



PAVE THE WAY

vision to action through planning

A Document of Personal Information

A resource for people with disabilities and their families

Pave the Way

Level 1, 1428 Logan Road

MT GRAVATT QLD 4122

Ph: (07) 3291 5800

1300 554 402

Fax: (07) 3291 5877

Email: pavetheway@pavetheway.org.au

Website: www.pavetheway.org.au



Ideas and
Strategies

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The National Disability Insurance Scheme and Participant Readiness.

The National Disability Insurance Scheme (NDIS) is a new Federal system to assist people with disability to engage more fully in social and economic life.

The Scheme will provide eligible participants with reasonable and necessary supports and change the way disability services are delivered to ensure participants have more choice and control over the supports they receive.

The NDIS is in its early stages and there are still many uncertainties about how the system will work. However, information coming from the NDIS trial sites in parts of Australia over the past year is that people with disabilities, their families and carers are able to make the most of the Scheme when they are clear about their vision for a good life. This clarity can assist you ahead of your meeting with the National Disability Insurance Agency (NDIA), the name given to the organisation responsible for delivering the NDIS.

This document explores how people with disability, their families or carers can develop a system for collecting, storing and sharing important personal information.

This information will assist you when planning with the NDIA and can also be used to inform important others, as well as when interacting with services you engage with.

Under the NDIS, participants will be encouraged to think about what will make a good life for them and look at the supports both formal and informal that will help achieve the desired future you are planning for. A particular focus of this document is on encouraging people to record important information about who you are: your gifts and strengths, hopes and dreams, rather than solely focussing on information related to your disability/ diagnosis.

Introduction

Pave the Way works with individuals, families and their relatives with a disability to develop and safeguard their vision and to encourage planning for a good life now and in the future.

An important safeguard for the future is ensuring there are people who are involved in your life. Through this involvement, other people will gain a richer understanding of you and be better able to support you in your decisions and planning for now and the future.

A useful tool that can be used to increase this understanding is for you to develop a document of detailed personal information.

The ideas presented here are a guide only. It is important to include information which is relevant to you and captures the essence of who you are to ensure the document is as personalised as possible.



Section One

The Why and How of Gathering Information

A document of personal information will serve a number of different purposes. It can be used in a very practical way to save you time and effort, but it also has the potential to greatly deepen others' understanding of you, both on a personal and practical level.

Benefits of such a resource

1. So the information you hold **exists outside your head**.
2. To **deepen others' understanding** of you and to act as an aid for important people in your life to get to know you more quickly.
3. To **share your vision** for you now and into the future with others. This will evolve and change over time.
4. To present a **positive picture** of who you are. It can also be a useful way to introduce you to others - new friends, support workers, circle members.
5. Developing a system of gathering information is one way of **involving others** through them contributing to the development of the resource.
6. To assist with **record keeping**. This saves time and emotional energy, and reduces the need for the repetition of information. (Although time and energy will be required to ensure that what is written is kept updated).
7. To provide up-to-date, factual **emergency information** that can be readily accessed when needed.
8. To assist with **developing consistency between the different support agencies** you are involved with.

To put important information in writing for **paid support people** and professionals including the NDIA

9. To use as a **journal of decision making** to reflect why certain decisions have been made.
10. To use as the basis for writing a **memorandum of wishes** of how your family want trustees to use trust funds in a way that reflects yours and their vision for your life. Although a memorandum of wishes is not legally binding it can be morally persuasive.

What will it look like?

. It is important when compiling a document of personal information, to consider what system to use and how the formatting and presentation can best enable you to find information easily and quickly. Everyone's document will look different but the following suggestions may help when you are thinking about the organisation of the information.

