

Decision-making support for people with cognitive disability

A guide for disability workers



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About these guidelines

This booklet sets out guidelines for disability workers 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 person 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 that 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.

The term 'disability worker' means anyone who is paid to work with a person with disability - this could be a support worker, a coordinator, a manager, a therapist or others in paid roles.

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 families and carers and legal professionals. The resources can be accessed from: www.scopevic.org.au.

Introduction to decision-making support

“*I make my own decisions and I'm quite happy about it.*”
(*person with disability*)

Decision-making support involves helping someone to express their will and preferences, have these preferences understood and then acted on. It is a way of supporting people with cognitive disability to make significant decisions and exercise their will and preferences. 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 to 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. At times, this process has been referred to as supported decision-making, but for this booklet we will refer to it as decision-making support.

Decision-making support does not focus on whether a person can or can't make decisions. Instead, it focuses on ensuring people have access to the right support they need to make decisions.

Many decisions can be made without support. Other decisions may just need one person to help out. The really big decisions take lots of support from lots of different people. That's where the people around the person with a cognitive disability come in. These people can provide support and facilitate opportunities for decision-making.

The level and type of decision-making support a person needs depends on the person's skills and abilities, as well as the nature of the decision to be made. On most occasions, support is informal and is provided incidentally when needed. There are, however, some circumstances when more formal support is needed from people with specific expertise. Examples of this might be a doctor being asked to provide a medical opinion, or a family member being asked to provide background information that has an impact on the decision-making process.

While decision-making is now expected, it can be challenging as cognitive disability has an impact on the thinking processes used to make decisions (for example, planning, problem solving, or perceiving risk).

Remember

Start with the assumption that all people have the capacity to make their own decisions.

At times, everyone needs support to make decisions - advice from the hairdresser about hairstyles, or advice from a lawyer about legal issues.

People with cognitive disability are expected to make their own decisions and should be provided with the support they need to do this.

Our days are full of decisions – if it’s not a routine matter, a decision is required. Even routines are shaken up sometimes – creating the need for more decisions!

Little decisions

What will I wear today? Will I have vegemite or marmalade?

Big decisions

Will I change jobs?
Will I move house?

Personal decisions

Will I eat a sandwich for lunch? Will I spend up big on my birthday party?

Decisions that affect other people

Will I tell my friend that I am really angry? Will I not clean up in the kitchen?

Simple decisions. A choice between just a few options

Will I choose the red shoes with polka dots or the blue shoes with stars?

Complex decisions – those with open ended options

How will I go about getting all these jobs done before the end of the day? How can I help my family to get through this crisis?

Key ideas in decision-making support

“ ... I believe very strongly that everyone has the right to a meaningful life.”
(family member)

The right to make one's own decisions is closely linked to quality of life, health and well-being. Making one's own decisions can lead to increased self-determination, autonomy, confidence, improved decision-making skills, strengthened support networks and better engagement with the community.¹

People who have a cognitive disability have the same right as everyone else to make their own decisions. Similarly, all people have the right to learn through experience, the right to change their mind and the right to make decisions that others might not agree with.²

The right to make decisions is reflected in state, national and international laws. These include the *United Nations' Convention on the Rights of Persons with Disabilities 2007*,³ the *National Disability Insurance Scheme Act 2013* (Cth),⁴ the *Victorian Charter of Human Rights and Responsibilities Act 2006* (Vic),⁵ the *Victorian Guardianship and Administration Act 1986* (Vic),⁶ the *Powers of Attorney Act 2014* (Vic)⁷ and the *Disability Act 2006* (Vic).⁸ These laws require service providers in Australia to develop policies, procedures and practices that ensure the preferences of those they support are at the centre of their service provision. Some of these are outlined as follows.



The Australian Law Reform Commission (ALRC)

The ALRC is a federal agency that reviews Australia's laws to ensure they provide improved access to justice for all Australians. The ALRC has identified four key national decision-making principles that can be used to inform our work with people with cognitive disability:

1. **Equal rights** - all adults have an equal right to make decisions that affect their lives and to have those decisions respected.
2. **Necessary support** - people who need support in decision-making must be provided with the necessary support for them to make, communicate and participate in decisions.
3. **Will, preferences and rights** - the will, preferences and rights of people who require decision-making support must direct decisions that affect their lives. In the past, at times others decided what was in the person's best interest. Recent law reform takes a human rights approach and places an individual's will and preference at the centre of decision-making. Support is aimed at acknowledging, interpreting and acting upon a person's will and preference rather than in their best interests (refer to <https://www.alrc.gov.au/publications/will-preferences-and-rights>).
4. **Safeguards** - laws and legal frameworks must contain safeguards to ensure that the potential for influencing decisions or abuse of power is minimised.⁹



Remember

Being guided by these principles will ensure you are doing the right thing when supporting someone with cognitive disability to make decisions.

Ask yourself:

Has the person's equal right to make their own decisions been considered?

Has the necessary support been provided to enable the person to make their own decision?

Has the person's will and preference driven the decision-making process?

Are safeguards in place so that the decision has not been unduly influenced by others?

