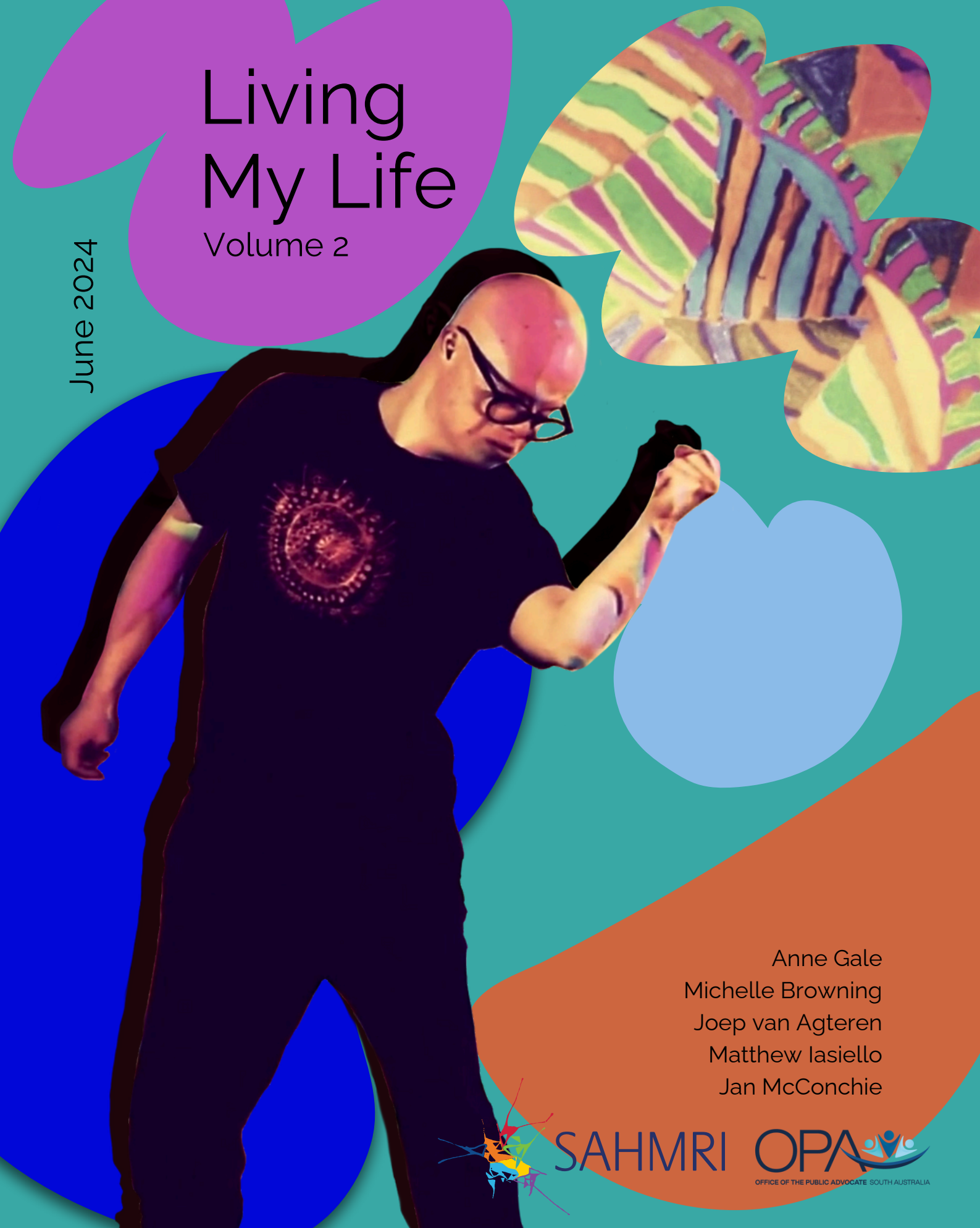
South Australian Health and Medical Research Institute and Office of the Public Advocate

Living My Life

Volume 2

June 2024



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Front cover picture:
The front cover of this report shows Lorcan Hopper, an artist from Tutti Arts Inc.
You can read more about Lorcan and his participation in the project in Section 4 of this report.

Authors: Anne Gale, Michelle Browning, Joep van Agteren, Matthew Iasiello and Jan McConchie
Designer: Lilian Choo
Photos: Tutti Arts Inc and Jan McConchie

Acknowledgement of Country
We acknowledge the traditional Country of the Kaurna people of the Adelaide Plains, where this research was conducted, and pay our respects to Elders past and present. We recognise and respect their cultural heritage, beliefs and relationship with the land, and acknowledge that they are of continuing importance to the Kaurna people living today.

Contents

Appendix 1:
Online resources related to this project

Supported decision making video resources

Created for this project by SAHMRI and SA Health
https://www.opa.sa.gov.au/guardianship/supported-decision-making/supported-decision-making-video-resources

Supported decision making e-learning modules

Created for this project by Michelle Browning
https://www.decisionagency.com.au/e-learning

Be Well activities videos

These short videos were created by Tutti in collaboration with artists with disability
https://www.bewellco.io/living-my-life-project

My Health Information

An easy read form for people with intellectual disability to fill out before they go to hospital
https://www.sahealth.sa.gov.au/wps/wcm/connect/d933364d-3114-46e3-9cc0-cf0c5e532028/20030.2+My+Health+Information-online+form.pdf

Be Well Certified Trainer Program

An information pack for those interested in becoming Be Well trainers
https://www.bewellco.io/_files/ugd/508c8d_44af4ba8fa294a238b00086f9238853a.pdf

Be Well Plan background research

Joep van Agteren, & Matthew Iasiello (2020). Advancing our understanding of mental wellbeing and mental health: The call to embrace complexity over simplification. Australian Psychologist, 55(4), 307–316. https://doi.org/10.1111/ap.12440
https://aps.onlinelibrary.wiley.com/doi/abs/10.1111/ap.12440

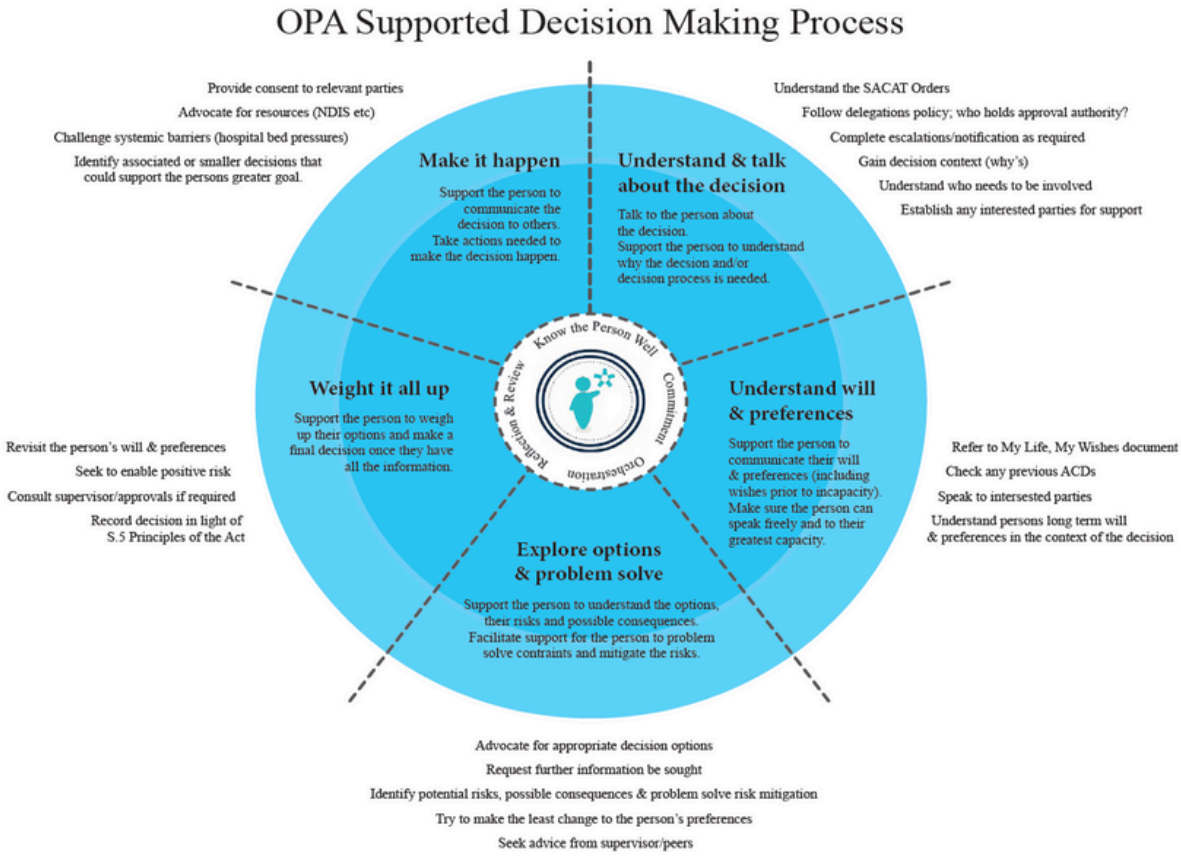
Joep van Agteren, Matthew Iasiello, Laura Lo, Jonathan Bartholomaeus, Zoe Koasati's, Marissa Carey, & Michael Kyrios (2021). A systematic review and meta-analysis of psychological interventions to improve mental wellbeing. Nature Human Behaviour, 5, 631–652. https://doi.org/10.1038/s41562-021-01093-w
https://www.nature.com/articles/s41562-021-01093-w

Appendix 2:
OPA supported decision making project history

Date	Type	Title	Funders/Partners	Aim
2009	Presentation	'Supported decision making in Australia' Presentation to Vic OPA and Vic Law Reform Commission	John Brayley (OPA SA)	An introduction to supported decision making policy and practice issues
2010	Submission	Submission to the Productivity Commission Inquiry into Disability Care and Support	Prepared by John Brayley and Dianne Chartres	A submission on the links between supported decision making, individualised funding and self-managed funding
2010-2012	Project	The Supported Decision Making Project(inc. Supported Decision Making Trial)	Cher Nicholson (OPA SA),Julia Farr MS McLeod Benevolent Fund,Margaret Wallace and Associates – independent evaluator	Assist people with a disability to set up supported decision making agreements to maximise their autonomy to exercise their legal decision-making rights.To study supported decision making when it is offered to people who have had a brain injury, stroke, intellectual disability, or a neurological condition affecting decision making.Trial an approach to supported decision making, in which a person nominates one or more people whom they know to act as a supporter. An extra person, a 'monitor', helps with the process and identifies problems if they occur.
2012	Presentation	'Supported decision making: Australian perspectives' Presentation to World Congress on Guardianship	Cher Nicholson (OPA SA)	An overview of results from the trial.
2012	Presentation	'The future of supported decision making'Presentation to World Congress on Guardianship	John Brayley (OPA SA)	Question exploration: can supported decision making replace substitute decision making?
2013	Website	What is supported decision making?	Cher Nicholson (OPA SA)	Info added to OPA website
2013	Presentation	'SA work on supported decision making'Presentation in Ireland	Cher Nicholson (OPA SA)	Presented the SA work in a session as part of a program on 'Supported decision-making in theory and practice: Ireland's Capacity Bill'
2013	Presentation	SA Supported Decision Making Project outcomes. Presented to David Bowen, CE, NDIS Launch Transition Agency, and Nick Hartland, senior executive at the DFHCSIA	John Brayley (OPA SA)	
2013	Presentation	'Supported decision making: A case for change'Presentation to the Supported Decision Making Forum (QLD Advocacy Inc and QUT)	John Brayley (OPA SA)	This case for change considered both cultural change and the need for law reform. A population-based model was introduced.
2014	Response paper	Response to the ALRC Issues Paper, 'Equality and disability in Commonwealth laws'	John Brayley (OPA SA)	Responded to questions raised by the ALRC related to equal recognition before the law for people with disabilities.
2014	Response paper	Joint response to ALRC Discussion Paper, 'Equality and disability in Commonwealth laws'	OPA Vic	The discussion included commentary on proposed National Decision-Making Principles, and the role of state-based tribunals and the NDIS.