Some ideas for the format:

- A series of A4 pages in plastic sleeves in a loose-leaf folder
- Card system
- Computer file
- Story book
- DVD presentation
- Online version i.e. Blog, website, TYZE
- Social media e.g, Facebook, Google+
- A combination of these

Some ideas for organising the information:

- Start with a **positive introduction** of yourself – first impressions count!
- Use an **index or tabs** to enable you to find information easily.
- Write a **table of contents** at the beginning if using a written document.
- Organise it so that certain sections can easily be **replicated, taken out or additional information** can be added. *(Remember that this will be a constantly changing document).*
- Consider making copies of the lift out **emergency information** and make sure that people know how to access this information quickly.
- **Personalise** the document by adding photos, drawings, stories etc. This will help to give a clearer sense of the essence of who you are and introduces you in a positive light *(You may like to include photos of yourself involved in a wide range of activities with different people).*
- Write in **first person** which will make the document more powerful.

Some ideas for storage:

- Hardcopies
- Computer file
- USB stick
- Hardcopies
- Online cloud systems e.g. Dropbox



Sharing Information

- *Public versus private*

- *Let people know where it is stored*
- *Consider giving a copy to your solicitor*
- Think about how the content in each section might have a **different emphasis** dependent on the intended recipient. For example, the language used for writing for a friend may be different from that intended for a doctor.
- Keep **copies** of some sections in different areas of the house, as a useful guide to support workers.

Strategies for developing this resource

Developing this document will be an on-going and ever-evolving project. In the first instance, it will require a big commitment of time and effort but over time, it will prove to be an invaluable resource.

- Write about your dreams, passions, interests etc.
- Have others (e.g. family members, friends, teachers, support workers) write appropriate sections on your behalf if this is helpful or appropriate.
- If you have a support circle, each member could take one section and talk with you and your family to document some aspects of your life. This would have a two-fold benefit as it would share the workload and also give the circle members another opportunity to get to know you better.
- If the prospect of doing all the writing yourself is daunting, you might like to find someone else to do the writing while you talk.
- Include an open explanation of how the document was developed. Make it clear who has written or contributed to the various sections of the document.
- Try a workshop style of starting – get together with others to share ideas for compilation.
- Do it in chunks rather than trying to tackle it all at once (write the factual/emergency information first or start with photos and stories).
- Back up the information!! (*Hard copy, digital copy, USB, CD, email it to others*).
- It is important for the information to be kept up to date – you will need to think about how best to do this on an ongoing basis.
- Make sure others know where the information is kept.



Section Two

The Heart of the Information: Deepening Understanding

Although factual information may be a good starting point, it doesn't actually tell people who you really are. e.g. your personality, emotions, likes/dislikes, passions, skills, hobbies, leisure activities, friends and social interactions.

Photos, drawings and personal stories can make this section come alive!



To help others understand you better and more quickly, you can use this written information as a starting point rather than having to begin such a conversation from scratch. (You could give people your binder and ask them to read certain sections, which you could then follow up with further conversations).

Introducing me

You could open the document with a personalised introductory statement.

My name is Emma. I am 25 years old and live at home with my family. I love music and especially love going to concerts. I enjoy going to church with my family every week and I am a member of the youth group. I am usually happy, have a great sense of fun and have a great capacity for friendship. I love my family but I find my brothers, Jason and Ben, a bit annoying at times and would eventually like to live in a place of my own. I have some cousins around my own age who I also enjoy spending time with.

Here is some more information about me that I think you will find interesting.

Some important things you need to know about me

These headings can be used as a guide. They are not listed in any order of importance. Each person's document will be different.

- My likes and dislikes (be specific about activities, food, music, outings, sports etc)
- My hopes and dreams
- My skills and abilities
- Things that make me feel anxious

Sharing the vision

It is important to clearly set out the vision you have to lead a rich and meaningful life. This vision will be a description of your desired future for yourself.

Ask yourself "What are the ingredients for a good life?"

Some things we all want in our lives:

- A safe and secure home
- Loving and meaningful relationships
- The ability to make a contribution
- The ability to make our own life choices
- Financial security
- Good health.

You will need to consider what the future will look like when your main support people such as your parents are no longer able to assist you the way they do now.