Are strategies such as monitoring of arrangements, accountability and regular reviews in place to prevent abuse of power?¹⁰

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

The right to make one's own decisions is a fundamental part of the UNCRPD. The UNCRPD marks a shift in thinking about disability from "a social welfare concern to a human rights issue, which acknowledges that societal barriers and prejudices are themselves disabling"³.

The UNCRPD states: "The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity ..."³. The Australian Government is one of 162 countries to have ratified the UNCRPD. Countries that have ratified the UNCRPD are required to introduce measures that promote the human rights of people with disability without discrimination. This means the principles of the UNCRPD should drive how we support and work with people with cognitive disability.

TIPS

Respect that people with cognitive disability have a right to make their own decisions.

Ensure that people with cognitive disability have the support they need to express their will and preferences.

Promote and support the development of policies and procedures that ensure the will and preferences of people with cognitive disability are heard.

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"⁴. 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. Disability workers are well placed to provide some of this support.

TIPS

Keep in mind the NDIS philosophy of choice and control for participants in all aspects of your day-to-day work, including when providing decision-making support.

The role of supporters

“Families are involved in how people ultimately make their decision, other services and stakeholders can be involved ... So it is sort of ensuring that the person has the benefit of all the people that they believe help them to make a decision.” (worker)

People with cognitive disability may have a team around them providing decision-making support. Supporters may be family members, other carers, disability support workers, therapists, service coordinators, residential workers, lawyers, advocates or friends.

Supporters are people who are known and trusted by the person with cognitive disability and are willing to respect and promote the person's will and preference. Having a broad group of supporters means there is more help and a variety of skills and experience to draw upon.⁹

The people involved in decision-making support differ depending on the type and nature of the decision. Often, but not always, one person has a bigger role in supporting a decision, with other people taking on other roles.

A supporter (this means you!):

- 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 well and is committed to keep learning about the person. This includes understanding how they communicate, as well as their background, history, goals, values and preferences.
- Can call on others to support the decision, if that is what the person wants.
- Is able to spend as much time as is required to support decision-making.¹¹

As a supporter, your role can change depending on the type of decision being made. It might include:

Being a history giver – a person who has tried it before, and who can reflect.

Being a fact finder - to gather and present relevant information about the decision being made.

Assisting with weighing up the pros and cons.

Assisting with predicting outcomes and consequences.

Assisting with evaluating available options.

In providing decision-making support, be aware that 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 differing roles with different friends or acquaintances.

The person who takes the lead on providing support may also change depending on the sort of decision being made.

There are some broad expectations about who will support people with different types of decisions, even though this will vary hugely between individuals:

Family members – are likely to support the making of all sorts of decisions but might be particularly involved in supporting major life transitions or health-related decisions, such as where to live and medical interventions.

Disability workers – are more likely to provide decision-making support in day-to-day choices and should consider seeking further advice about supporting major decisions.

Specialists such as lawyers – typically assist with supporting major decisions with long-term implications that happen infrequently. This could be matters such as compensation matters or financial arrangements.

It is important that supporters work together and understand each others strengths and skills.

TIPS

Know your boundaries. Try asking yourself these questions - if you are not sure, get help!

Do you really understand what the person is saying and their intention?

Can you communicate in a way the person understands?

Can the person trust you to support their will and preference on this decision?

Who else should be involved in supporting the person to make the decision?

Who does the person want involved and what will their role be?

Does the person making the decision need access to specialist knowledge like legal or medical knowledge?

Do you know the implications this decision will have for the person you are supporting?

Have you given the person the opportunity to change their mind?

