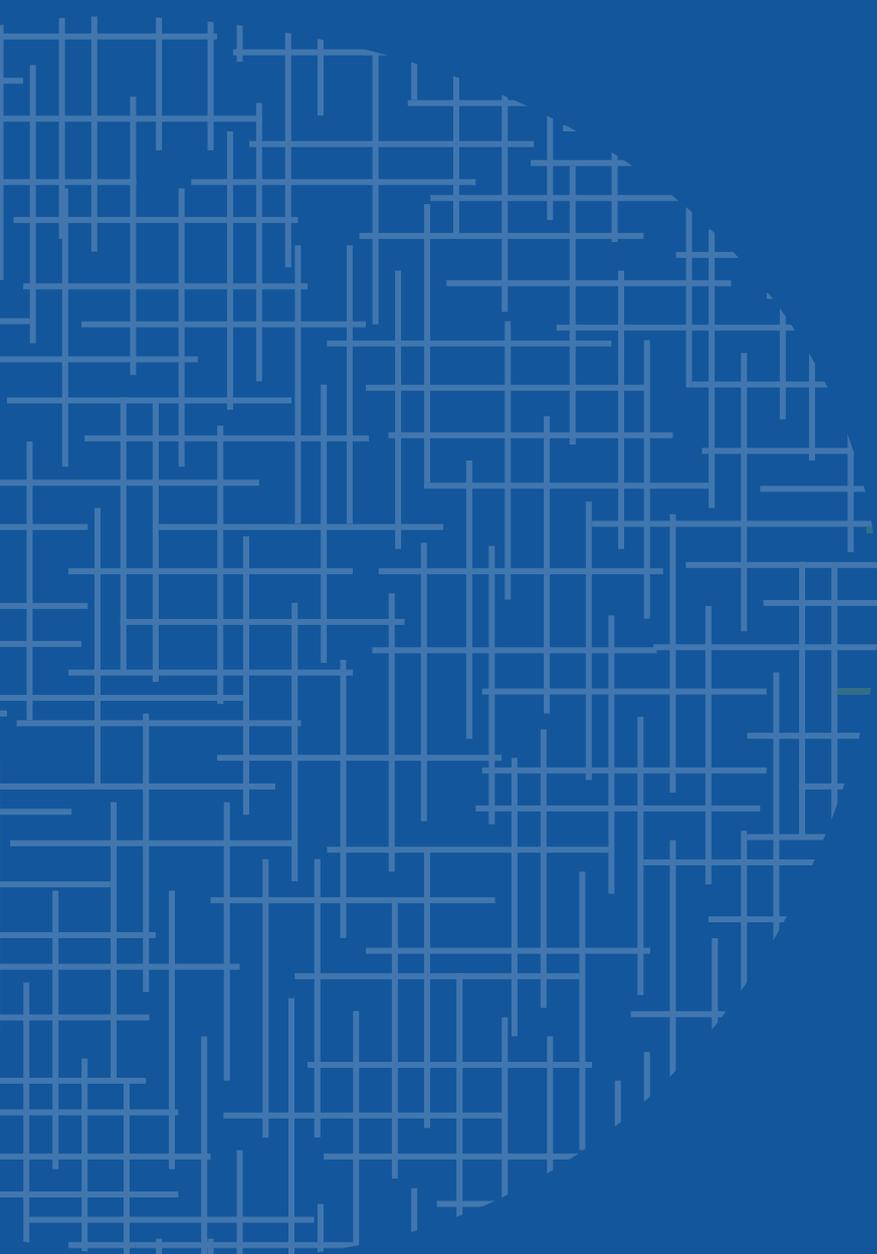
- Carers Victoria: www.carersvictoria.org.au
- Centre for Developmental Disability Health Victoria:
<http://www.cddh.monash.org/products-resources/fact-sheets.html>
- Deakin University and Uniting Care: Picture My Future: <http://picturemyfuture.com/>
- Department of Human Services - Supporting Decision-making Guide:
<http://www.dhs.vic.gov.au/for-individuals/disability/self-directed-support/supporting-decision-making>
- Scope Victoria:
 - › Non-electronic Communication Aid Scheme (NECAS):
www.scopevic.org.au/service/communication-aids-resources
 - › Accessible information service: <http://www.scopevic.org.au/service/accessible-information/>
 - › Watson, J., & Joseph, R. (2011). *People with severe to profound intellectual disabilities leading lives they prefer through supported decision-making: Listening to those rarely heard. A training package developed by Scope*. Melbourne: Scope.
<http://www.scopevic.org.au/shop/listening-rarely-heard-guide-supporters/>
- Office of the Public Advocate, Victoria: www.publicadvocate.vic.gov.au/
- Villamanta Disability Rights Legal Service: www.villamanta.org.au

Australia

- Advokit: Disability Advocacy Network Australia Limited (DANA). Decision Making:
<http://www.advokit.org.au/decision-making/>
- The A.C.T. Disability, Aged and Carer Advocacy Service (ADACAS) - Support My Decisions:
<http://www.support-my-decision.org.au/>
- Speech Pathology Australia (n.d.). Augmentative and Alternative Communication. Melbourne:
http://www.speechpathologyaustralia.org.au/library/2013Factsheets/Factsheet_AAC.pdf [Easy read version also available]
- The Office of the Public Advocate, South Australia. 2014. Assisting Someone with Decision-making:
http://opa.sa.gov.au/making_decisions_for_others/assisting_someone_with_decision_making
- The Intellectual Disability Rights Service (IDRS), Sydney: www.idrs.org.au

International

- National Resource Center for Supported Decision-Making: <http://supporteddecisionmaking.org>



Sean's decision

Decision-making support for people with cognitive disability

Guidelines for families and carers