Some questions to consider:

- Where will I live?
- How will I spend my days?
- What kind of work will I do?
- How will I manage my money?
- Who will assist me to buy food/clothing etc.?
- Who will help me plan holidays and celebrations?
- Who will assist me to hire paid support workers?
- Who will assist me to take care of my health and manage any medications?

(See the suggested headings in the Template for more ideas)

You may also want to include the things that you definitely DO NOT want to happen in your life e.g.

- You may not want to spend your days only in services or segregated settings
- You may want to make it clear the type of situation you do not want to be living in such as an institution or group home.
- There may be people (or agencies) you or your family do not want involved in supporting you to make decisions.

Important people in my life

Include a list of names, addresses, phone numbers and their relationship to you. You may wish to include this in the emergency section too or have this as a separate section, like an address book.

- Next of kin
- Support circle members
- Friends
- Neighbours

Recording how you maintain these relationships is equally important, for instance, how you celebrate birthdays with others, the important traditions and rituals you share and regular dates you have with others.

(See the suggested headings in the Template for more ideas)

Section 3: The Practical Day to Day Information

People lead increasingly busy and complex lives. When you have a disability, life can become even more complex and time seems to be an ever diminishing resource. You are required to fill in multiple forms which often require similar information e.g. Medicare number, Pension number, Private Health Fund information. This paperwork can become quite overwhelming at times so it is very useful to have the information in one place rather than having to search through wallets and files each time.

Also, you are asked over and over to repeat the history of your disability to the numerous people who come into your lives – e.g. doctors, teachers, therapists and support staff. If all of this information is organised and documented, it makes the transfer of information much easier and less time consuming.

Personal information

The following is some of the information to consider including:

- Date of birth
- Medicare number
- Bank details
- Pension number

(See the suggested headings in the Template for more ideas)

Disability and related medical information

It can be quite emotionally draining for you to have to continually explain to people, including health care professionals, the details of your disability and how this impacts upon you. If all this information is well documented, it can be handed to the doctor/occupational therapist/physiotherapist etc and then all you need to do is answer their questions.

Diagnostic information is also helpful in medical emergencies.

The following is some of the medical information to consider including:

- Disability/ Medical diagnosis/medical issues
- Contact details for current doctors/specialists/dentist/therapists/ pharmacist
- Current medications/ dosage/ strength/ where kept/ when and how to be administered
- Medication supply/ pharmacy
- Vaccinations
- Health precautions/health alerts.



(See the suggested headings in the Template for more ideas)

Personal care information:

Diet
Toileting
Safety
Personal Hygiene
Sleeping
Mobility
Daily Health care/ Medications

Communication

It is important for others to understand how you communicate your needs, particularly if you do not use standard speech. People also need to know how to interpret your communication and to know of any ways that communication can be fostered.

Possible information to include:

- What is my preferred method of communication?
- How do I indicate how I am feeling?
- How do I receive communication?
- What is my literacy/reading ability?
- What is the level of my telephone skills?
- What do changes in my behaviour indicate?
- How do I communicate if I am under stress?
- Are there any devices/ aids I use to assist me to communicate?



(See the suggested headings in the Template for more ideas)

Daily routine

Think about what a typical week looks like for you. Of course, there may be no such thing as a typical week but there may be some routines on certain days. Set out the weekly routine, giving specific details about what typically happens each day both within and outside the home and details of who is involved in these activities (This may need to be continually updated).

Contacts for daily routine

Often a person with a disability has contacts with many different places and professionals. It is very useful to have readily accessible information in one place rather than searching for information. The contact details for support workers could also be included in this section.

Financial and legal arrangements

Include details of wills, executor, trusts (estate planning), trustees, power of attorney, health directive and guardianship arrangements. (Make sure the trustees are informed). Include details of who is taking responsibility for your financial affairs.