Characteristics of an effective supporter

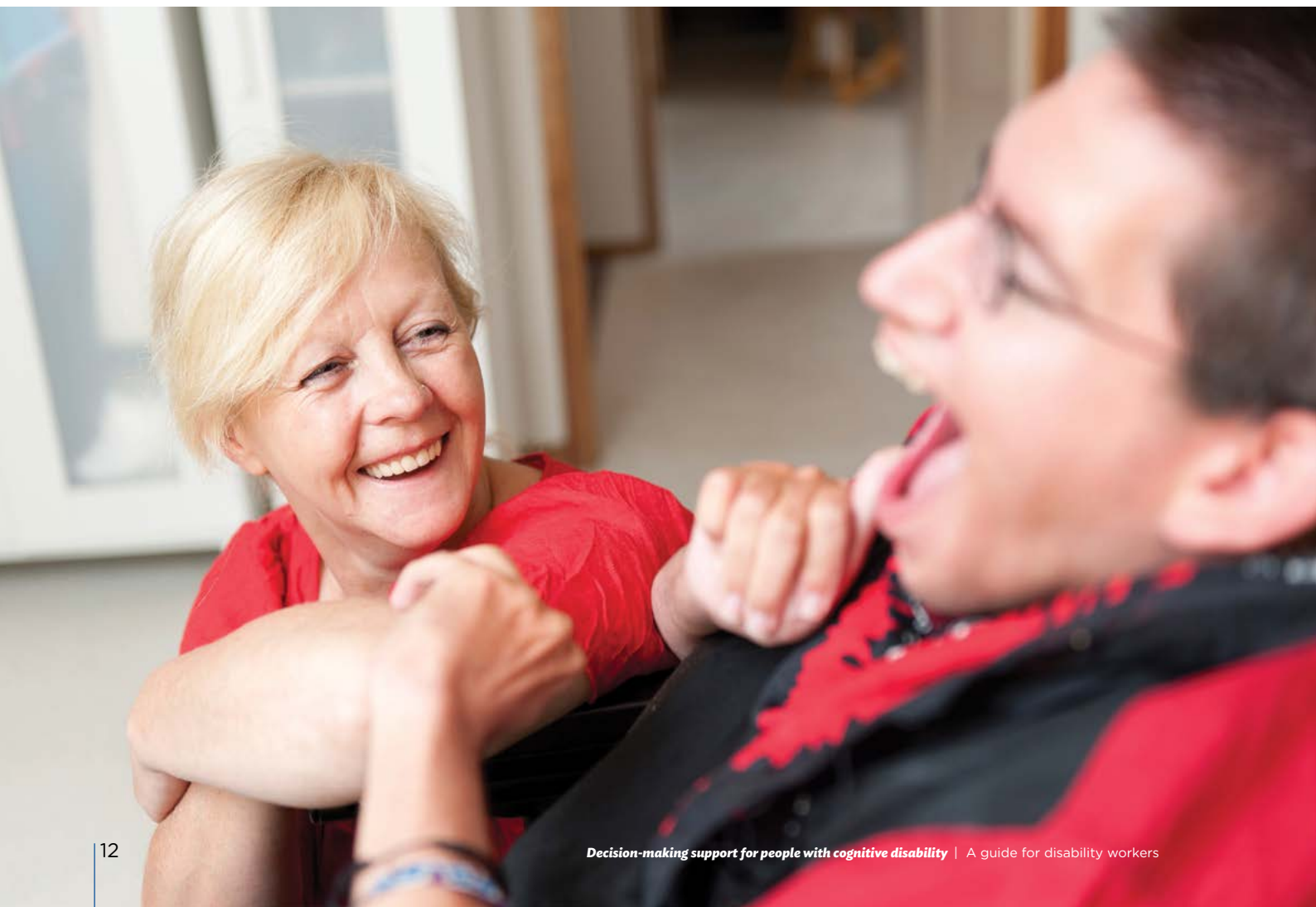
- Changes his or her expectations to reflect the person's individual needs.
- Focuses on the will, preference and rights of the person, as well as choice and control.
- Is neutral - suspends his or her own judgement and adopts a neutral and non-judgmental position.
- Doesn't limit the options - helps build awareness of all the options, or isn't limited by previous experience.
- Is aware that it is easy to influence others when in a position of power.
- Respects the decision made whether or not he or she perceives it as good or sensible.

Steps in decision-making support

“It’s breaking it down into little steps, so this is the first thing we have to consider and then, if you have a solution for that, then this is the next thing we have to consider ... just take a little step at a time ...” (family member)

There are some key steps in supporting someone to make their own decisions. By asking carefully framed questions or making neutral statements as prompts, you can support the person with cognitive disability to think through each part of the process so a considered decision can be reached that reflects his or her will and preference.

It is important that the person’s will and preference drives the decision-making process. This means you will need to focus on what the person wants rather than what others judge to be in the person’s best interests. It is also important that your communication is pitched at a level that is right for the person you are supporting. There are many resources you can use to help you with communication (refer to the Additional selected resources section).



Steps in decision-making	Description	Ideas for questions and prompts to use with the person
1. Identify the decision	Clearly identify the decision that needs to be made. This may not always be straightforward. It is often helpful to break a decision into smaller components	<ul style="list-style-type: none"> • What is the main issue? • What could stay the same? • What could change? • Who needs to be involved in the decision?
2. Involve other people in the decision-making process	Help the person determine who else might be involved in providing decision-making support. Identifying these people at the beginning of the process means more perspectives are provided, a broader range of options are identified, and greater cooperation in the implementation of decisions.	<ul style="list-style-type: none"> • Is this a decision that affects only you? • Are other people affected by the decision? How? • Should other people be involved?
3. Support the person to gather, understand and consider relevant information	We all benefit from knowing the facts about a particular decision. Consider different ways to get relevant information about the decision, including talking to other people who have experienced this situation, looking up information or examples online. Present the information in a way the person understands (refer to the section about Understanding individual strengths and needs).	<ul style="list-style-type: none"> • Do you have all the facts? • What information might be helpful? • Where can you find this information?
4. Work out what the options are	Using the facts, support the person to work out the options available for the 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 option. Also consider the resource implications (refer to section about Dealing with dilemmas in providing decision-making support).	<ul style="list-style-type: none"> • What are some of the things that could be done about this? • What are some ways to go about it? • What has and has not worked in the past? • What has to be done to make this happen?
5. Identify and weigh up the pros and cons of the options	Get the information together and work with the person to identify the pros and cons of each option.	<ul style="list-style-type: none"> • Will it work immediately or take a long time? • Will it affect other people in a good or a bad way?

