# An introduction to supported decision-making

This guide is an introduction to supported decision-making. It describes what supported decision-making is, and what it isn’t, what the responsibilities of a support person (supporter) is, and the aspects of supported decision-making that make sure a disabled person is truly part of the community in which they live.

As we move through the levels in this Covid-19, this information reminds family, carers and supporters about their role when supporting people to make decisions for themselves.

It’s important to note that this guide provides an outline only. For additional information, see the section “More information”.

## What is supported decision-making?

Supported decision-making is a way for people to make their own decisions based on their will and preferences, so they have control of their life. It ensures the person who needs support is at the centre of all decisions that concern them.

Supported decision-making is an important process for people who might need support to make decisions, like some people with dementia, acquired brain injuries, neurodisabilities, mental health issues, and other kinds of cognitive or physical conditions.

The person who needs to make a decision works with appropriate support, which can be one or more supporters. The supporters make sure the person gets the right information, at the right time, in the right way, with the time they need to consider their decision.

Supported decision-making is different from ‘substitute decision-making’. Substitute decision-making is when someone else makes decisions for a person, including making decisions in the person’s best interests. While substitute decision-making has often been used informally, by family or friends, or formally, such as an Enduring Power of Attorney or by service providers, there is now a move to supported decision-making.

Supported decision-making is considered best practice by the United Nations Convention on the Rights of People with a Disability (UNCRPD), of which New Zealand is a signatory, and is recognised as a right for everyone in New Zealand.

## Responsibilities of a supporter

As a supporter, it’s your responsibility to assist the person to make decisions for themselves. You might be one of many supporters, as different decisions might need different support people, or part of a team that works together.

The key to being a good supporter is knowing how the person prefers to communicate. You also need to know and understand what is important for the person – from their relationships, what they like doing, their culture, rituals and routines.

If you’re asked to be a supporter, consider whether you’re the right person for the decision being made and whether you know the persons will and preferences. Is there any potential or actual conflict of interest where you have a personal interest in the outcome?

It’s also important to be aware of any health and safety concerns, including physical and emotional health and safety.

You can get additional information from a personal plan (if they have one) and by talking with family, friends, support staff and other people who care about and know the person.

## The aspects of supported decision-making

Below is an outline of the main aspects of supported decision-making. For more detailed information, see the section “More information”.

### Identifying the decision

As a supporter, it’s important to identify when a decision needs to be made (such as health care, employment, relationships, finances), what the actual decision to be made is, and the type of support that the person will need.

Is it an everyday decision (such as what to eat) or a decision that’s more long term, complicated or important (such as a medical procedure or moving house)?

Are there multiple decision points within the one decision that could be broken down into separate decisions?

### Providing easy-to-understand information

Prepare relevant and easy-to-understand information for the person so they can make informed decisions.

When preparing the information, consider:

* the ways the person prefers to receive information, including reading Easy Read, pictorial, talking, video or augmentative and alternative communicators
* information from friends and peers that might help, including actual experiences
* what you might need to support them to imagine or see how things might be different
* all the options and their outcomes.

### Exploring options

Exploring options will help the person identify what they want, such as:

* checking you both have the same understanding of concepts and words
* giving the person time they need to think about the options and the possible outcomes before making a decision
* presenting options in different ways if you need to.

If the person chooses to take risks, think about ways to put in safeguards. Only intervene when the choice is seriously risky.

### Making decisions

Confirm with the person their preferred option by finding out:

* which option they think is best for them
* if they have concerns about their preferred option
* how the person feels about the options: happy, excited, unsure, comfortable, unhappy, or worried. Do their words match their behaviour?

### Acting on decisions

Record the decision and next steps in a way the person can understand. Make sure you include:

* next steps and who should do what (with the supported person being responsible for as much as possible)
* what supports the person needs to progress what they need
* how long it will take to action
* keeping in touch about progress.

### Making decisions work

After the decision has been made, check in with the person and see if the decision things are going as planned or if they’ve changed their mind.

If you need to revisit earlier steps, and think about:

* whether the person considered all their options
* if anything has changed
* if there is new information or ideas to consider.

## Examples of supported decision-making

Note: these are examples only and are not based on actual people or events.

### Going back to work under Alert Level 3 restrictions

Alex’s work will be re-opening under Covid-19 Alert Level 3 restrictions. Alex’s manager gets in contact with them to ask if they think about coming into work at Level 3.

The manager let’s Alex know that they will have a minimum number of workers who will be working 2-metres away from each other, they have put in place hygiene measures like hand sanitiser and regular cleaning of work areas.

Alex says they’re not sure and needs to think about it. The manager agrees to this and let’s Alex know to contact them at any time to ask questions.

Alex talks with their supporter. Alex would like to go back to work, but Alex is worried about what this means for their bubble. Alex and the supporter look up information on the Covid-19 website and talk about it. Alex, with the supporter, talks with the people in their bubble. They are happy for Alex to go to work.

Alex calls their manager and let’s them know he will come into work. The supporter checks with Alex a couple of days before work begins to make sure Alex is okay with their decision. Alex is happy to go to work.

### Getting medical help when it’s needed

Sam mentions to their group’s carer that they have itchy skin and it won’t go away. Sam doesn’t want to go to the doctor because the doctor is busy with the virus. Sam thinks the itch will go away.

The carer talks with Sam and finds out they’ve had the itch for two weeks. Sam wants to talk to his mother, as his designated supporter about the next steps. The carer knows his mother is part of Sam’s support network and encourages Sam to contact her. Sam and the mother decide to look up the doctor’s website to see if they have information about how the doctor is working under the Covid-19 restrictions.

The website says it’s important to call if there is a medical problem. The doctor will call and talk with you about it first. And then ask you to come in if they think they need to see you. The website explains what the doctor is doing to keep everyone safe, including seating everyone so they’re 2-metres apart at all times. The website also explains the doctor will be wearing a mask and reception has set up a barrier so you stay 2-metres away.

Sam decides to call the doctor. The receptionist tells Sam they think it’s important for Sam to talk with the doctor. Sam agrees and makes a time for the doctor to call. Sam asks the carer to be with them when the doctor calls.

The doctor calls Sam and finds out about the rash. The doctor can’t see the rash over the phone and let’s Sam know they need to come in. The doctor let’s Sam know what they will do to keep Sam, the doctor and other people safe during the visit to the doctor. The doctor makes an appointment time with Sam, and let’s Sam know they can call if they need to talk about anything that’s worrying them.

#### Expanding the home bubble

Jo wants to expand their bubble. The group home worker says we want to keep the bubble the same size because it is easier for us to manage. Jo contacts their supporter, Sandy, who comes in and wants to talk with Jo about what Jo thinks are the next steps. They agree they would like to have a discussion with the group home worker and together work through the points that Jo will raise in the meeting. Jo and Sandy attend the meeting with the group home worker and Jo understands why its important to stay in the bubble.

## More information

Information and decision-making tools from the perspective of the person making the decision:

<https://www.peoplefirst.org.nz/supported-decision-making-tools-you-can-use/>

For information about tools to help with supported decision-making:

* Health passports:
<https://www.health.govt.nz/your-health/services-and-support/health-care-services/health-passport>
* Personal communication passports or personal profiles: <http://waindividualisedservices.org.au/wp-content/uploads/2019/02/WAIS0008_4-Booklets-in-One-May15.pdf> [PDF; 549.31KB]

For information about what you can do as a family, carer or a supporter to help people make decisions:
<https://ihc.org.nz/sites/default/files/documents/10007_1511_SupportedDecisionMaking_Resource_V4.3_PRINT.pdf> [PDF; 13.59MB]