Personal Income and Information about Funding Support

Personal income and budget considerations

- What is my regular income (pension, wage, trust)?
- What is my daily/ weekly/ fortnightly/ monthly / yearly budget?
- What percentage of my personal income will you save?
- Can I manage my own finances?
- What assistance do I need with this?
- Who provides this assistance?
- How do I pay for my regular bills and living expenses?
- What safeguards have been put in place around my finances?

Funding sources and accountability

- This can at times be quite complex and the contact people in departments change frequently. This information will need to be regularly kept up to date.
- It would be useful to outline what funding is currently being received, from what sources and how it is being used.
- Additional to supports already in place, what funded supports do I need through the NDIS?
- How will I receive these funded supports? (directly through the NDIA, through an approved provider, or through a self-managed arrangement?)
- Do I have capacity to self-manage my supports/funding or can a family member/ supporter assist me with this?
- What are the accountability requirements for this funding?

Emergency plan

- This information needs to be easily found.
- It may need to include some of the information that was also included in the personal details section.
- You would need to distribute this information to people who you would need to rely on in an emergency.
- It would be beneficial to set out a step by step plan.
 - Who needs to be contacted and contact details?
 - Where to find essential information such as medical records, medication, daily schedule, wills etc.
 - Details of who would provide accommodation support.
 - Details of who would provide financial support.
 - Details of who would make health care decisions.

Expectations of support workers

Sometimes it is difficult to verbally outline all of your expectations of support workers who come into your home or who support you in the community. Expectations can change depending on your individual needs, the dynamics of the team supporting you and the skills of particular workers. A document outlining what is expected can be a useful tool to help workers support you in the way you want. It can make this communication easier but it is important to be very specific about what you expect. You would also need to include practical information such as where they can find things in the house, safety issues etc.

Much of this information could be copied from other sections of your document.

(See the suggested headings in the Template for more ideas)

Template of suggested headings

This template is a suggested outline to assist with gathering important information based on the ideas presented in this document. This is a guide only; you might choose to use some, none or all of the template. It is important to include information that is relevant to you and make it as personalised as possible.

If you would like a digital version of this template please contact Pave the Way at pavetheway@pavetheway.org.au

Deepening Understanding

Introducing me.

A brief personalised introduction to me:

Some important things you need to know about me

My likes
My dislikes
My gifts, skills and abilities
My interests
Other

Valued roles

Family
Work
Study
Volunteer
Club membership
Other

Some more important things to know about me

Things that make me feel safe/calm
Things that make me feel valued
Things that make me anxious
My spirituality
Other

Note to family members and others supporting people to document information: Remember to use first person language when documenting people's personal information.

Vision Statement

My vision for the future:

What I don't want for the future:

Important people in my life

My family

My friends

Support circle members

My community connections

How I maintain these relationships?

Traditions

Celebrations

Dinner dates

Contact details for important people in my life

RELATIONSHIP	NAME	PHONE NUMBERS	ADDRESS	EMAIL ADDRESS
family				
friends				
neighbours				
support circle members				
support workers				

Personal Information

Name

Date of Birth

Address

Telephone Numbers

Email Address

Citizenship

Blood Type

Current Height

Current Weight

Eye Colour

Hair Colour

Documents and card numbers

Birth Certificate

Medicare Number

Disability Pension Number

Tax File Number

Health Care Card number

18 Plus Card

Passport Number

Private Health Cover

Disability and related medical information

Disability/ medical diagnosis

Other medical issues

Allergies

Contact details for:

- GP
- Specialists
- Dentist
- Therapists
- Pharmacist

Current medications

Date started	Brand name/Generic name	Dosage	Times	Purpose	What it looks like	How to administer	Where it is stored
					e.g. small yellow tablet		e.g. fridge, cupboard

Medical history/ medical records

Vaccinations

Hospitalisations

Past doctors

Medications used in the past

Preferred hospital

Health precautions/health alerts

Any medications that MUST NOT be taken

Reactions to medications

Personal care information

Diet

- Likes
- Dislikes
- Food allergies
- Specific dietary requirements

Eating

- Meal times
- Assistance needed
- Special equipment needed
- Special instructions