Steps in decision-making	Description	Ideas for questions and prompts to use with the person
6. Prioritise the different options	<p>It can be useful for a person to work out what is important to them in relation to a decision. By assisting a person to identify their priorities, it's more likely the decision will be followed through. Encourage the person to list or consider things which are important.</p>	<ul style="list-style-type: none"> • What are the top three priorities? • What are the bottom three priorities? • What would be the perfect outcome in the face of the current situation?
7. Explain the potential consequences of the options	<p>Many people with cognitive disability may find it difficult to predict outcomes and consequences, and will benefit from support to evaluate these. Outline as clearly as possible the consequences of each option including both positive and negative outcomes.</p>	<ul style="list-style-type: none"> • What might happen if you decide to go ahead with the decision? • What do you have to do if you go ahead with the decision to be made? • What steps would you have to take if you chose to make this decision?
8. Make the decision and follow it through	<p>Once the decision has been made it is important to ensure the person has appropriate support to implement it within a reasonable timeframe. Consider what supports the person will need to be able to participate in the actions that flow from the decision. Check in with the person as the decision is being implemented to make sure their expectations are being met and that they are feeling emotionally supported and confident.</p>	<ul style="list-style-type: none"> • How are you feeling about getting started? • Do you want some help to do this? • Is this going well for you?
9. Check in to see how the decision went in practice	<p>Keep in mind that supporting a person with a cognitive disability to build experience in decision-making will broaden their understanding of what is possible. It will also help them practice the skills they have learnt.</p>	<ul style="list-style-type: none"> • How did that go? What did you like about it? What didn't you like about it? • Would you do it the same way next time? • Would you do something differently?

Steps in decision-making	Description	Ideas for questions and prompts to use with the person
<p>10. Keep the big picture in mind throughout</p>	<p>Remember lots of small decisions together can 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 so decisions can be made in line with these goals, if that is what the person wants. Sometimes people may choose to ignore the longer term goals - 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 longer term goals are.</p>	<ul style="list-style-type: none"> Remember that you set yourself the goal of (big goal) - will this decision help you reach that goal? Do you still want to (big goal)? Would doing this make it harder to reach your (big goal)?

TIPS

Make sure the person is aware of the impact smaller decisions have on their longer term goals.

Assist the person to see lots of options that might become seeds of ideas for the future.

Take time to reflect about how the process went so you build your skills in decision-making support:

- Did you help the person have choice and control?
- How well did you support a decision?
- What could you have done better?
- What could you do differently next time?
- Did the supporters work well together?
- Did your support increase the person's confidence to make decisions?

Case study

Steps in decision-making support

I'm a disability support worker who works with Joe at the Berry Avenue house. The other day his old sound system stopped working. He loved that old thing, it had good sound and he could play all his favourite Jazz music. He could work the big dials and use it without anyone needing to give him a hand. He wanted to get a new system - but what to get? We talked about the smaller decisions he would need to make before he finally worked out what to get:

- Do you want one that just plays your old CDs, or do you want one that could play music from an iPod?
- Do you want one that fits in the same space in the bedroom, or will a bigger one be OK?
- Does it need dials or buttons that you can use yourself?
- Do you want one that looks a certain way?
- How much money do you want to spend?
- Who else can you ask to help you decide what to buy?

First Joe decided to phone his brother, Peter, who is into music too. He asked Peter what would be a good brand and which shops would be good to go to so that he could check out some sound systems. Joe decided it was really important for him to be able to use the system without help and that it needed to fit on the shelf in his room as there was nowhere else it could go.

Joe needed more information before he could make the next decision. So, on my next shift, we went down to the shop that Peter had recommended and Joe had a look at some of the options. He tried most of them to see if he could work the controls and also decided that two of them were too big to fit in his room. We took home leaflets about five others, and I wrote the prices that the salesman quoted onto the leaflets before we left.

Next, Joe asked the house supervisor, Felicia, what was left in his recreation budget. There wasn't enough for any of the sound systems. He asked Felicia if there was any money he could get from somewhere else. Felicia got out Joe's financial records and together they worked out that he had some money that he had saved for presents. He also had some money that he had put aside for a holiday. The other option was for him to wait until his birthday and ask his family to combine their gifts to help pay. He decided he wanted the sound system now so waiting for his birthday was not an option. He really wanted to go on holiday and so he decided to use the present money - he said he would make nice cards instead of giving presents.

Joe said he wanted the system to look modern, to have cool speakers, to take CDs and digital music, and not cost all of his present money. He looked at the leaflets with the prices next to them. He gave each system a 'coolness' rating: one was not cool, two was OK, and three was really cool. I helped him work out what each number meant by drawing a sad face next to the one, a neutral face next to the two and a happy face next to the three. We put a tick next to each option that had both CD and digital capacity.

In the end, it came down to Joe choosing between two options. The other three options either didn't have a digital option or did not look cool enough. Price was the final decider for Joe - he really does quite like being able to give presents!

Needless to say, we went and got the chosen sound system and I spent a happy Sunday shift working with Joe to set it up. I even brought along a memory stick with some Jazz music for Joe to try out.