2015	Presentation	'Promoting the dignity and worth of peoples' Presented to the Annual World Social Work Day Breakfast	John Brayley (OPA SA)	This general presentation had a section on the harm to individuals caused by avoidable substitute decision making, linked to the need to provide supported decision making.
2017	Project	Implementing Supported Decision Making for Adults with a Guardianship Order in South Australia	Law Foundation, Margaret Brown (UniSA),Anne Gale, PA	To identify opportunities, barriers and best practice for implementing supported decision making in guardianship practice in South Australia, and to make recommendations for legislative and practice reform to enable supported decision making for adults with mental incapacity living in South Australia.
2018	Project	The law and policy on decision making by, for and with clients in SA guardianship practice	Law Foundation, Margaret Brown (UniSA), Anne Gale, PA	Further research from above project to:develop a practice and policy guide in relation to supported decision making for OPA staff as well as other health and legal professionals, andidentify areas for law reform in GAA.
2018	Project	Supported Decision Making for the Lifetime Support Authority	Lifetime Support Authority, Anne Gale, PA	To produce a policy and practice framework to implement supported decision making principles for Lifetime Support Scheme clients with an acquired brain injury.
2019	Project	Supported Decision Making and My Life Decisions in DHS Accommodation	Anne Gale, PA,Margaret Brown (UniSA),Disability SA	Implement supported decision making utilising the My Life Decisions plan for residents of DHS accommodation services, particularly those under the guardianship of the Public Advocate.Utilise the supported decision making model developed by the Office of the Public Advocate to complete the My Life Decisions plan so residents can plan ahead and maximise their NDIS plans.Train and skill the DHS capacity building and service coordinator staff in supported decision making for implementation and utilisation of the My Life Decisions plan.
2021	Response	Updated GAA 'exposure draft'	Anne Gale, PA	Provide comment on 'exposure draft'
2020–22	Project	OPA Supported Decision Making Project(a component of Living My Life)	OPA, NDIS (ILC), SAHMRI, SA Health and WellbeingConsultants:Decision AgencyJulia Farr Purple OrangeSouth Australian Council on Intellectual Disability	To trial the use of available and purpose-developed tools to seek and record the wishes of people with a guardianship order and consider application of supported decision making practice at OPA within legislative and resourcing constraints. Co-design with people with disability the My Life, My Wishes and My Health Information forms Recommendations for an OPA Advisory Group of people with disability.Develop OPA Supported Decision Making Position Statement and Practice Guide
2022	Response (attendance at Royal Commission)	Policy Roundtable – Best Practice Models of Guardianship, Royal Commission into the Violence, Abuse, Neglect and Exploitation of People with Disability	Anne Gale, PA	Provide response regarding options for reform to guardianship and administration regimes in Australia and how supported decision making can be incorporated within guardianship and administrative regimes.

Appendix 3:
OPA supported decision making process visual guide – draft



Appendix 4: OPA decision record template

SUPPORT FOR DECISION MAKING RECORD						
Completed by name	Date					
Person name	Age	Broad Diagnosis	Behavioural support needs	Complex communication needs	Cultural	GTR
Order: *Choose an item.*			Special Powers: *Choose an item.*			
The decision needed: *Click or tap here to enter text.*				**Decision area:** *Choose an item.*		
Decision context or case background:						
any useful background or context info not included in the above or below						

I HAVE...	I DID THIS BY...	THIS WAS EASY BECAUSE...	THIS WAS DIFFICULT BECAUSE...	I WAS NOT ABLE TO DO THIS BECAUSE...	Case detail	TIME (hrs)
Followed the Steps:						
Found ways to know the person	*Choose an item.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	0
Identified & described the decision	*Choose an item.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	0
Understood the person's will & preferences in relation to the decision	*Choose an item.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	0
Refined the decision with constraints & consequences considered	*Choose an item.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	0
Reached a final decision & associated decision	*Choose an item.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	0
Advocacy needed to implement the decisions	*Choose an item.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	0
Applied the Principles:						
Commitment	*Choose an item.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	0
Orchestration	*Choose an item.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	0
Reflection & Review	*Choose an item.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	0
Used the Strategies:						
Attention to communication	*Choose an item.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	0
Educated about consequences	*Choose an item.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	0
Listened & engaged	*Choose an item.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	0
Created opportunities	*Choose an item.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	0
Enabled positive risk taking	*Choose an item.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	*Click or tap here to enter text.*	0
				TOTAL TIME		0
				Resulting decision type: *Choose an item.*		
				Resulting decision date: *Click or tap to enter a date.*		
General feedback/notes on trying to implement the framework in practice:						
e.g. time taken, difficulty of engaging in the process and workload pressure...						

Appendix 5:
My Life, My Wishes form – easy read

Easy Read

My Life My Wishes Form

My wishes for me.

How to help me with decision making.

OPA

OFFICE OF THE PUBLIC ADVOCATE SOUTH AUSTRALIA

This is the My Life My Wishes Form.

This form will help to tell people:

- Your **wishes**.

  Wishes are the things that you really want.

- How to help you with decision making.

- Information to get to know you.

It was made by the Office of the Public Advocate.

The Office of the Public Advocate are also known as OPA.

When you see we or us that means OPA.

You can ask someone you trust to help you fill out this form.

Look at the User Guide for help on how to fill out this form.

What is in this form

About you

Name

Date of Birth

Address

Suburb

Postcode

4

Part A: My decision-making profile

Part A is about your decision-making profile.

This is information to help people who support you understand what help you need to make decisions.

It is about you.

Help you need to make decisions

What is your disability?

What help do you need to make decisions about your life?

5

Your communication needs

What help do you need to talk to others?

Where and when is it easier for you to speak to others?

What languages do you speak? Do you need an interpreter?

6

Your culture and faith

Culture is the behaviours and beliefs that people follow together.

Faith is the trust in something outside of yourself, for example God.

What culture do you connect with?

How do you make decisions in your culture?

Who do you need to include?

7

Your values and beliefs

Values are what you think is important in your life.

Beliefs are the strong thoughts that something is true.

What is most important to you in your life?

8

Personal history

What do you want people who support you to know about what has happened in your life?

9

Your supporters

Who do you want to help you make decisions?

Name

Organisation

Relationship

Name

Organisation

Relationship

Name

Organisation

Relationship

Name

Organisation

Relationship

10

Name

Organisation

Relationship

Name

Organisation

Relationship

Name

Organisation

Relationship

Name

Organisation

Relationship

Name

Organisation

Relationship

11

Part B: My life, my wishes

Part B is about your life and wishes.

There will be questions about:

- Where you live.
- The services you use.
- Your health.
- Access to the community,
- Other things in your life.

There will also be questions about how you wish these things could be.

Where you live – Your life now

Answer these questions by thinking about where you live now.

What type of house do you live in?

- ☐ Own my home.
- ☐ Live with family.
- ☐ Rental.
- ☐ Housing trust.
- ☐ Supported Independent Living.
- ☐ Specialist Disability Accommodation.
- ☐ Group home.
- ☐ Aged care.
- ☐ Other.

Other information about my home.

When did you move in?

What supports do you have at home?

How much support do you have?

For example, how many staff per person living in the home with disability.

Describe your home.

Who do you live with?

14

Do you have any worries or problems with your home?

Where have you lived in the past?

Does your guardianship order say that your Guardian needs to agree to where you live?

☐ Yes

☐ No

☐ Not sure

15

Does your guardianship order say you cannot leave your house without your support staff for your safety?

☐ Yes ☐ No ☐ Not sure

Does your team use **Restrictive Practices** with you?

Restrictive Practices are things in place that stop someone with disability doing something.

☐ Yes ☐ No ☐ Not sure

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Where you live – Your wishes

Answer the next questions by thinking about how you wish you could live.

What do you think about where you live?

What do you like about where you live?

What do you **not** like about where you live?

Where do you want to live?

Who do you want to live with?

18

What should your home be like?

What home supports should you have?

19

Services – Your life now

Answer these questions by thinking the services and supports that you use.

What supports do you use?

What activities do you do?

What job do you have?

Do you have any problems or worries about your supports?

21

Services – Your wishes

Answer this question by thinking about the services and supports you want in your life.

What supports do you want?

What activities do you want to do?

What job do you want?

23

Health – Your life now

Answer the next questions by thinking about the support you have to look after your health.

What are your main **health conditions**?

Health conditions are things that affect how you live your life. For example sickness or injury.

24

Who helps you with your health?

This might be:

- Taking you to appointments.
- Explaining things to you in a way you can understand.
- Helping you with your medication.
- Other health things.

25

Health – Your wishes

Answer the next questions by thinking about the support you want to look after your health.

What health care do you want in your life?

26

Dying wishes

Dying wishes are things that you want when you come to the end of your life.

Who do you want to be told when you die?

Where do you want to be when you pass away?

What do you want to happen when you come to the end of your life?

☐ I want to be comfortable and pain free at my home.

☐ I want doctors to do anything they can to keep me alive. This includes starting my heart again if it stops.

☐ I want a tube in my throat if I cannot breathe by myself.

☐ I want to go to a hospital room for very sick people.

☐ I want treatment that the doctor recommends.
This might be

- Medicine, food or drink through a needle.
- Tablets.
- Surgery.
- Blood cleaning.

Is there anything that you do **not** want to happen at the end of your life?

28

Access – Your life now

Answer the next questions by thinking about the **informal people** in your life.

Informal people are people who are not paid to be in your life, for example:

- Friends.
- Family.

Who do you see?

How often do you get to see these people?

Where do you usually see these people?

30

What support do you need to be able to see these people?

Do you have any problems or worries about seeing these people?

31

Access – Your wishes

Answer the next questions by thinking about the people that you do and do not want to see.

Who do you want to see?

Why do you want to see these people?

How often do you want to see these people?

Where do you want to see these people?

Who do you **not** want to see?

33

Why do you not want to see these people?

34

Other – Your life now

$

What is your money situation?

What is your legal situation?

35

Do you have any other problems or worries in your life?

36

Other – Your wishes

Do you have any other wishes in your life?

37

Agreement

The information in this form:

- Has come from you.
- Is true.

The person who this form is about:

Name _____

Signature _____

Date _____

The supporter agrees that the information in this form is true to the best of what they know at the time it was filled out.

The person responsible or substitute decision maker:

Name _____

Signature _____

Date _____

Other supporter:

Name _____

Signature _____

Date _____

Other people who helped you to fill out this form:

Relationship _____

Name _____

Signature _____

Date _____

Relationship _____

Name _____

Signature _____

Date _____

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This resource was funded by the Australian Government Department of Social Services and the South Australian Health & Medical Research Institute.

SAHMRI
South Australian Health & Medical Research Institute

This document has been made in an easy-to-read way by the South Australian Council on Intellectual Disability using images from Microsoft 365 and Photosymbols. Images cannot be used without permission.

This document was tested by people with intellectual disability.

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Appendix 6:
My Life, My Wishes form user guide – easy read

Easy Read

My Life My Wishes Form

User Guide.

OPA

OFFICE OF THE PUBLIC ADVOCATE SOUTH AUSTRALIA

This is the My Life My Wishes Form User Guide.

This user guide will help you to know how to fill out the My Life My Wishes form.

This was made by the Office of the Public Advocate.

The Office of the Public Advocate is also known as OPA.

When you see we or us that means OPA.

You can ask someone you trust to help you go through this user guide.

What is in this user guide

My Life My Wishes form

The My Life My Wishes form is a form to write down things about:

- Your life now.
- Your wishes for the future.
- Help you need to make decisions.

This form can help you to make choices about what you want in your life.

You can use the form to share with your supporters your choices around:

- What you want or need.
- What you want for your future.
- Important information about you.

Supporters are people in your life, they could be:

- Family.
- Friends.
- Support workers.
- Guardian.
- Other important people.

You can fill in this form if:

- ☐ You need support to make decisions in your life.
- ☐ You live in South Australia.
- ☐ You cannot make an **Advance Care Directive.**

An Advance Care Directive is a legal document that tells others about:

- Your health care in the future.
- End of life wishes.
- Where you would like to live in the future.
- Anything else that is important.

You can only make an Advance Care Directive if you:

- Are over 18 years old.
- Have decision making capacity.

The My Life My Wishes form is NOT:

- A legal document.
- An Advance Care Directive.

Principles

The My Life My Wishes form was made for everyone to:

- Be involved with making decisions about their life.
- Be supported to make decision and choices.
- Tell your supporters your choices about your life.
- Have supporters to ask and listen to what you want in your life.
- Have supporters to make decisions that include your decisions and choices.

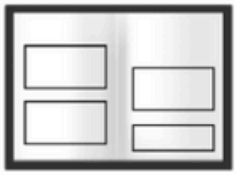
How to complete the form

You can have a supporter to help you to fill out the form.

In the form, write or draw:

- Your wishes for the future.
- Your life now.
- As much information as you want.
  This could be a lot or only a small amount.

You can take your time to fill out the form.



You do not have to answer every question.

7

Part A. My Decision Making Profile

Your decision making profile is where you write what you want your supporters to know about you.

You might be asked questions about:

- What support you need to make decisions.
- Your culture and faith.
- Your history.

- How you tell people what you want or need.
- Who you want your supporters to be.

Part B: My Life, My Wishes

The My Life, My Wishes part is where you write:

- Your wishes for your health.

- Your wishes for where you live.

- Your wishes for other areas of your life.

- What type of support you need to make decisions and choices.

- Any other information that your supporters should know to help you.

Signing the My Life My Wishes form

The My Life, My Wishes form can be signed by:

- You.
- Your supporters.

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Who is your supporter?

A supporter is someone who can help you to complete your My Life My Wishes form.

If you need support to make decisions, you can ask someone to help you.

The supporter might be able to make some decisions for you if you are not able to.

Supporters can be different types of people.

Your supporter could be an **informal support** like a:

- Family member.
- Friend.

An informal support is someone who is not paid to support you.

Your supporter could be a **guardian.**

A guardian is someone who can make decisions for you about:

- Your health.
- Where you live.
- Who you live with.
- Other personal decisions.

Your supporter could be a **substitute decision-maker.**

A substitute decision maker is someone who makes decisions for you.