Drinking

- Assistance needed
- Special equipment

Safety

- At home
- In the community
 - Road sense
 - Awareness of danger/ personal safety

Personal Hygiene (Assistance needed with):

- Bathing
- Teeth cleaning
- Toileting
- Dressing

Sleeping

- Waking time
- Bed time
- Routines
- Specific requirements (positioning, turning, CPAP)

Mobility

- Support needed – transfers /Equipment needed
- Transport arrangements

Daily Health care

- Medication
- Therapy
- Diet
- Exercise and wellbeing

Communication/Behaviour

Preferred method of communication

How I indicate how I am feeling

How I receive communication

My literacy ability

- Reading
- Writing
- Numeracy
- Money
- Telling time

My telephone skills

What the changes in my behaviour indicate

How I communicate if I am under stress

Daily routine

Time	Support used	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morning								
Afternoon								
Evening								

Contacts for daily routine

NAME/ORGANISATION	ACTIVITY	ADDRESS	EMAIL ADDRESS	PHONE NUMBERS

Financial and legal arrangements

Name and address of solicitor
Location of current will
Details of person taking responsibility for financial affairs
Executor/s
Trust arrangements
Trustee
Name and address of power of attorney and its location
Health directive and location
Guardianship arrangements

Income and funding

Funding body and type of funding	Amount	How used	Contact person	Contact details

Budget/financial considerations

My banking details
This is how I manage my finances
Assistance I need with this
Those who provide this assistance
The safeguards I have in place around my finances

Emergency Plan

In case of an emergency please carry out the following instructions:

--

Who needs to be contacted?

RELATIONSHIP	NAME	PHONE NUMBERS	ADDRESS

Is there anyone who SHOULD NOT be contacted?

Where can the following information be found?

- Medical records
- Medication
- Wills
- Power of Attorney
- Daily Schedule

Details of who will provide:

- Accommodation support
- Financial support
- Health care support

Supporting documents for the National Disability Insurance Scheme.

How do I become a participant of the National Disability Insurance Scheme (NDIS)?

To become a participant in the NDIS you will be required by the National Disability Insurance Agency to provide some specific information to check your eligibility. These include:

Completing the Access Request Form

http://www.ndis.gov.au/sites/default/files/documents/completing_access_request_form.pdf

Evidence of your Disability

<http://www.ndis.gov.au/community/information-health-professionals>.

Documents to verify your age and residency

<http://www.ndis.gov.au/funnelback/search?query=documents%20to%20verify%20your%20age%20and%20residency>

Participant Statement

Adult

http://www.ndis.gov.au/sites/default/files/documents/participant_statement_adult.pdf

Child

http://www.ndis.gov.au/sites/default/files/documents/template_participant_statement_child.pdf

More information about the NDIS can be found at <http://www.ndis.gov.au/>

Bibliography

Klees . J (2002, 2005). "*All About.....*" *A guide to develop respectful, comprehensive personal information*. Toronto, Ontario: Resources Supporting Family and Community Legacies Inc.

Etmanski. A (2004). *A Good Life*. Vancouver: Orwell Cove.

Resources you may like to use to help to compile your document:

Klees . J (2002, 2005) *All About....* Toronto, Ontario: Resources Supporting Family and Community Legacies Inc.

This is a comprehensive guide to develop respectful, comprehensive personal information which is continually being revised and edited. For permission to use this resource and to receive an electronic template with the document, contact the author, Janet Klees at janet@legacies.ca

A colourful series of templates entitled, "What I'd Like You to Know About Me" (2009).

www.livesforliving.com.au; www.aboutme.org.au

Freely downloadable templates in Microsoft PowerPoint with particular reference to communication

<http://www.communicationpassports.org.uk/Creating-Passports/Templates/>