Making decision-making a part of life

As a disability worker it is important to not only provide support for decision-making, but to also actively expand opportunities for decision-making. It is also important to help the person develop skills and independence in decision-making. Skills in decision-making will improve if the person has opportunities to practice.

Create opportunities for the person to engage in decision-making

Consider actively reframing situations to encourage the person to participate in decision-making. Acknowledge the person may be lacking in confidence, or might not expect to be involved in making decisions.

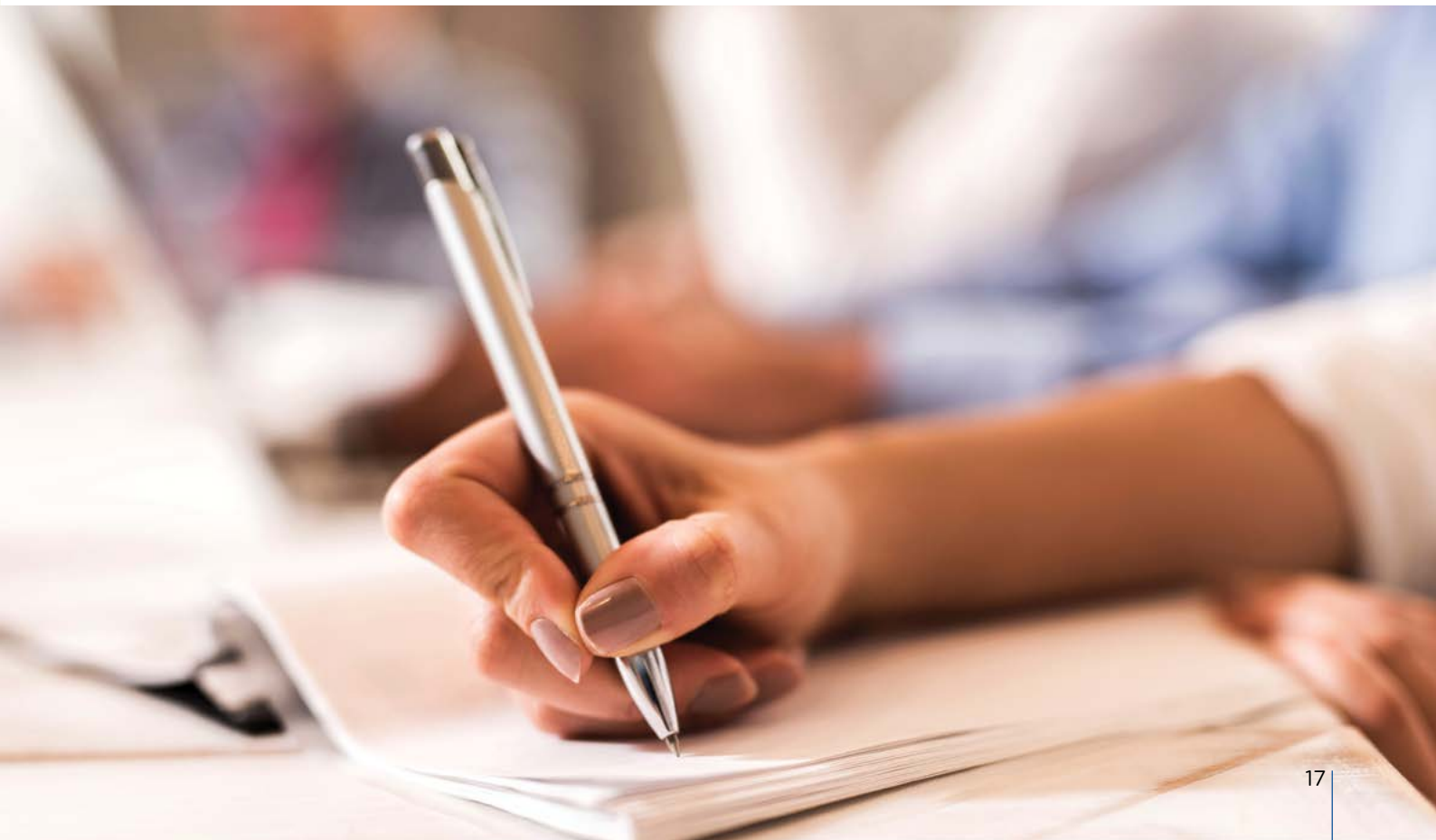
Try asking yourself these questions:

How can I encourage the person to make his or her own decision about this?

Have I asked the person what he or she thinks about this?

Can I prompt the person with some questions to support him or her to make a decision?

Can I work out a way that the person can try some of the options?





Take the long view - introduce and nurture the seeds of ideas

Think about subtly introducing ideas and possibilities that might help the person consider other options for the future.

Try asking yourself these questions:

What possibilities are there for the person to have more control in his or her life?

What ideas might be relevant to support this person to see more possibilities?

Encourage more autonomy

Creating some distance can sometimes assist people to take more responsibility for making their own decisions. A person's reluctance to make decisions might be a learned behaviour through years of others making decisions on their behalf. Or it might be that the person lacks confidence in their own abilities. Stepping back and saying less may empower the person to make decisions.