Your supporter could be a **person responsible.**

This is someone who makes decisions about your health care.

You can get more information about decision making and supporters on the OPA website.

www.opa.sa.gov.au

Know your rights

Consent

Consent means you say it is ok for someone to do something.

The form does not mean you have agreed to any decision.

You should be asked each time there is a decision to made about you or your life.

You can get more information about consent to medical treatment here

www.opa.sa.gov.au

Capacity

When you are over 18 years old there are life decisions that you need to make.

These decisions might be:

- Signing legal documents.
- Agreeing to a service.
- Giving consent to medical treatment.

If you can make decisions, you have decision making capacity.

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You can still make decisions if you:

- Do not understand all the information.
- Can only remember the information for a short time.
- Make a decision that does not have a good outcome.
- Can make some of the decision.

Some people need support to make some decisions.

You might be able to make some decisions but need support to make other decisions.

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Some people might need support to make decisions if they:

- Have a disability.
- Are really sick.
- Have an injury.

You might need support to make a decision if you do not understand:

- All of the information about a decision.
- What might happen after a decision is made.

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This document was tested by people with intellectual disability.

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Appendix 7:
Presentation by Anthony Beazley

Hi Brian (not real name[1]). Can you tell everyone here a little bit about yourself?
I am from Wagga. From a broken home. A Wurundjeri man.

Can you tell us about how you met your guardian Lois (not real name)?
I met Lois at the Aboriginal hospital where Lois was working. Flinders Hospital. I was living in a drain at the time. Lois saw me and said I'll find some accommodation. First, I lived in two different motels short term. Then I ended up at the Department of Human Services Disability.

How long have you known Lois?
I have known Lois for 10 years.

Why did Lois become your guardian?
I was living in a drain and wanted Lois to be guardian because she brought up my past about family. Lois contacted my auntie for me. Lois accepted me into her family.

What type of decisions does Lois make for you?
Lois makes medical decisions such as go to hospital or any other medical concerns. Lois will ring and speak to me if I have concerns. She will talk to me and resolve the situation.

Can you tell us, Brian, about a decision Lois has made for you?
Lois sent me to hospital for drugs. She made the decision for me. It was the right decision at the time. Also Lois helped have a zoom meeting with Department of Humans Services. She was present for support.

Do you like having a guardian? Why or why not?
I love my guardian, Lois. I bounce ideas off her. When we talk, she listens. She is caring.

Brian, what do you like when you are helped to make decisions?
I must have a caring person help with making decisions.

What don't you like when you are helped to make decisions?
I don't like being told what to do and especially ignored as well.

What difference has having a guardian made for you?
Lois has made a difference in my life by being caring, showing respect to me, having empathy, a good heart and listening to me. She saved me from having nowhere to go or live.

What advice would you give to guardians or people supporting others to make decisions?
They must be caring, understanding, show empathy, not to belittle, have respect, not rush anyone when making decisions or talk over the person. And have a good heart.

[1] The OPA has received permission to use Andrew's actual name in this report, but a pseudonym was used in the training materials.

Appendix 8:
Training materials from OPA training session 1 on supported decision making

Exploring will and preferences

Example story: Samantha

Samantha is a 46-year-old woman with an intellectual disability. Samantha's verbal communication is limited. Samantha has been in hospital for approximately 4 months after being relinquished from an aged care facility. Staff at the aged care facility reported that they are unable to manage Samantha's needs, and have evicted her from the facility.

Prior to the hospital admission, Samantha's cousin Beth was her guardian and administrator. Social work staff at the hospital made an application to VCAT for independent guardianship and administration after reports from Samantha's mother that Beth was not acting in the best interests of Samantha. In addition, Beth had refused Samantha's access to NDIS and had reported to staff that she 'would only consider Samantha living with me or in aged care'.

At the VCAT hearing, OPA was appointed as guardian with accommodation and access to services authority. Beth retained her role as administrator for Samantha. When the guardian initially met with Samantha, she reported that she wants to 'live with Beth'. When the guardian asked if she would consider any other accommodation options, she repeated that she wants to live with Beth. When the guardian asked Samantha if she was happy for Beth to be involved in managing her money, Samantha did not respond and looked down at the floor nervously.

At the end of the meeting, Beth arrived and told Samantha, 'Don't worry, you will be coming to live with me. No one else can take care of you like I do.' The guardian observed that Samantha did not respond and again appeared to look down at the floor anxiously in response to this comment.

Hospital staff have indicated that they will soon be ready to discharge Samantha, and that they believe they have found an SRS that would be suitable with NDIS supports in place. Hospital staff have reported that they would have serious concerns about Samantha residing with Beth, as they do not believe that she would be able to provide Samantha with an appropriate level of care.

Question: How would you go about clarifying Samantha's will and preferences?

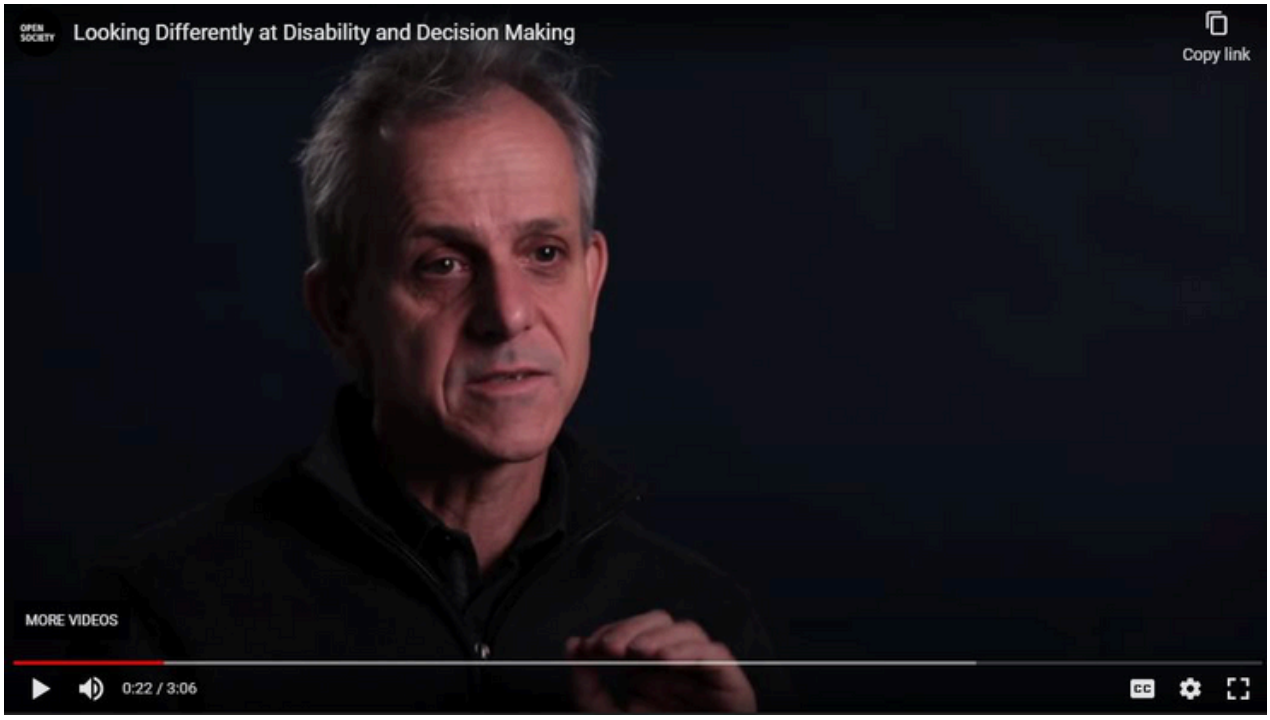
Supported decision-making
Resource summary, October 2021

Dr Michael Bach discussing legal capacity and supported decision-making

Resource Type: Video on YouTube

Focus: A three-minute video explaining the importance of legal capacity and how it can be realised for people with disability through the practice of supported decision making. Michael Bach is a Canadian researcher and leader in the Community Living movement.

He was one of the champions of supported decision making at the drafting of the United Nations Convention on the Rights of Persons with Disabilities. Press control and click on the image below to watch Dr Bach's video.



La Trobe University Support for Decision Making Practice Framework

Resource type: Online learning resource including videos and downloadable tools

Focus: An evidence-based supported decision making practice framework designed primarily for professional decision supporters including frontline managers, disability support workers, clinicians and case managers.

The e-learning resource developed by La Trobe University's Living with Disability Research Centre is an evidence-based framework designed to guide supporters through the process of assisting someone with cognitive disability to make decisions. The framework consists of six modules which outline specific steps, principles and strategies supporters can use to develop their skills as a decision supporter. Press control and click on the image below to explore the La Trobe Support for Decision Making Practice Framework.

Enabling risk: Putting positives first

Resource type: Online learning resource, videos and tools

Focus: This e-learning resource provides information about enabling people to take risks as an integral part of disability support work.

The resource developed by La Trobe University is based on a review of research about risk and from piloting materials with disability support workers and people with intellectual disability. There are five e-learning modules which define risk, its types of outcomes and the factors that influence risk taking behaviour. The resource describes the four essentials of risk enablement, the process for supporting people with cognitive disabilities, as well as how to apply the process in different situations. It also describes the benefits of working in a way that enables choices that involve risk. Press control and click on the image below to explore Enabling Risk: Putting Positives First.

A process of decision-making support: Exploring supported decision-making practice in Canada

Resource type: Academic journal article (open access)

Focus: This journal article explores research into the practice of supported decision making conducted in Canada. It compares the decision-making processes of two people with intellectual disability who were supported by paid professionals and the range of factors which influenced the processes and outcomes. Press control and click on the image below to explore the article online.

Dr Joanne Watson discussing autonomy and supported decision-making

Resource type: Video on YouTube

Focus: A twelve-minute video explaining the importance of autonomy and the right of people with complex disabilities to receive the support they need to make decisions and determine their own lives. Dr Watson explains this work is difficult, time and resource intensive and yet necessary as Australia is a signatory to the United Nations Convention on the Rights of Persons with Disabilities.

The video provides a powerful example story about Tom and the way his decision supporters identify a decision opportunity, help Tom to explore his options and use video to collectively interpret his expressions of preference. The actions of his supporters enable him to decide how he wants to spend his time and money. Press control and click on the image below to view Dr Watson's video.

Appendix 9:
Supported decision making training case studies

Supporting protected persons to make their own decisions

Example stories

Access decision

Jack is a 20-year-old who lives alone in a unit and is supported by staff. He enjoys talking with others and meeting new people. Jack has a mild intellectual disability and autism spectrum disorder. Sometimes he has difficulty understanding the consequences of his actions and there have been times when he has been negatively influenced and exploited by others.

Jack has a consistent care team who know him well and have worked with him for some years. He is in contact with his mother daily via phone, visits her regularly and when he stays at her home gets to see his extended family.

Jack's mother and father separated 10 years ago and since this time his father moved interstate and they see each other approximately once per year. Visits and phone calls from Jack's father are unpredictable and unplanned.

Jack's father applied to SACAT to become his guardian as he felt that his mother was blocking his ability to see Jack. SACAT appointed the Public Advocate joint guardianship with the mother to support a mutual decision-making approach to access decisions.

The delegated guardian initially spoke with Jack to understand his views on seeing people involved in his life. He was able to clearly describe arrangements with his mother as well as concerns he had about his father. Jack reported that he loved his father but was unable to problem solve the pressure from his father for access with the concerns he had about spending time with him.

The delegated guardian had further conversations with Jack. Jack reported his father didn't understand him and didn't allow him to do things that made him feel better, for example playing with toys or bringing a toy with him to visits. It was clear Jack loved his father and being able to have contact with him. The delegated guardian gathered information on the current arrangements, risks to Jack and his susceptibility to being influenced. There were reports after calls from Jack's father he would contradict his previously expressed wishes saying he wanted access to occur.

Jack was supported to explore a range of access options. He requested the care team handle his mobile phone if his father calls too often and becomes heightened. He wanted access to be arranged on a case-by-case basis. Doing this would allow Jack to be involved in deciding whether he wants to see the person and be involved in shaping the circumstances.

The delegated guardian made an open-ended decision which will allow Jack to be supported to decide when he sees his family members and in what circumstances.

Health decision

Fernanda is a 43-year-old woman who lives in supported accommodation with 24-hour support. She has a mild intellectual disability, schizoaffective disorder and a range of chronic health conditions including epilepsy, chronic pain syndrome, obesity and chronic respiratory disease.

Fernanda was admitted to Lyell McEwin Hospital for pneumonia, a urinary tract infection and a leg infection. After resolving the acute health issues Fernanda was discharged from hospital with a 7 Step Pathway document that had not been explained to her. The document notified that there was medical consensus between two respiratory specialists on limitations of future treatment for Fernanda's future hospital admissions. The limitations were:

- Not for CPR due to medically ineffectual and medical inconsolable.
- Intubation will not be considered if found to be required ongoing due to obesity, poor lung stability and any further disability would lead to a life not worth living.

The delegated guardian visited Fernanda at home and she was able to easily engage in conversation and express a clear view. The delegated guardian explained the form to Fernanda. She offered clear end-of-life wishes for all care to be provided and remarked 'so they are just going to leave me to die'. The delegated guardian followed up with doctor for further explanation but was given no additional information as the doctor did not need guardian consent before it was made active.

The delegated guardian discussed the document with the NDIS Coordinator who was also concerned. The coordinator explained Fernanda has complex behaviour and extreme sensitivity to pain, which can lead to behaviour escalation when she presents in hospital. The delegated guardian took this information back to the doctor. Fernanda was not in support of the document and presented very differently now to when she was in acute pain in hospital. A review was requested. The doctor maintained his position on no CPR and no intubation. His justifications were: low probability of meaningful quality of life; psychological and emotional intolerance given ID; prospect of not being able to speak.

The delegated guardian escalated the matter to the Department Heads of ICU and Respiratory Medicine and wrote to the Lyell McEwin Hospital for impartial review of the document via letter. The Director of ICU emailed to confirm the 7 Step Pathway document had been cancelled and the OPA letter had been included in Fernanda's medical file.

Discussion questions

- Do you believe there is a legislative context that allows delegated guardians to be able to support protected persons to make their own decisions? For example, principle 5(d) of the GAA.
- Reflecting on these two recent decision-making scenarios, please discuss when you have been able to support a protected person to make their own decision in your work as a delegated guardian. Please explore as a group whether there are commonalities between your experiences. For example, were there particular types of decisions that lent themselves towards a supported decision making approach?
- Please discuss how you record decisions when the protected person is supported to make their own decision. Do you feel confident in how to document a supported decision?

Exploring La Trobe Practice Framework

The La Trobe Support for Decision Making Practice Framework centres around three practice principles: commitment to the person and their rights; orchestration of others involved in the person's life; and reflection and review on your own values, influence and support. It promotes the use of six key decision support strategies:

1. attention to communication
2. education about consequences and practicalities
3. listening and engaging to ensure all options are considered
4. creating opportunities
5. breaking things down and
6. enabling risk.

And the six steps of the decision-making process relevant to OPA's work are:

1. knowing the person
2. identifying and describing the decision
3. understanding the person's will and preferences
4. refining the decision and taking account of constraints
5. reaching the decision and associated decisions and
6. implementing the decision and advocating if necessary.

Example stories

Elizabeth is a 72-year-old woman who is a retired school principal and who has been described as 'fiercely independent, opinionated' and 'likes her own way'. She is well educated and articulate; however, she lacks insight into her physical and cognitive disabilities. Elizabeth has been diagnosed with bipolar–schizoaffective disorder with an underlying neurological condition Lui body dementia. Elizabeth has been a long-term client of geriatric mental health services and has been very difficult to engage, refusing to let people into her home. There is a history of Elizabeth's home being squalid, of her not taking medication, not getting out of bed as a result of depression, and losing weight from not eating.

Elizabeth has had several admissions to hospital for biopsychosocial reasons. She is always resistant to admission; however greatly improves physically and mentally after a few weeks of 'respite' in an aged care facility. At the last admission, the hospital considered her unsafe to return home. During respite she insisted on returning to where she has lived for the last 30 years.

The delegated guardian met with Elizabeth to discuss her accommodation options. They discussed that, if she wanted to return home, she would need to accept increased services at home including an L4 package, daily nursing visits for medication, assistance with getting up and dressed and Meals on Wheels. The staff where Elizabeth was on respite reported she was in good spirits, albeit still insistent on returning home. The geriatric mental health team were not supportive of Elizabeth returning home even for a four-week trial.

Elizabeth had challenged the need for the guardianship order and disputed her diagnoses in detailed medical reports and evidence to the contrary. She expressed a strong will and preference to return home. The delegated guardian spent time speaking with Elizabeth at the guardianship and administration hearings, providing accurate information, building trust and discussing the risks and barriers openly with Elizabeth.

The delegated guardian thoroughly explored the option to return home, liaising with services in readiness for discharge and reported back what was being put in place. The delegated guardian identified the key constraint to being able to return home was the need to accept services. After some discussion Elizabeth agreed to services coming into the home.

The delegated guardian considered the possible risks involved with returning home (evidence of previous decline of supports into the home, and her care needs becoming higher than support levels) and determined it was appropriate to enable the risk at the very least for a trial period, given there had been some improvement while Elizabeth had been in respite. The delegated guardian had the support of their line manager to do so.

The delegated guardian returned to Elizabeth to confirm the decision, discuss the daily contributions required and sign the service agreement. At this meeting Elizabeth said she had changed her mind. Over time she had come to realise returning home was beyond her ability to manage even with the highest level of in-home supports. She expressed if she couldn't move home, she wanted to move to a retirement village and the delegated guardian explored this option with Elizabeth further.

The delegated guardian engaged in deep listening. She supported Elizabeth to gradually build a realistic picture of this alternative option. In doing so, it increasingly became apparent to Elizabeth that she did not have the ability to view retirement village options, sell her property and physically move. Through conversations Elizabeth came to realise her preference to move to a retirement village was outside her capacity and remaining in an aged care facility was the best option and her preference.

At Elizabeth's request, the delegated guardian went on to advocate for her to be offered a place in an aged care facility in the same area as her home, close to the shops, with a larger room that would also allow a bird to be brought from home. The delegated guardian resisted significant pressure from the hospital to accept the first available bed. Elizabeth is now settled in an aged care facility that reflects her will and preferences.

Discussion questions

- Does this example story illustrate all six steps of the La Trobe Practice Framework?
- Can you identify any specific decision support strategies that are used?
- Do you think this Practice Framework might be useful to you when you have the opportunity to support the decision making of protected persons?

Exploring orchestration

Decision making is often a shared task and there can be a range of people who are needed to support someone to be able to make decisions well. The concept of orchestration recognises that supported decision making processes often require one person to lead or orchestrate the process by drawing in other supporters from various parts of the person's life as well as mediating any differences between supporters or others potentially affected by the decision.

Orchestration is an important aspect of the work you do as delegated guardians. You identify supports and services that are missing in the lives of protected persons and advocate strongly for them to be realised. You work to improve the networks of support that are in place for people, often mediating conflict, and this can have a significant impact on the protected person's ability to be supported to make decisions.

Example Story: Nicole

Nicole was a 23-year-old woman with borderline personality disorder and an intellectual disability. She had made allegations of sexual abuse by her father and brother, and police took out Family Violence Intervention Orders on her behalf. The Public Advocate was appointed to make accommodation and access to persons decisions for Nicole.

At the commencement of the order Nicole was completely unable to articulate her will and preferences. She was in a state of trauma and her personality disorder was florid. She didn't have adequate structure and support in her life generally and as a result 'things were in chaos'. The advocate guardian took over decision making in relation to Nicole's family visits because Nicole was at risk of self-harming and there was a significant concern that she would be sexually assaulted by her father.

The advocate guardian sought to put appropriate supports in place for Nicole. This required obtaining a significant amount of funding from the National Disability Insurance Scheme as Nicole needed ongoing support from a psychologist, psychiatrist, support workers (24/7) and the advocate guardian. The advocate guardian established a care team for Nicole that met regularly (six weekly) and was responsible for supporting her with decision making. How the care team engaged with Nicole was directed by a Behaviour Support Plan developed by her personality disorder specialist.

It took two years for Nicole to fully engage with the care team meetings. Having this structure in place changed Nicole's decision making. With a greater level of support, she was able to clarify and express her will and preferences. Decisions were no longer made on the run, and she was able to set boundaries with respect to seeing her family. Nicole sought the support of the care team with her decision making, specifically her key worker and psychologist. Nicole's guardianship order was reviewed recently and was revoked given the robust decision-making support that was in place which enabled her to have decision-making capacity.

Discussion questions

-
- Does the concept of orchestration resonate for you and your experience as a delegated guardian?
- What are the activities you do that build the decision-making ability of protected persons?
- What are the challenges you face to orchestrating good decision support in the lives of protected persons? Do you have any ideas as to how they might be overcome?

Exploring risk

Supported decision making asks us to take a risk enablement approach when exploring risk as an important constraint in the decision-making process. There are a few key features of a risk enablement approach. Firstly, it is collaborative and involves the person in the whole consideration of risk. Secondly, it approaches risk from a positive standpoint. Thirdly, it invests time and energy assisting the decision maker to be able to understand the nature and consequences of the risks. Fourthly, when harm minimisation is necessary it asks us to explore alternative ways to reach the same goal for the person that have the least change to their will and preferences.

Example story: Sally

Sally is a 70-year-old woman with early onset dementia. She has lived with her partner and 2 dogs on a rural farm for the past 6 years. Her capacity has only recently declined. Sally's partner is retired and provides full-time care to Sally at home. This includes providing medication management, transport assistance, meal preparation and general prompting and supervision as a result of Sally's memory difficulties. Sally has no difficulties with her mobility and is able to shower and toilet independently. She is content where she is living.

Sally's brother Ronald and her long-term friend Margaret were appointed as substitute decision makers under an Advance Care Directive and her brother was appointed as attorney under an Enduring Power of Attorney. Ronald and Margaret made an application to SACAT to appoint 2 of Sally's daughters as guardian and administrator due to difficulties fulfilling their role in the face of significant conflict with Sally's partner. Shortly after, further applications were put to the SACAT by the 2 daughters (guardian and administrator) recommending appointment of the Public Advocate due to their roles also becoming unworkable due to conflict with Sally's partner.

At the hearing, it was reported that the 2 daughters, brother and best friend had been prevented from accessing Sally and as a result had concerns about her wellbeing and the state of her care. A full guardianship order was made appointing the Public Advocate including special powers (S32(1).A) in the event that Sally required alternative accommodation.

The delegated guardian visited Sally at her partner's home. Strong rapport was witnessed between Sally and her partner, and no care concerns were noted. The home was well kept and Sally presented as well cared for. Sally was spoken to away from the company of her partner. She reported that she loves where she is living, specifically she loves the peace and quiet, the expanse of the land she looks onto from her lounge room window, and living with her partner and his two dogs. She reported that it would be her 'worst nightmare' to move from her partner's home or to be separated from him. She explained she was aware that some of her family do not visit because her partner can get 'aggro', but she is happy to visit them at their homes. She also reported she was visiting her family regularly and would wish to continue doing this; however this was not in fact the case – she had not seen her family for many months. Sally also reported that 1 of her daughters resides in her privately owned home, and she wishes this arrangement to continue as this daughter has always needed more support that the others and Sally would like to provide this support.

The 2 other daughters requested OPA make a decision to place Sally in an aged care facility as, according to them, Sally is not adequately cared for by the partner in addition to him preventing contact with the family. The guardian sought further information on Sally's care needs and health status via an ACAT assessment and Sally's regular GP. The GP reported that the partner supports Sally to see the GP regularly, she has presented at required assessments and the partner is managing Sally's medication adequately. The guardian spent significant time arranging an ACAT assessment on behalf of Sally as the partner objected due to fears it would result in placement in an aged care facility. ACAT advised that Sally's partner was obstructive to assessments; however with a home visit and collateral was able to complete the assessment. Sally became eligible for a low-level home care package and respite.

Excluding the daughter residing in Sally's home, the family continued to pressure the delegated guardian for a decision about transfer to an aged care facility. The delegated guardian discussed the option of using special powers with the family, who advised it would be too 'heavy handed' but wanted resolution from the delegated guardian about access between the family and Sally. The delegated guardian contacted Sally to discuss with her the concerns from her family and the options, with intention to start short-term respite and devise a plan agreeable to Sally for when her partner was unable to care for her. Sally advised, again, that she did not want to move to an aged care facility or take up respite. If she needed to, she would like to return to her own home with supports in that home. At this point in the conversation the partner took the phone and became angry and verbally abusive towards to the delegated guardian. The partner reported he would refuse home care package supports entry to the home.

Discussion questions

- What are the risks involved in this situation? Please consider the positive and negative benefits of these risks to Sally.
- What strategies could be used to mitigate each of these risks?
- Do you think it would be possible to develop a plan for mitigating the risks with Sally (and her partner)?
- How could you minimise harm by making the least modifications to her will and preferences?

Appendix 10: Worksheet from SAIDHS advanced SDM training for practitioners

Decision making scenario 1

Ted is a 35-year-old male with mild intellectual disability, autism, ADHD and anxiety. He resides in a house with three other people and is supported by two carers. Ted has a history of challenging behaviour and property damage. He has a Positive Behaviour Support Plan and is prescribed 3 types of antipsychotic medications, which he has been taking since his early 20s. Ted was referred to SAIDHS due to increasing incidents of physical aggression. SAIDHS clinicians are concerned about the impact of multiple high-risk medications on Ted's long-term health. Ted's carers have voiced concerns about reducing any medications.

Reflection questions

- What are the range of factors that might be influencing the use of high-risk medications for Ted?
- How could we explore more deeply what Ted is expressing through his behaviour? From your experience with others what are some possible reasons he may become physically aggressive?
- What options, strategies and supports might address these reasons (other than medication)?
- How could we better understand Ted's will and preferences around his current medication use? How could we be more directed by Ted's will and preferences when exploring future medication use?