Try asking yourself these questions:

Is what I'm saying and doing interfering with the person making his or her own decisions?

Can I say less and use silences to encourage the person to think more for themselves?

Does the person need more positive feedback and encouragement to develop confidence in decision-making?

Understanding individual strengths and needs

“Some [people] might just need information to make a decision, but others will need information explained - maybe through pictures or audio or whatever.”
(worker)

Every individual has differences in cognitive skills and abilities, whether they have a disability or not but there are some generalities that can be made about the impact of intellectual disability and acquired brain injury on decision-making that should be considered. There are many resources available to assist you with understanding the impact of cognitive disability (refer to the Additional selected resources section).

The table below presents potential impacts of cognitive disability and strategies to support the person.

Impact of cognitive disability	Ways to support the person	Examples of how it might look or sound
<p>Slower speed of learning and processing of information</p>	<ul style="list-style-type: none"> • Present information slowly • Present information in smaller chunks and help to connect the chunks when needed • Repeat information as needed 	<p><i>“The first part of (the activity) is to ... and then ...”</i></p> <p><i>“Remember last time we talked about ...”</i></p>
<p>Difficulty with abstract concepts such as money and time</p>	<ul style="list-style-type: none"> • Present information in concrete terms with real life examples • Teach skills in specific areas that support areas of interest and need 	<p><i>“ Drinking lots of alcohol makes some people relax so much they fall asleep, but some people get angry and they want to hit other people.”</i></p> <p><i>“Let’s look at your receipt from the supermarket so we can see how much things cost today. Then you can see how much you have left over before you decide if you want to spend it or save it.”</i></p>
<p>Difficulty understanding the subtleties of interpersonal interactions</p>	<ul style="list-style-type: none"> • Explain what is happening in social situations • Use social scripts like Social Stories to improve understanding about what to expect and good options for responding 	<p><i>“Did you notice that your friend looked sad when you ...”</i></p> <p><i>“Let’s read over the story that you wrote with (therapist) to help remember what might happen and what you could do when we get there.”</i></p>

Impact of cognitive disability	Ways to support the person	Examples of how it might look or sound
Increased fatigue (mental and physical)	<ul style="list-style-type: none"> • Allow additional time • Allow for rest breaks as needed • Reduce the effort needed for some parts of making the decision 	<p><i>“How about we talk about this after you have a break ...”</i></p> <p><i>“Let’s go to the other room where it is a bit quieter.”</i></p> <p><i>“While you are thinking about that why don’t I look up some more information about it on the internet.”</i></p>
Some slowing down in speed of processing information, planning and problem solving	<ul style="list-style-type: none"> • Present information in understandable ways - use simple words, short sentences, use pictures, write key points down 	<p><i>“There is a choice of x, y and z.”</i></p> <p><i>“Let’s write a list of who you could ask.”</i></p>
Changes to behaviour and personality	<ul style="list-style-type: none"> • Be aware of impulsivity, changes to judgment and other effects • Relaxation • Behavioural therapies 	<p><i>“OK I can see you want to do it straight away, but let’s sit down and think about it first.”</i></p> <p><i>“Breathe in ...2...3; out 2...3...4...5...”</i></p> <p><i>“Remember the new technique that you practiced with (psychologist).”</i></p>
Changes to physical and sensory abilities	<ul style="list-style-type: none"> • Additional and alternative methods of receiving and expressing information (communication methods) including communication aids, hearing aids, vision aids 	<p><i>“Let me get your communication device set up properly.”</i></p> <p><i>“Have you got your hearing aids turned on?” ... “Where are your glasses?”</i></p> <p><i>“I will turn on the light so that we can both see better.”</i></p> <p><i>“Try this one - it has a bigger handle.”</i></p>
Changes to thinking and learning	<ul style="list-style-type: none"> • Use memory aids like diaries and notebooks, relevant apps • Step-by-step support to help turn decisions into actions 	<p><i>“You could write that in your diary so that you remember.”</i></p> <p><i>“You want to go to the shops on your own. Let’s think about what you can do now and what you will need to learn or get some help with.”</i></p>

Source:

The Better Health Channel. (2014). *Acquired Brain Injury*. Retrieved September 17, 2015, from <https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/acquired-brain-injury>

The Better Health Channel. (2014). *Intellectual Disability*. Retrieved September 17, 2015, from http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/intellectual_disability

Decision-making support in action

Mark has an acquired brain injury. He lives in supported accommodation with four other men. He doesn't like living with these men, as he finds them noisy.

I've been a support worker at the house for 10 months and get on well with Mark. I know his family and some of the support workers from the day program, and Mark has come to see me as a person to help him make decisions about his home life.

Recently, Mark was becoming agitated and demonstrated some aggressive behaviours towards another resident who was making a lot of noise after dinner. Mark wanted to go to sleep but couldn't because of the noise. This situation had been escalating for some time.

I worked with Mark to help him calm down. We went to the garden to get away from the other men and we spoke about what was worrying him. Finally, Mark stated: "I need to do something about this place, I can't live here anymore. I've gotta get out - this noise is driving me nuts."