Decision making scenario 2

Sasha is a 42-year-old female with severe intellectual disability and barriers to communication. She lives in supported accommodation with one-to-one supports and is under the guardianship of the OPA. Sasha was referred to SAIDHS due to concerns about weight loss of unknown cause. SAIDHS clinicians completed a medical assessment and recommend a blood test and MRI to investigate; however the carers reported this would be traumatic, and she would not be able to tolerate the tests.

Reflection questions

- What communication support might Sasha need to be able to understand the concerns about her weight loss? Consider approaches, tools and resources.
- If the key barrier to having the blood test and MRI is fear because of a lack of understanding, what creative strategies could be explored to help Sasha understand what is involved? How might you go about trying to reduce her fears and the possibility of trauma?
- If after exploration and reflection the blood test and MRI are not appropriate investigative strategies (e.g., there is history of trauma and a strong likelihood of re- traumatisation), what alternative investigative options could be explored with Sasha?
- After communication support is provided, and options are explored, how might you work with OPA and her carers to clarify and act on Sasha's will and preferences about the blood test and MRI?
- How might you advocate for Sasha's will and preferences to direct decisions about her future health?

Decision making scenario 3

Harry is a 22-year-old male with moderate intellectual disability and Down syndrome. He lives with both parents and has 2 younger siblings. He was referred to SAIDHS due to his parents' concerns about his oppositional attitude at home towards his parents' requests and day option coordinators indicating he is becoming verbally 'aggressive' with other participants and can no longer attend the program. SAIDHS clinicians completed a mental health assessment and identified no mental health conditions; however his frustration is likely relating to seeking more independence as a young adult. Harry indicated to SAIDHS clinicians that he wanted to move out of home, but his parents were reluctant to agree to this idea.

Reflection questions

- How could we explore more deeply what Harry is expressing through his behaviour? How can we understand his will and preferences?
- Are there any decision opportunities presenting themselves?
- What role might SAIDHS clinicians have in supporting Harry to communicate more effectively what he wants (his will and preferences)?
- What role might SAIDHS clinicians have in supporting Harry's parents to become more open to hearing and acting on his communication (will and preferences)?
- What organisations and groups might be able to offer Harry support? What organisations or groups might be able to offer support his parents?

Appendix 11: Supporting the decision making of people with psychosocial disability: A challenging decision-making scenario

Kevin is a 61-year-old single man, living alone with chronic schizophrenia. He has been admitted to an inpatient psychiatric ward with a relapse of psychotic symptoms following a period of non-concordance with treatment. He is an NDIS participant and lives alone in private rental; he receives 10 hours of support per week and a recent review of his support plan with assistance from the community mental health team has concluded he would be safer and optimally supported in supported independent living accommodation. Kevin has been reluctant thus far to engage with this plan.

Since coming onto the ward, a number of other psycho-social issues have come to light; Kevin is in arrears with his rent, the property is becoming squalid and he is at risk of losing his accommodation. His mother, who acts as his carer but has no formal decision-making responsibilities, is very worried and upset about her son's future. She has expressed concerns that, when she passes away, he will have no one to 'bail him out' and advocate on his behalf. She is of the view he shouldn't be making independent decisions and he needs to be in supported care with someone taking care of his finances for him.

Kevin's cognition is somewhat impaired based on previous assessments; likely secondary to a dozen or more episodes of psychosis resulting in admission over the last 30 years. He has also used illicit substances in the past to dangerous levels. However, Kevin has been assessed as having decision-making capacity in relation to his accommodation and support choices. There has been some doubt cast on his ability to make more complex decisions regarding finances.

What role might you play in assisting Kevin to make an informed decision about his support and accommodation in readiness for planning his discharge from hospital?

Reflection questions

1. Looking into and understanding the decision
- Why is the decision important?
- What might it mean for Kevin?
- What might it mean for other people in Kevin's life?
- Who needs to be involved in making this decision?
- What might help the process (e.g. involving the right people, supporting communication)?
- What might hinder the process (e.g. available time, money, resources)?

2. Understanding the person's will and preferences
- What are Kevin's preferences?
- How does this decision align with Kevin's vision for his life?
- How does the decision relate to his values, beliefs and prior experiences? (If we don't know, how could we find out?)

3. Gathering information and exploring options
- How could you support Kevin to explore his options?
- How could you present information to Kevin that would work best for him?
- How could you explore the good and bad things that could come from each option with him?

4. Working through barriers and risks
- What are the barriers to acting on Kevin's will and preferences?
- How could the barriers be overcome?
- What are the risks (positive and negative)?
- How could the negative risks be reduced and managed?

5. Weighing it all up and making the decision
- How could you help Kevin weigh up the benefits and risks?
- How would you know what Kevin's final decision is?
- What support would Kevin need to communicate his decision to others?

6. Reflecting on the decision and what happens
- Do you need to advocate alongside Kevin for the decision to be acted on?
- Are there more decisions to be made as a result of the decision?
- What has the impact of the decision been on Kevin and others?

Reflecting on your influence

Think about a time when you helped someone to make a decision. I would like you to consider three questions.

- Were you trying the influence the person's decision?
- Can you identify the biases you brought to the decision-making process? (For example, you thought the person was too unwell to decide, some options were too risky, you value relationships more than personal autonomy.)
- Did you approach the decision-making process with a specific outcome in mind? (For example, you felt one option was the best for the person, you needed to get the person to agree to something.)

Appendix 12: Supporting the decision making of people with psychosocial disability training: Content summary and digital resources

What is supported decision making?

- Supported decision making is the process of providing practical assistance with decision making. It offers people with disability a broad range of supports to be able to make their own decisions and stay in control of their lives.
- Practical assistance can be ensuring the person knows there is a decision to be made. Explaining and clarifying information and creating opportunities to try new things. It can involve helping the person identify and weigh up their options, solve problems and minimise their stress and anxiety.
- Practical assistance can also involve identifying possible risks, developing an understanding of consequences and helping the person implement their decision.
- For people with psychosocial disability it can also involve removing distractions in the environment, simplifying information and conversations so as to not overwhelm people, building trust and providing a safe space, using diaries lists and photographs to help remember important conversations, and encouraging people to take time and not act impulsively.
-

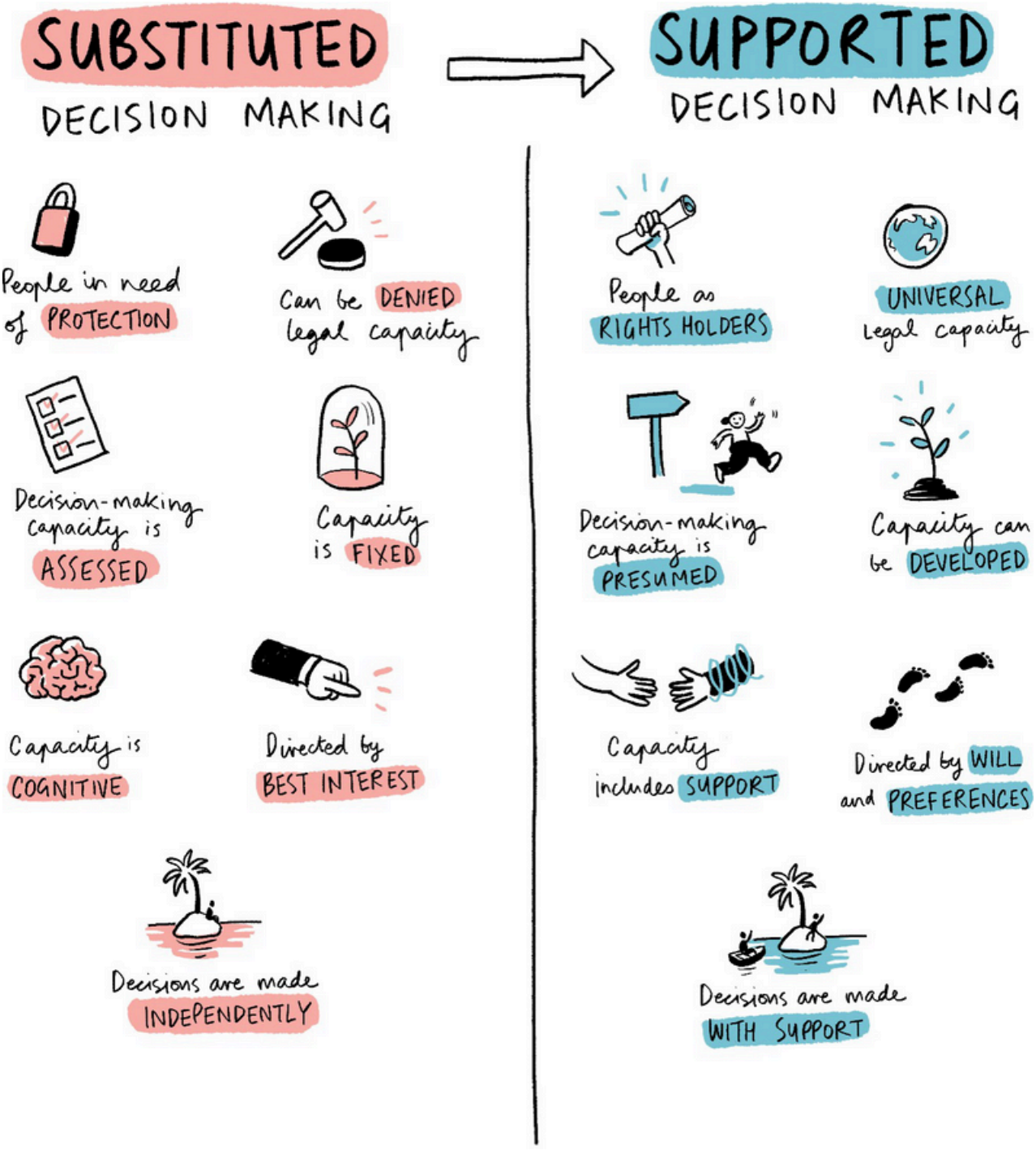
Why is it important?

- The Convention on the Rights of Persons with Disabilities states we must provide people with disability with the support they need to exercise their legal decision-making rights.
- Supported decision making is a practical and legal alternative to substitute decision making.
- Substitute decision making is when someone else makes decisions for you. This can be informally or formally through mechanisms like guardianship and financial management.
- Supported decision making recognises we all need support to make decisions in our lives at different times, and we draw on the support of people we know and trust.
- Our ability to make decisions is shaped not only by our skills and experience as individuals but also by our context and the quality of support available to us.

Ability + supports and accommodations = decision-making capability

- The support you provide has the power to change a person's decision-making capability. What you do or don't do can have a big impact.

How is supported decision making different to substitute decision making?



To read more about this go to:
www.decisionagency.com.au/resources

Three important decision support strategies

1. Strengthening relationships: we develop the quality of our relationships with decision makers including mutual knowledge, respect and trust. We also foster the relationships the decision maker has with others.
2. Minimising your influence: we approach the decision-making process from a neutral standpoint, acknowledging and working to minimise our biases. We need to focus on a good process rather than achieving a specific outcome.
3. Enabling risk: we see risk as something that is not inherently negative, collaborating with people to identify possible harm, and find ways to reduce the harm that respect their will and preferences.

A process to help guide practice

To access a tool which guides you through this process go to:
www.belongingmatters.org/product-page/supported-decision-making-guide

Supported decision making digital resources

What is SDM?

An animation exploring supporting decision-making in practice.
A series of five videos explaining what it is and why it's important in the health context.

Why is SDM important?

Supported decision-making is about enabling the exercise of legal capacity.
Stories from people who have experienced severe mental health problems and been supported with their decision making in health contexts.
Autonomy can be realised for people with complex communication support needs through decision-making support.

How do you provide support?

Factsheet on supporting decision making in the health context.
A research-based support for decision-making practice framework.
A research-based approach to supporting decisions involving risk.
Journal article exploring the range of factors which influence the supported decision-making process.

What tools can you use to better support communication?

Practical tips on communicating with people with disability in the health context.
Using tools such as My Health Information.
Using tools such as Talking Mats.
Providing information in Easy Read.
Understanding the importance of communication partnering for people with complex communication support needs.

What tools can you use to talk about decision making?

WAiS SDM plain language and Easy Read resources.
ADACAS online decision-making toolkit.
My Rights Matter SDM Hub including resources such as SDM Conversation Cards.

Appendix 13:
Overview of the Be Well Plan sessions

Session 1: Getting on the same page

- Introduction to facilitators and the group norms. If presented online, particular focus will be placed on explaining the software.
- Participants self-reflect on the reasons for participating in the program and reflect on their personal drivers. Facilitators provide insight into their own drivers to work on their mental health by sharing them with the group.
- Participants share their personal drivers with other group members in small groups.
- Participants acquire basic knowledge on mental health and definitions for key concepts such as mental health and resilience to create a common language and understanding.
- Facilitators delineate scope of the program: focus on building mental health not treating mental illness.
- Participants explore importance of believing in malleability of mental health and the need to have a growth mindset. Evidence on malleability is presented.
- Participants are asked to reflect on most surprising thing they learned so far. Participants do a small group sharing exercise where they discuss their choice
- The evidence for different psychological interventions is presented. Participants learn that finding activities that work for their specific situation is key.
- Participants are introduced to a number of easy mindfulness activities and are asked to choose one to practice during the week.
- Participants are asked to set a goal and are introduced to the concept of tiny habits/implementation intentions as a technique to improve the chance of goal attainment.

Homework: complete measurement if participants have not completed it before the training.

Session 2: Using your mental health profile

- Participants reflect on their first week of using their plan and how their mindfulness activity worked during the past week. They reflect on whether they need to adjust their plan. Participants share reflections in small groups.
- Participants get familiar with the concept of self-compassion (as opposed to self-criticism) and how it can be used to learn from failure and shape our thinking patterns.
- Participants practice a self-compassion activity and share their reflections in small groups.
- Participants interrogate their measurement result stemming from the integrated measurement. Facilitators can share their own results with the group.
- They identify areas they can improve on and select one outcome (wellbeing, resilience, mood, anxiety, stress) they want to focus on for this session.
- Participants share their outcome of focus.
- Participants are introduced to activity finders: flow charts that map evidence-based activities to each of the activities.
- Participants use the activity finders to explore activities they can add to their plan focused on their outcome of choice.
- Participants pick one activity from the activity bank to add to their Be Well Plan and set new goals for the week.
- Participants are introduced to the use of prompts and reminders as another method to increase goal attainment.

Homework: complete a survey that allows participants to identify their own values.

Session 3: Your resources and challenges

- Participants reflect on week 2 and make changes to their plan if needed. Participants share reflections in small groups.
- Participants work with (and are reminded of) existing resources to their own mental health via two practical activities.
- The first activity gets participants to choose pictures that display sources of meaning in their life. Participants share the pictures in small groups. Facilitators show their own pictures to start the activity.
- The second activity gets participants to identify core values that can be used to guide their life decision and their goals. Participants share which values are important to them. Facilitators share their own values.
- Participants then use a custom questionnaire to identify a key resource or challenge they want to work on for the next week. These resources and challenges can be psychological, health behavioural or external.
- Participants are introduced to a second activity finder that maps evidence-based activities to each of the challenges and resources.
- Participants explore new activities mapped to the resources and challenges and pick one new activity from the activity bank to add to the Be Well Plan.
- Participants finish the session by adjusting their Be Well Plan and are reminded of the importance of celebrating small wins related to their mental health (i.e. when they practise activities in line with their Be Well Plan).

Homework: Participants are asked to choose and reach out to a social supporter as part of their weekly activities.

Session 4: Stress, coping and resilience

- Participants reflect on week 3, adjust their plan if needed and share their reflections in small groups.
- The concept of stress and eustress is introduced and participants learn the effect of stress on our mind and body.
- Participants learn about coping strategies (avoidance-focused coping versus more helpful ways, e.g. problem-focused coping). They complete an activity where they reflect on when they used different coping strategies and what impact it had on them.
- Participants are then walked through various ways of effective coping using psychological techniques, including identification of cognitive traps, positive reframing and the use of thought defusion.
- Participants complete example activities related to cognitive traps, positive reframing and thought defusion in their own life. They share their reflections with other participants in small groups. Facilitators provide examples of their own life.
- Participants learn about the importance of asking for help, both from their social support network and professional services.
- Participants then choose one new activity specifically focusing on stress and resilience. They add this to their Be Well Plan.

Homework: participants are asked to complete another measurement, the results of which will be used during the next session.

Session 5: Future proofing your Be Well Plan

- The participants reflect on the past 4 weeks, what has worked and what has not. Participants share reflections in small groups.
- Participants are asked to investigate how their measurement results have changed over the four weeks.
- The facilitator will introduce the concept of realistic optimism, growth, the fact that progress comes with ups and downs and that it is a slow and gradual process to see change.
- Participants will then build their final Be Well Plan, which aims to summarise key learnings from the previous weeks into a standalone plan.
- Participants summarise what their best possible mental health looks like. They share their best possible mental health with group members.
- Participants highlight their unique drivers and motivations, and existing resources and challenges in their life. They write down the values that are important to them.
- Participants set a longer-term mental health goal.
- Participants choose the activities they wish to add to their 'final' Be Well Plan. They identify their key supporters and reflect on what support services they need in case of emergency.

Appendix 14:
Train the trainer description

The project has left the sector with a number of Be Well Plan train the trainers. Those trained through the grant are based in South Australian disability sector peak body organisations SACID and BISA, central government agencies SA OPA and SA Health (Centre for Disability Health and Division of Palliative Care which oversees hospital long-term stay discharge) and exemplar disability organisation Tutti Arts, among others.

These organisations give good coverage to the sector:

- Guardianship/substitute decision makers: Office of Public Advocate
- NDIS peak bodies and community training and program providers: Brain Injury SA (BISA), South Australian Council on Intellectual Disability (SACID) and Tutti Arts
- Department for Health: long-stay transition and disability health services unit SA Intellectual Disability Health Service (SAIDHS), mental health nurse training unit and Northern Adelaide Local Health Network People and Culture training unit.

Even before the completion of the project on the basis of having an accredited trainer from the program BISA won a grant to continue the work. Beyond the project they will continue to deliver training to family members and friends network and to extend the work with funding from their grant for a new train the trainer from their lived experience cohort.

SACID will enhance their current training programs which include Healthy Minds, My Life My Choices and Relationship-wise as they continue to strength their sector contributions.

Tutti Arts programs will be enhanced by the skills inhouse.

SA Government will continue to deliver the program internally and to family members.

Appendix 15:

My Be Well Plan activity book – easy read

Easy Read

My Be Well Plan

Activity Book

Find an activity that works best for you.

Be Well Co

SAHMRI South Australian Health & Medical Research Institute

Flinders University

What is mindfulness?

Lots of the activities in this book talk about **Mindfulness**.

Mindfulness is:

- Thinking about what you are doing now.
- Not worrying about anything else that is happening.
- Not being distracted by anything else.

Mindfulness helps you feel **grounded.**

Being grounded means distracting yourself from emotions, such as

- fear,
- sadness,
- anger.

This book will have different mindfulness activities that can help you feel grounded.

Each activity will tell you:

- How long to do it.

- How often to do it.

- How **difficult** it is.

  This will tell you if the activity is:

  - Easy.
  - Medium.
  - Hard.

It will also tell you what areas it can have a positive impact on.

You can choose an activity that works best for you.

Activity list

1. Mindful Breathing

Different ways to breathe that can help if you are feeling stressed.

How long	How often	Difficulty
10 minutes	1 a day	Easy

This activity can have a positive impact on:

- Wellbeing.
- Resilience.
- Mood.
- Anxiety.
- Stress.

What is Mindful Breathing?

We all breathe every day, all day.

Sometimes we do not notice we are breathing.

If you think about your breathing for a minute, it can help you to feel calm.

Why I should do Mindful Breathing

This can help you to **ground** yourself.

This means to distract yourself from emotions, such as

- fear,
- sadness,
- anger.

How to do Mindful Breathing

1. Breathe slowly in through your nose.

2. Breathe slowly out through your mouth.

3. Breathe in through your nose for 6 seconds.

4. Breathe out through your mouth for 6 seconds.

5. Try to focus just on your breathing.

6. Think about how your breathing feels as you breathe in and out.

7. Do this for 1 minute.

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2. Progressive Muscle Relaxation

Relaxing different muscles in your body.

How long	How often	Difficulty
15 minutes	1 a day	Medium

This activity can have a positive impact on:

- Wellbeing.
- Resilience.
- Mood.
- Anxiety.
- Stress.

What is Progressive Muscle Relaxation?

This is a mindfulness activity for your muscles.

You will **tense** different muscles.

Tense means to squeeze different muscles.

Then you will relax different muscles.

Think about your muscles when they are tense and when you relax them.

You can tense and relax all your muscles in your body.

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Why I should do Progressive Muscle Relaxation

Sometimes your muscles may tense because you feel anxious or stressed.

This can help you to relax your muscles.

How to do Progressive Muscle Relaxation

1. Find a space you can lie down or sit.

2. Breathe slowly in through your mouth.

3. Breathe slowly out through your mouth.

4. Choose 1 body part of your body.

5. Tense this body part for 30 seconds.

6. Relax this body part for 15 seconds.

7. Repeat with other body parts.

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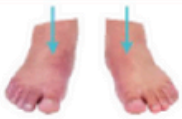
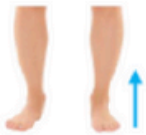
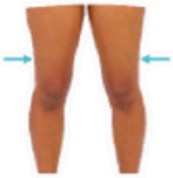
How to tense different muscles in your body



Feet: curl your toes downwards.



Lower leg: Pull your toes towards you to stretch your calf muscle.



Upper leg: Tighten your thigh muscle.

Bottom: Squeeze your bottom muscles.

Hands: Make a fist.

Upper arm: Bend your arm up and make a fist.

Jaw: clench your jaw.

Eyes: squeeze your eyes shut.

Forehead: raise your eyebrows and hold them high.

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3. Mindful walking

Think about your walking and how it makes you feel.

How long	How often	Difficulty
10 minutes	1 a day	Easy

This activity can have a positive impact on:

- Wellbeing.
- Resilience.
- Health.
- Mood.
- Anxiety.
- Stress.

What is Mindful Walking?

Sometimes when you walk you think about

- What you are doing that day.
- What problems you have.
- Stress in your life.

Mindful walking is when you just think about the steps you are taking.

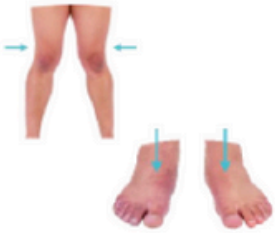
You do not think about other things.

Why I should do Mindful Walking

Mindful walking can help you:

- Reduce stress.
- Concentrate.
- Regulate your emotions.

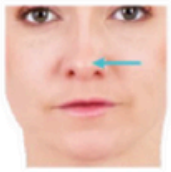
How to do Mindful Walking



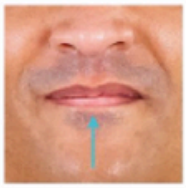
1. As you walk think about how your body is feeling. Think about the feelings you feel in your:
    - Legs.
    - Feet.
    - Arms.

2. Think about how your body moves as you take a step.

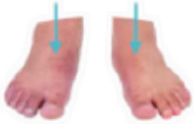
3. If you start to think about something else, stop and think about your next step again.



4. Use your nose and smell what is around you.



5. Use your mouth and see if there is anything you can taste around you.



6. Think about your feet touching the ground and how it feels.

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4. Online Mindfulness

You can use an app or website to practice Mindfulness.

How long	How often	Difficulty

Depends on the activity you choose.

This activity can have a positive impact on:

- Wellbeing.
- Resilience.
- Mood.
- Anxiety.
- Stress.

What is Online Mindfulness?

There are different mindfulness activities you can find on:

- Websites.
- Mobile apps.

It is important to find one that works on the device that you want to use.

Why I should do Online Mindfulness

Online mindfulness can help you find ways to practice:

- Meditation.
- Deep breathing.

How to do Online Mindfulness

1. Go on the internet or app store.

2. Type in the word mindfulness.

3. Different videos, instructions will show up.

4. Click on 1 to try.

5. Try it!

Keep going if you like it.

If you do not like it, try a something else.

Here are some free apps you can try:

- Smiling Mind.
- Insight Timer.
- Headspace.

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5. Mindful Eating

How does it feel when you eat?

How long	How often	Difficulty
10 minutes	1x a day	Easy

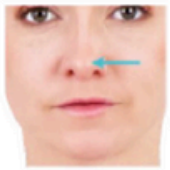
This activity can have a positive impact on:

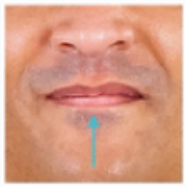
- Wellbeing.
- Resilience.
- Mood.
- Anxiety.
- Stress.

What is Mindful Eating?

Sometimes when you eat you think about:

- What you are doing today.
- What makes you sad and angry.





Mindful eating is when you think about what you are eating.

- How the food smells.
- How the food feels in your mouth.
- How the food tastes.

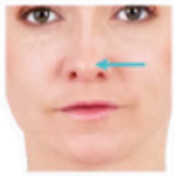
Why I should do Mindful Eating

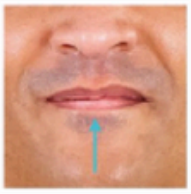
Mindful eating can help you to think about the yummy food you eat.

How to do Mindful Eating

1. Eat your food slowly.

2. Are you still feeling hungry or are you full?





3. Think about the food.
    - How does it smell.
    - How does it taste.
    - How does it feel.

4. Do not do anything else when eating.

    Do not look at your phone or the TV.

5. Did you cook your food or need to get it ready to eat?

You do not have to do this with every meal.

Start with 1 day and see how you go.

6. Yoga

Connecting the breath, mind and body.

How long	How often	Difficulty
15 minutes	1 a day	Easy

This activity can have a positive impact on:

- Wellbeing.
- Resilience.
- Health.
- Mood.
- Anxiety.
- Stress.

What is Yoga?

Yoga helps you think about:

- Your breathing.
- How your body feels.

Why you should do Yoga

Yoga can help your body in different ways:

- Stronger heart.
- Stronger muscles.
- Stronger spine.
- Staying healthy.
- Blood flow.
- Relaxation.
- Sleep.
- Reduce stress.