I confirmed: "So you are saying you want to change where you are staying so that it is quieter?"

Having determined there was a decision to be made, I helped Mark to work out what some of the options might be. Some of the options Mark identified were:

- To move to his brother's house
- To run away
- To make the other guy "tone it down when he is told"
- To "move to a different bedroom in the house"
- To move houses

Although, Mark would love to move to another house, after a long discussion we both realise that this is not an option right now but, may be in the future.

Case study

As we worked on the ideas, I used pictures from magazines to model Mark living in different places. This helped Mark remember the options we had come up with. Just having identified some options helped him to feel calmer and in control.

Over my next few shifts, we discussed the pros and cons of each of the options. Thinking of all of the pros and cons together, I asked Mark to choose a number from 1 to 5 to describe how good the option is. 1 is a very bad option and 5 is a very good option. I used numbers because I know that Mark is good with numbers, but I also have a smiley face system in case it gets too confusing for him.

Eventually Mark decided he wanted to stay at the house and that moving to the back bedroom was probably going to work for him. With my support, Mark understood the other residents might not want to swap rooms and that he would need to get cooperation from many different people to get it happening. With support, he also understood it would take some time.

My role then became to support Mark to explain the situation to the other residents, the house coordinator and his family.

The move to the other bedroom did happen but it took a number of weeks to organise. Mark learned a lot of skills through the process and had greater control in determining his living situation.

Dealing with dilemmas in providing decision-making support

“Juggling rights, practicalities and risks, ‘it’s like twirling plates on a stick’.”(worker)

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

Remaining neutral

Decision-making support is just that - a support role. As a supporter, you should remain 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 you work with the person to identify the full range of options, and avoid a situation where only those options that 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.

“Being conscious not to direct them towards what you think is right for them, but rather presenting the information and getting them to get to their own conclusion.”
(worker)

TIPS

Be aware of your preferences and beliefs and avoid imposing these on the person.

Reflect on how you are providing support and whether your own beliefs and preferences are influencing you.

If you feel you can't avoid influencing the person, find someone else to provide support to the person for that decision.



Conflicting perspectives amongst supporters

Different supporters have different roles in a person's life.

Families might have the longer term goals or the bigger picture in mind and may advocate for what they feel is in the person's best interest, or support decisions that only move the person towards their longer term goals. Workers may have a different view of the person and may not be aware of the longer term goals that families are working towards. These differing roles and views mean that, at times, supporters may disagree about a decision and there may be conflict or tension.

“*Too often people think they're being kind to let her have a little treat, and treats only become an iced coffee, which is full of ice cream and sugar ... and I don't want to be critical of staff because they want to have happy people around them and (my daughter) will gravitate to choices which are not going to help from a health and weight point of view.*” (family member)

TIPS

Work together and understand each other's roles, motivations and strengths.

Be respectful of each others views and opinions.

Commit to being open and honest with each other.

Talk about conflict openly.

Think about how you will resolve conflict, if it arises.



Managing risk and best interests

At times, supporters may be concerned about the risks associated with a decision the person has made, or might make. These situations can be tricky to navigate, but it is important to understand there are often risks in making decisions, and that everyone has a right to make poor decisions, or badly timed decisions.

That isn't to say risks, duty of care or occupational health and safety requirements are ignored. Duty of care must be balanced with dignity of risk, that is, the right to take calculated risks. Most organisations will have a Risk Assessment/Management Framework or tools that can be used to identify and manage risk.

Key components of risk management include identifying:

What is the risk?

What harm could occur and what would its impact be?

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)?

TIPS

What are your organisation's policies and procedures for identifying and managing risk?

Check back that the person is fully informed about the potential consequences of a decision.

Where risk is identified, what strategies can mitigate their impact so the person's choice can still be enacted?

Are you meeting your responsibilities of duty and care?

Are you aware of your legal responsibilities at work – Occupational Health & Safety, confidentiality/privacy?

“So often OH&S is trotted out or privacy legislation, if I hear one more time; ‘oh no we can't do it because of the privacy legislation’ or ‘it's an OHS issue’ ... those have become the big excuses for ‘we can't do what people want’.” (worker)



Limits in resources to make a decision happen

Even though 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, and manage the person's expectations about what is and isn't possible throughout the decision-making process.

“... And another thing that will happen is in a group situation, like five people that we work with, sometimes you've got to reschedule their choice.” (worker)

“Some things take a lot longer than maybe it would be for you or I to do but time is a different animal. At times that doesn't fit in well with house timetables or schedules.” (worker)

TIPS

Help clarify what is a realistic option now and what is a dream for the future.

Work with the person to develop priorities.

Know what resources are available to the person throughout the decision-making process.

Be creative in identifying ways to spread resources - share with others who have similar interests, look for alternative resources.

Dilemmas in decision-making support

We had a pretty interesting situation at work the other day. Phil decided she didn't want to go to the Catholic church anymore. She was brought up in the Catholic church and she kept going to her family church, even when she moved into this house. I guess she's been going there for about 25 years now.

One Sunday after church, Phil announced she didn't like going to the family church anymore, didn't like the people, and was sick of it. She thought she might like going to the local Baptist church where one of the other ladies in the house goes and where they have more modern music. Even though she liked the thought of changing to a different church, she didn't want to upset her family and lose that special time with them. She was not sure what to do. That put us in a bit of a dilemma because her family are very into the church, and they wouldn't be happy about her swapping churches just because her friend goes to another church. I'm a churchgoer myself, as is my family, so I could see why they might be upset.

The first thing I had to do was to put aside my own opinions. That wasn't so easy, but I tried my best to just listen really well.

We organised a family meeting. Phil's mum and dad put forward lots of reasons why they wanted her to keep going to their church and we supported Phil to put forward her side of the situation. Phil's parents said they wanted to spend church time with her, that being Catholic was important to them, and that it was a family tradition. Phil said that she wanted to spend time with her family too, but she was bored with the music, wanted to spend more time with her own friends, and make new friends. In the end it was Phil's decision. I guess maybe it's a sign of her maturing and being able to separate herself from her family.

Now she goes to the other church and she gets quite a lot out of it. I think it's pretty sad though that she misses out on spending all that time with her family every Sunday. I am wondering if Phil would be interested in working out some other ways to catch up with her family on a regular basis.

Case study

Decision-making support and the workplace

“It was like you’re tackling the situation and thinking I need to solve it within myself - no this is a structural problem that is creating consequences for everybody.” (worker)

Providing decision-making support happens throughout every day and every shift. Much of the time it is easy to work out how to provide support - suggesting options, listening and reflecting. That said, there are likely to be times when you might get stuck or don’t know what to do. What happens then?

Accessing support

All workplaces have structures for supporting employees to do their work. Of course, how well this works will vary from place to place. You can have a role in making things work well.

Having strong and supportive relationships with co-workers and managers is very important to ensure you are able to support the people that you work with. Similarly, you may be the one who can help a co-worker who is providing decision-making support.

If you need help or don’t know what to do in a particular situation, consider the following:

What are the structures at your workplace for support and seeking help? Who is your immediate line manager?

Who can you ask when you are not sure? Is there someone working with you? Is there someone you can phone?

When do you need support? Should you seek support straight away or can it wait? Should you write it down as a note or formal record?

TIPS

Recognise when you need help to support someone to make a decision.

Know where and from whom you can get support (formal support through line managers and informal supports through co-workers).

Be aware of your skills in supporting other workers when they need it.

Organisational issues

The willingness of an organisation to put procedures into place which support people to make their own decisions is essential to ensuring workers can do their job as supporters effectively.

Some examples of workplace systems which lead to good practice in this area are:

- Flexible scheduling to allow time where decisions are taking a long time and need the support of a specific disability worker.
- The use of good local workplace communication strategies such as meetings, formal note taking, thorough handovers and communication books to keep all staff informed of issues that might affect decision-making.
- Opportunities for feedback through line managers about what is working well and what is not working well.
- Inclusion of decision-making support principles into formal policies and procedures.

TIPS

Be active in giving your line manager feedback about what is working well and what is not working well so that structural issues can be addressed.

Contribute to your organisation getting the structures right for decision-making support.

Partners in decision-making

One of the women at the house I work in was going through some health issues, a hysterectomy. How does that work? Where does the information for that sort of decision making and choice come from? Where do I go? I spoke with my manager and we worked with OPA (the Office of the Public Advocate) to get an independent advocate. We ended up going off to VCAT (Victorian Civil and Administrative Tribunal) and there was a big process involved.¹²

Case study

Additional selected resources

For people with cognitive disability

- Advocacy for Inclusion - Supported Decision Making App:
<http://www.advocacyforinclusion.org/index.php/resources/supported-decision-making-app>
- My Choice Matters - NSW Consumer Development Fund - Videos and guides for people with Intellectual Disabilities : <http://www.mychoicematters.org.au/choices-and-decisions.html>
- The A.C.T. Disability, Aged and Carer Advocacy Service (ADACAS) - Support My Decision:
<http://www.support-my-decision.org.au/>

For disability workers

- Advokit: Disability Advocacy Network Australia Limited (DANA) - Decision Making:
<http://www.advokit.org.au/decision-making/>
- Department of Human Services - Supporting Decision-making Guide:
<http://www.dhs.vic.gov.au/for-individuals/disability/self-directed-support/supporting-decision-making>
- Scope Australia - Accessible information service:
<http://www.scopevic.org.au/service/accessible-information/>
- The Office of the Public Advocate - Assisting Someone with Decision Making:
http://opa.sa.gov.au/making_decisions_for_others/assisting_someone_with_decision_making
- Villamanta Disability Rights Legal Service: www.villamanta.org.au
- 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/>

Places to get more information

- Carers Victoria: www.carersvictoria.org.au
- Centre for Developmental Disability Health Victoria:
<http://www.cddh.monash.org/products-resources/fact-sheets.html>
- Disability Services Commissioner: www.odsc.vic.gov.au
- National Resource Center for Supported Decision-Making <http://supporteddecisionmaking.org>
- The Intellectual Disability Rights Service (IDRS): www.idrs.org.au

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