How to do Yoga

You can join a Yoga Studio.

Search for Yoga Studio's online.

You can ask for help to do this.

You can also do yoga at home.

Search for home yoga exercise online.

You can find some beginner Yoga exercises at:

www.yogidia.com

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7. Mindful Attention

5 – 4 – 3 – 2 – 1

Focus on what is happening around you.

How long	How often	Difficulty
5 minutes	1x a day	Easy

This activity can have a positive impact on:

- Wellbeing.
- Resilience.
- Mood.
- Anxiety.
- Stress.

What is Mindful Attention?

Mindful attention is knowing what is happening around you.

Why I should do Mindful Attention

Mindful attention can help when you feel:

- Stressed.
- Anxious.
- Overwhelmed.

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How to do Mindful Attention

Think about where you are right now.

5 

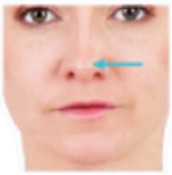
Find 5 things you can see.

4 

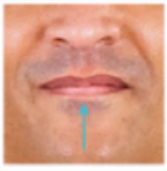
Find 4 things you can hear.

3 

Find 3 things you can feel.

2 

Find 2 things you can smell.

1 

Find 1 thing you can taste.

Take a deep breath in between each activity.

8. Being Grateful

Think about what you are grateful for.

Think about the good things in your life.

How long	How often	Difficulty
15 minutes	1x a day	Easy

This activity can have a positive impact on:

- Wellbeing.

What is being grateful?

Being grateful is thinking about all of the good things in your life.

This could be things like:

- Family.
- Friends.
- Holidays.
- Pets.

It is thinking about things that go right and well for you.

It is not thinking about what has gone wrong.

Why you should think about being grateful

Being grateful helps you to feel:

- Positive.
- Happy.

It can help you to focus on something good when things are hard for you.

How to think about being grateful

1. Think about yesterday.

2. Think of 3 things you are grateful for.

3. Why did these things go well for you?

4. Who helped these to go well?

9. 3 Funny Things

Thinking about the good and funny things that have happened.

Life is better when you are laughing.

How long	How often	Difficulty
10 minutes	1x a day	Easy

This activity can have a positive impact on:

- Wellbeing.
- Mood.

What is 3 Funny Things?

Sometimes life can be hard.

This activity asks you to think about good and funny things that have happened.

Why should I think of 3 Funny Things

It can help you forget sad and hard things.

It can make you feel happy.

How to think about 3 Funny Things

1. Write down 3 funny things that happened today.

2. How did they make you feel?

3. Why were they funny?

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10. Re-thinking Thinking Traps

Stopping yourself from using **thinking traps**.

Thinking traps are negative ways of thinking.

How long	How often	Difficulty
20 minutes	3x a week	Medium

This activity can have a positive impact on:

- Wellbeing.
- Mood.
- Anxiety.

What is a Re-thinking Thinking Traps?

Sometimes we might think about things in a negative way.

That is thinking something bad will always happen.

Sometimes our brain will make us think what happens is worse than what really happened.

This is called a thinking trap.

Why I should use re-thinking Thinking Traps

Changing how you think can change it from a bad to good thought.

This can help with how you are feeling.

It can help your anxiety.

How to Re-Think Thinking Traps

1. Think of something that happened recently where you did not leave feeling good.

2. Stop thinking.

3. Think about what happened again.

4. Try to think about the real events that happened.

   Do not think about how what happened made you feel.

5. How else could you have thought about the event?

Example of Re-thinking Thinking Traps

My partner did not come to an event with me. This means my partner does not care about me.

Think of other reasons why your partner could not come.

For example, they were busy or sick.

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11. Expressive Writing

Write thing down when you have had a hard time.

How long	How often	Difficulty
20 minutes	1x a day	Medium

This activity can have a positive impact on:

- Mood.
- Anxiety.
- Stress.

What is Expressive Writing?

Everyone has things happen that are hard.

Expressive writing is writing what you are thinking down.

You can write about how you were feeling.

Why you should do Expressive Writing

When something is hard you may not want to talk about how you feel.

You can write down all of your feelings.

This can help you to

- Work through your feelings.
- Not feel as worried or stressed.

How to do Expressive Writing

1. Think about a hard time in your life.

2. Write down how you feel about this hard time.

3. Write down the thoughts you had in this hard time.

4. Write down how this hard time has made life for you now.

When you are doing Expressive Writing, remember:

- You can write anything you want.

- Do not worry about spelling.

- Focus on times that you can work through on your own.

- Get professional help with really hard times.

- It is OK if you are not ready to write about the hard time.
  Choose a different time in your life.

- You do not need to show anyone what you have written if you do not want to.

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12. Self-Compassion

Looking after yourself when you are having a hard time.

How long	How often	Difficulty
20 minutes	1x a week	Medium

This activity can have a positive impact on:

- Resilience
- Mood.
- Anxiety.
- Stress.

What is Self-Compassion?

Self-compassion is being kind and helping yourself during a hard time.

You might try to help other people when they are having a hard time.

But when you are going through a hard time, you might not give yourself the same amount of help.

Why you should use Self-Compassion

Self- compassion can help you to feel better.

It helps you to not judge yourself.

How to do Self-Compassion

1. Think about a friend who had a hard time.

2. What would you say to help your friend?

3. How would you feel if this was you?

4. Think about what you would say to yourself if you were in the hard time.

5. Could you help yourself the same as you would help a friend?

13. Acceptance of Your Experience

Thinking about the feelings you had during an event.

How long	How often	Difficulty
20 minutes	1x a day	Medium

This activity can have a positive impact on:

- Wellbeing.
- Resilience
- Mood.
- Anxiety.
- Stress.

What is Acceptance of your Experience?

You will feel lots of different emotions in your life.

It is important to let yourself feel the emotions you have.

Do not ignore the hard emotions.

Think about how the hard emotions make you feel.

Why I should do Acceptance of your Experience

Accepting your experience can help you deal with emotions such as:

- Anger.
- Sadness.
- Anxiety.
- Frustration.

How to do Acceptance of Your Experience

1. Think of an emotion you feel that can be hard.

2. How does it make your body feel?

3. It is ok to feel this emotion.

   This emotion will only last for a short time.

4. After feeling that way, how does your body and mind feel?

5. Your body is going to feel different emotions every day.

6. Why do you think you felt this emotion?

7. Did something happen that made you feel this emotion?

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14. Getting in Touch with your Values

Think about what is important to you in your life.

How long	How often	Difficulty
20 minutes	1x a week	Medium

This activity can have a positive impact on:

- Wellbeing.
- Resilience.

What are values?

Values are things that are important to you.

It is good to know what kind of values you want in your life.

Different types of values in life can include:

- Teamwork.
- Love.
- Kindness.
- Honesty.
- Forgiveness.
- Family.
- Friends.
- Creativity.
- Learning.
- Gratitude.
- Hope.
- Humour.

What are your values in life?

1. Think about a time that was very important in your life.

2. What happened at that time that made it important?
    - Your friends or family were there.
    - You won something.
    - You go a new job.
    - Something else important to you.

3. What are 3 important values in your life?

4. How can you add your values in your life every day?

Knowing our strengths can help us to think about what our values might be.

Go to www.viacharacter.org/ to find out your strengths.

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15. My Goals and Values

Thinking about your goals and what is important to you in your life.

How long	How often	Difficulty
15 minutes	1x a day	Medium

This activity can have a positive impact on:

- Wellbeing.
- Resilience.

What are your goals and values?

Setting a goal can help you get something you really want.

Values are things that are important to you.

You might have a life goal. This could be:

- To get a job.
- To be a good partner.
- To get fit and healthy.

If your goals and your values in life are similar it makes it easier to achieve them.

Why I should think about my goals and values

Thinking about your goals and values at the same time can help you choose personal goals you want to have.

Choosing a goal that connects to your values will help you reach your goal.

How to choose goals with your values

1. What are your top values?

2. What life goal do you want to achieve?

3. How can you use your top values to reach your goal?

4. How can you break down your big goal into smaller goals?

16. Thought Defusion

The way you think can make you feel different emotions.

How long	How often	Difficulty
15 minutes	1x a day	Hard

This activity can have a positive impact on:

- Wellbeing.
- Resilience.
- Mood.
- Anxiety.
- Stress.

What is Thought Defusion?

What you think can make you feel different emotions.

You might feel:

- Sad.
- Happy.
- Angry.

Thought defusion is knowing that what you think can be true or not true.

You do not have to agree or believe what you are thinking.

Listen to what you are thinking if it will help you.

Why I should use Thought Defusion

Thought defusion can help when you are feeling sad or upset.

It can help you try and solve a problem.

How to use Thought Defusion

1. Think of a time when you felt sad or upset in the past week.

2. Do you think you would feel this again another time? Think about how you could change how you think.

3. Write down what you were thinking when you were sad or upset.

4. Try to change how you talk about what you are thinking.

   Instead of saying, 'I am going to fail.'

   Try to say, 'I am having the thought I am going to fail.'

5. Think of a time when you could practice this.

17. Thank you letter

Writing a letter to someone to say thank you.

How long	How often	Difficulty
20 minutes	1 time	Medium

This activity can have a positive impact on:

- Wellbeing.

What is it?

Write a letter to someone you know to say thank you.

The letter can tell the person how they helped you feel happy.

What can I use it for?

It can help you:

- Make your relationships stronger with people.
- Feel happy and healthy.
- Focus on good things that happen in your life.
- Know that other people care for you.

How to write a thank you letter

1. Think about a person who you want to thank.

   Write their name down.

2. Write a letter to the person about:

   - How they helped you.
   - How their help made you feel.

3. Give the person the letter to say thank you.

18. Reflective and active listening

Reflective means to think back on things.

Active listening is when you give the person talking all your attention.

Reflective and active listening is listening to other people and thinking about the conversation.

How long	How often	Difficulty
5 minutes	4x a day	Medium

This activity can have a positive impact on:

- Wellbeing.
- Resilience.

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What is reflective and active listening?

Reflective and active listening is a good conversation.

It is about giving the person talking all your attention and thinking about what they are saying.

Learn how to be a good listener and how to talk to other people.

What can I use it for?

Reflective and active listening can help you to build relationships with other people.

It can help you improve:

- Your communication skills.
- Relationships.
- How you feel.

How to do Reflection and Active Listening

When someone is talking to you:

1. Listen to the other person.

2. Look interested in the other person.

3. Ask questions about what the other person is talking about.

4. Try not to talk too much about yourself.

5. Try this with someone you know.

When you are active listening, try to listen and not talk about a holiday that you have been on.

Example of reflective and active listening

Person 1: I went on a holiday on the weekend.

Person 2: That sounds fun. Where did you go?

Person 1: I went to Queensland with my family.

Person 2: What did you like most about Queensland?

Person 1: It was good to just relax with my family and go on some rides.

Person 2: That sounds really great, glad you got to have a rest and do something fun with your family.

19. Assert Yourself

Telling other people what you think.

How long	How often	Difficulty
15 minutes	2x a day	Medium

This activity can have a positive impact on:

- Wellbeing.
- Resilience.

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What is Assert Yourself?

Assertiveness is to tell other people what you think and how you feel in a nice way.

It can be used when needing to deal with tricky situations.

What can I use it for?

It can help to:

- Reduce conflict.
- Reduce anger.
- Tell others how you feel.
- Have positive conversations with others.

How to assert yourself

1. Practice the **broken record technique**.

   The broken record technique is when you keep saying the same thing if someone keeps asking you something.

   For example, when someone does not listen to you when you say 'no', you keep saying 'no' every time they ask.

2. Write down when you practiced this.

3. What was the situation?

4. How did you use the broken record technique?

5. What could you do different next time?

Example of how to assert yourself

Someone wants you to buy something, but you do not want to.

You can say 'No thank you I do not want to buy anything.'

The person keeps asking you.

You say again 'No thank you I do not want to buy anything.'

Stay calm and repeat the same thing each time.

20. Goal Setting

Working towards something you want.

How long	How often	Difficulty
15 minutes	1 time	Medium

This activity can have a positive impact on:

- Wellbeing.
- Resilience.
- Health.
- Mood.
- Anxiety.
- Stress.

What is Goal Setting?

Goal setting is working towards something that you want.

Think of something you really want that is a big goal.

Then think of small steps that you can do to reach your bigger goal.

What can I use it for?

You can use goal setting to:

- Try and do something you want to do.
- Help you feel good if you reach a goal.
- Help you make a plan to reach a goal.

How to set a goal?

1. Write down a goal you want to do in the next couple of weeks.

2. Why do you want to reach this goal?

3. Break down the goal into smaller steps.

4. Is there anything that might make the goal hard to do?

5. Write a **SMART** goal.

A SMART goal is:

- **Specific.**

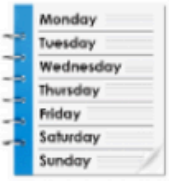
  Make the goal clear.

- **Measurable.**

  Think about how you will know if you have reached your goal.

- **Achievable.**

  Is your goal possible to do.



- **Realistic.**

  Is it a goal that will work for you in your life.

- **Timely.**

  When will you do the goal.

21. Meaningful Pictures

Think about pictures or photos that are important to you.

How long	How often	Difficulty
5 minutes	3x a day	Easy

This activity can have a positive impact on:

- Wellbeing.
- Resilience.

What is it?

Meaningful pictures is thinking about:

- Things that are important to you each day.
- Why those things are important in your life.

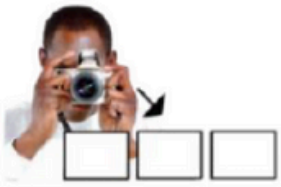
What can you use it for?

You can use meaningful pictures to:

- Think of things that are important in your life.

- Help you feel happier in life.

How to do this?



1. Take photos of 3 things that are important to you.

2. Write or draw why the photos are important to you.

3. Print out or post these photos online to look at them again.

   This can remind you why they are important things in your life.

Some ideas of things that could be important to you is:

- Your job.
- Your pets.
- Your friends.
- Your family.
- Going for walks.

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Write or draw about each photo.

What is photo 1 of?	Why is it important to you?

What is photo 2 of?	Why is it important to you?

What is photo 3 of?	Why is it important to you?

22. Finding Flow

Doing something you enjoy and not thinking about anything else.

How long	How often	Difficulty
10 minutes	1x a day	Easy

This activity can have a positive impact on:

- Wellbeing.
- Resilience.
- Mood.
- Anxiety.
- Stress.

What is Finding Flow?

Flow is when you are doing something you enjoy and forget about everything else.

What can I use it for?

When you find your flow it helps you to be focussed on something you like.

It can help you to forget about things that may be hard.

It can help you to feel happy.

How to Find Flow

1. Think of an activity that you love.

2. Make sure this activity is a bit hard for you.

3. Think of a time of the day that is quiet.

4. Remove anything that stop you from doing your activity. This could be your phone.

5. Begin your activity.

You might need to change your activity if what you chose does not get you into the flow.

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23. Problem Solving

Feel more in control of your life.

How long	How often	Difficulty
15 minutes	1 time	Medium

This activity can have a positive impact on:

- Wellbeing.
- Resilience.
- Health.
- Mood.
- Anxiety.
- Stress.

What is it?

Sometimes you will have problems.

It is good to know different ways to solve problems that you have.

What can you use it for?

Problem solving can be helpful all parts of your life.

It can help when you have:

- Negative feelings, like stressed or angry.
- Relationship problems.
- Problems at work.

Being able to problem solve is important.

It means you can do something to try and make things better.

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How to do it?

1. Think about a problem you have.

2. Think of some ways you could solve the problem.

3. What are some good and bad things about the way you could solve the problem.

4. Choose the best way to solve the problem.

5. Make a plan to solve the problem.

6. Check if the plan is working.
   If it is not working, change the plan.

24. My Character Strengths

Find your strengths and what you like about yourself.

How long	How often	Difficulty
15 minutes	Ongoing	Medium

This activity can have a positive impact on:

- Wellbeing.

What is it?

Your character strengths are the good things about you as a person.

Some character strengths are:

- Creativity.
- Honesty.
- Humour.
- Kindness.

- Leadership.
- Teamwork.

What can you use it for?

It is important to use your strengths every day.

This can help you to reach your goals and make you feel happy.

How to do it

1. Do the Signature Strengths test on www.viacharacter.org/

2. Choose 1 strength to use.

3. Think about different ways that you could use the strength you have chosen.

4. Think about how you could use the strength to reach a goal.

5. Write a SMART goal.

A SMART goal is:

- **Specific.**

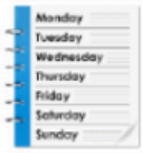
  Make the goal clear.

- **Measurable.**

  Think about how you will know if you have reached your goal.

- **Achievable.**

  Is your goal possible to do.



- **Realistic.**

  Is it a goal that will work for you in your life.

- **Timely.**

  When will you do the goal

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Notes:

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This resource was funded by the Australian Government Department of Social Services.

Go to www.dss.gov.au for more information. The development of the original Be Well Plan resources was supported by a grant by the James & Diana Ramsay Foundation.

This document has been made in an easy-to-read way by the South Australian Council on Intellectual Disability using images from Microsoft 365 and Photosymbols. Images cannot be used without permission. This document was tested by people with intellectual disability.

Appendix 16:
My Life Decisions

My
Life Decisions

A form for people who are unable to make a legal document but want to have their goals and wishes written down so that it can guide their future supported decision making.

1. This form is for people in South Australia who are unable to complete the legal **Advance Care Directive** and require support.
2. This document **does not** replace an **existing legally binding Advance Care Directive**, which should be completed by people who have legal capacity.
3. This document is intended **to replace** all other **advance care planning forms** in South Australia for people who require support to make decisions or who lack decision-making capacity, including the Palliative Care Plan, the Statement of Choices and specific aged care facility forms or plans.

This document has been developed by the Documenting My Life Decisions Committee in collaboration with the Office of the Public Advocate SA. It is based on the principles of the South Australian *Advance Care Directives Act 2013* and the United Nations Convention on the Rights of Persons with Disabilities 2006.

Further information:

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Introduction

Principles

This form provides a supportive framework to establish the goals of care which will guide future decision making for those people who require support and are unable to make their own decisions about their future health care, residential and accommodation arrangements and personal affairs near the end of their lives.

It incorporates principles from the following South Australian legislation:

Advance Care Directives Act 2013

Consent to Medical Treatment and Palliative Care Act 1995

Guardianship and Administration Act 1993

It also draws on the important guiding principles of the United Nations Convention on the Rights of Persons with Disabilities and in particular Article 12: Equal recognition before the Law. This includes the right to make decisions with support. This convention was ratified by the Australian Government in July 2013.

The SA *Advance Care Directives Act* at s 10(d) is consistent with the convention when it states:

> *A person must be allowed to make their own decisions about their health care, residential and accommodation arrangements and personal affairs to the extent that they are able, and be supported to enable them to make such decisions for as long as they can.*

This is known as the principle of supported decision making.

Planning documents in South Australia

Advance Care Directive. If a person is competent, they should complete a legally binding Advance Care Directive. Copies of the South Australian *Advanced Care Directive DIY Kit* are online at ww.advancecaredirectives.sa.gov.au or available at Services SA.

My Life Decisions. This document does not override an existing Advance Care Directive. This document is for people who require support to make decisions or who lack decision-making capacity

Resuscitation Plan – 7 Step Pathway. Medical practitioners developing a clinical care plan involving resuscitation and end-of-life care should take an Advance Care Directive or My Life Decisions Plan into account when completing a Resuscitation Plan – 7 Step Pathway. (If a Resuscitation Plan is later found to have been completed prior to this form, it is advisable to check if the instructions on the plan are consistent with those on this form.)

Definitions

1. **Consent to medical treatment**: This My Life Decisions Plan **does not give legal consent to medical treatment**. It provides guidance for future decision making. A medical professional can only provide medical treatment to a person if the person consents (if they have capacity to do so), they have previously given consent through an Advance Care Directive, a parent or guardian consents (if the person is a child), a substitute decision maker or person responsible consents, or if it is an emergency.

2. **Capacity:** The ***Advance Care Directives Act 2013*** **(SA) presumes** all adults have full legal capacity to make decisions about their health care, residential and accommodation arrangements and personal affairs. However, a person has impaired decision-making capacity in relation to a decision if they are not capable of:

    a) understanding information that may be relevant to the decision (including the consequences of making the decision)
    b) retaining this information
    c) using this information in the course of making the decision, and
    d) communicating his/her decisions in any manner (*ACD Act* s 7).

People are presumed to have decision-making capacity unless there is clear evidence that they don't. They can still have decision-making capacity if they do not understand some technical information, or if they do not retain information for long, or if they fluctuate between impaired and full capacity, or even if they make decisions that others may believe are not in their own best interests (*ACD Act* s 7(2)).

3. **A substitute decision maker** is a person who has been legally appointed as a substitute decision maker in an Advance Care Directive or under a previous legal document (*ACD Act* s 21).

4. **A person responsible** is:
    a) a guardian (if one has been legally appointed)
    b) if there is no guardian, then a spouse, domestic partner or adult relative who continues to have a close and continuing relationship with the person (including someone related by adoption or by Aboriginal or Torres Strait Islander kinship rules)
    c) if no guardian, spouse, domestic partner or relative is available, an adult friend who has a close and continuing relationship with the person
    d) if none of the above are available, an adult who oversees the day-to-day supervision, care and wellbeing of the person (*Consent to Medical Treatment and Palliative Care Act* s 14(1)).

    The concept of 'person responsible' replaces the concept of 'next of kin'.

How to use this form

Who should be involved?

It is important to have a meeting to discuss the wishes and goals of care for the person concerned which are then documented on this form. The meeting should include the person concerned if he/she can understand the conversation and express their own wishes (with support if necessary), those close to the person and also those responsible for the ongoing care of the person. These people may include the responsible doctor, the **substitute decision maker** (if one has been appointed), the person's family or carers (**person responsible** – see definition) and (if the person is a resident of an aged care facility) a nursing professional.

The **My Life Decisions** form should be completed as soon as possible after the meeting and signed by:

1) the person concerned if possible;
2) the **substitute decision maker** or **person responsible**; and
3) the **health professional** involved in the ongoing care of the person such as a doctor or nursing professional.

Role of health professionals

All health professionals assisting clients in completing this **My Life Decisions** form should:

a) have some training in how to introduce the conversation with the client, the person responsible and those who care for and support the person. It is important to understand the concept of supported decision making, that is, 'stepping into the person's shoes' or 'being the person', when the client does not have capacity or is non-verbal.
b) be familiar with the prompts provided in the *Advance Care Directive DIY Kit* (part 3: ***What is important to me – my values and wishes***)
c) arrange a suitable time to meet and notify the relevant people who will be involved in the meeting.
d) take notes on a separate sheet of paper, in order to complete the plan so that it will capture the person's wishes clearly and be legible.
e) tick each decision box according to the supported decision-making framework (below)
f) once the plan is completed, make sure all the relevant people sign the document.

Does the person have a doctor who is available and willing to complete a *Resuscitation Plan – 7 Step Pathway?* If **'Yes'**, a Resuscitation Plan – 7 Step Pathway should be completed by the person's doctor and informed by the person's wishes expressed in this My Life Decisions Plan.

Points to remember

This My Life Decisions Plan should:

a) reflect the wishes of the person so far as they are known
b) reflect the decisions they would have made in these circumstances if they were able to fully express their own wishes (stepping into the person's shoes)
c) protect the person's interests as they would currently understand them
d) avoid restricting the basic rights and freedoms of the person, as far as possible.

Types of decisions in a supported decision-making framework

To assist future decision making based on this document, it will be helpful if each category of decision is marked as one of the following.

Self-determined decisions (green) reflect the expressed wishes of the person with minimal intervention from supporters (substitute decision makers or persons responsible).

Collaborative decisions (amber) involve collaboration and negotiation between the person and their supporters.

Substitute decisions (red) are made by the person's supporters on behalf of the person.

A Plan for 'My Life Decisions' – Including End of Life

Date this form was completed:

Name of person: .....

Date of birth: .....

Address: .....

1) Making an Advance Care Directive

Is the person competent to complete an Advance Care Directive?

If '**Yes**' he or she should complete an Advance Care Directive.

If ' **No**' proceed with completion of this form.

2) Values and wishes

2.1 What I want:

_____

_____

_____

_____

Type of decision made:
☐ Self-determined ☐ Collaborative ☐ Substitute

2.2 What I don't want:

_____

_____

_____

_____

Type of decision made:
☐ Self-determined ☐ Collaborative ☐ Substitute

2.3 Health care I want:

_____

_____

_____

_____

Type of decision made:
☐ Self-determined ☐ Collaborative ☐ Substitute

2.4 Where I want to live and what care I want:

_____

_____

_____

_____

Type of decision made:
☐ Self-determined ☐ Collaborative ☐ Substitute

2.5 Other personal arrangements:

_____

_____

_____

_____

Type of decision made:
☐ Self-determined ☐ Collaborative ☐ Substitute

2.6 My dying wishes:

_____

_____

_____

_____

Type of decision made:
☐ Self-determined ☐ Collaborative ☐ Substitute

3) [ ] Mark this box if it is agreed that the person would NOT WANT TRANSFER TO HOSPITAL if palliative care measures can be provided that are adequate to maintain their comfort and dignity in their place of residence (which may be a residential care facility).

Type of decision made:
☐ Self-determined ☐ Collaborative ☐ Substitute

A Plan for 'My Life Decisions' – Including End of Life

4) These are the people who agreed that the goals of care recorded in this 'My life Decisions' form are what .....would have wanted (insert resident's name).

List names:	Relationship to the person
_____	_____
_____	_____
_____	_____
_____	_____

5) Signed by

a) If the person is able to understand (with support if necessary) they may sign here:

Signature: _____ Date: / /

b) Person responsible or substitute decision maker

Name: _____ Relationship: _____

Signature: _____ Date: / /

c) Health or other professional*

Name: _____ Profession: _____

Signature: _____

**** such as doctor responsible, nursing professional or other responsible professional***