



Pave the Way

A Document of Personal Information: Ideas and Strategies

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Introduction

Pave the Way works with 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.

One strategy that many families have found helpful is to involve other people in their lives and in the lives of their family members with a disability. Through this involvement, other people will gain a richer understanding of the family who in turn, will gain support in their decisions and planning for a better life for their family member.

A useful tool that can be used to increase this understanding is for families to develop a document of detailed personal information about their family member with a disability. In some families, the person themselves, will be able to speak through the document with their own voice, whereas other families may have to write on behalf of their family member.

The ideas presented here are a guide only. It is important to include information relevant to each individual and to make your document as personalised as possible. Whichever way the document is compiled, it is essential that the true essence of the person with disability is captured.

Jason and Claire are very private people without a family network around them. They recently moved to Queensland and English is not their first language. They would very much like to become more involved in their local community and have the opportunity for others to get to know their daughter better. However, because of some language difficulties and because they are quite shy people, they find it difficult to open up to others and have not met many people since their move. To ask other people to become involved in their lives and help them in their decision making around their young daughter with a disability is a rather daunting prospect. However they do feel that they could introduce their daughter to others through the use of written information and photos. Compiling a document of personal information would be a good first step in involving others in their lives.

Benefits

This resource will serve a number of different purposes. It can be used in a very practical way to save your family time and effort but it also has the potential to greatly enrich the life of your family member with a disability.

1. It can **deepen others' understanding** of your family member and can act as an aid for important people in their lives to get to know about them more quickly.
2. It can be a way of **sharing your vision** for your family member with others.
3. It can present a **positive picture** of your family member and can be a useful way to introduce them to others - new friends, support workers, circle members.

"You control the information that is entered into the pages and therefore you can have either a positive or negative impact on how others see your child!" (Janet Klees)

4. It can 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.)
5. It provides up-to-date factual **emergency information** that can be readily found when needed.
6. It can assist with **developing consistency between agencies** if your family member is involved with a number of different support agencies. (You do need to allow for people to be seen differently in different circumstances and it is important to be careful about who needs to know what.)
7. It puts important **information in writing for paid support people** which can assist them to get to know more about your family member. (Of course it is important to insist that paid support people take the time to read these documents.)
8. It is a useful tool to impart **written information to professionals** – e.g. health practitioners, therapists, teachers, hospital staff.
9. It can be used as a **journal of decision making** and could reflect why certain decisions have been made, especially in the situation where parents/family members are constantly making decisions on behalf of their family member.

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.

- If possible, talk to your family member. (Get them to tell you about their dreams, passions, interests etc.)
- Have others (e.g. family members, friends, teachers, support workers) write about your family member. (What they do well; what they like about them.)
- If you have a support circle, each member could take one section and talk with your family member to document some aspects of their 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 your family member better. If this is not possible, they could write about your family member from their perspective.
- 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 other families 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.



What will it look like?

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

Some ideas for the format:

- Series of A4 pages in plastic sleeves in a loose-leaf folder.
- Card system.
- Computer file.
- DVD presentation.
- A combination of these

Some ideas for organising the information:

- Start with a positive introduction to the person – first impressions count!
- Use an index or tabs to enable you to easily find information.
- Organise the document for the easy deletion and addition of information. *(Remember that this will be a constantly changing document.)*
- Write a table of contents at the beginning if using a written document.
- Repeat some sections under different headings if there is an overlap of information.
- Organise it so that certain sections can easily be taken out and/or copied, to give to relevant people such as support workers, health practitioners, therapists, teachers. *(You might not want to give all the information to everyone.)*
- 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. *(Keep in mind how best to do this discreetly, considering that this is a home, rather than someone else's workplace.)*
- Consider making copies of a lift out of emergency information and make sure that people know how to quickly access this information.
- Personalise the document by adding photos, drawings, stories etc. This will help to give a clearer sense of the essence of the person and introduce them in a positive light. *(You may like to include photos of your family member involved in a wide range of activities with different people.)*
- Write some sections in the first person which will make the document more powerful.



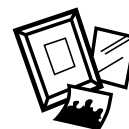
Be creative! Remember that this is a unique and intensely personal document.

Suggested sections/contents

Deepening Understanding

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

Photos, drawings and personal stories can make this section come alive! Writing this section in the first person from the viewpoint of your family member is also a good idea.



To help others understand your family member 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.)

You could open the document with a personalised introductory statement from your family member or, if this is not possible, you could write the statement on their behalf with whatever level of participation they are able to contribute.

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.

Information you could include to foster deeper understanding:

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

- What has happened in my life so far
- My hopes and dreams
- My personality/emotions
- My strengths and gifts
- My skills and abilities
- My likes and dislikes (be specific about activities, food, music, outings, sports etc)
- Things that make me feel anxious
- Things that make me feel safe/calm
- Things that make me feel valued
- About my family
- My connections in the community and how these can best be fostered
- My learning and educational history/needs/desires
- My spirituality
- How I contribute
- My relationships and how these can be maintained
- Important roles I like to carry out (e.g. being a brother, organising morning tea once a month)
- Important people in my life/ my social networks.

Include a list of names, addresses, phone numbers and their relationship to your family member. (You would also probably also include this in the emergency section or at least have an easy to find link to this information. You may even have this as a separate section, like an address book.)

- Next of kin
- Support circle members
- Friends/neighbours
- Support workers.

Sharing the Vision

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

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 you are no longer in the life of your family member with a disability.

Some questions to consider:

- Where do I want my family member to be living/where do they want to live?
- How will they spend their days?
- What kind of work will they do
- Who are the people who will be in their lives?
- Who are their friends likely to be?
- Who will manage their money
- Who will decide on support funding and planning?
- Who will assist them to buy food/clothing etc
- Who will help plan holidays and celebrations?
- Who will hire paid support workers?
- Who will look after their health care?

You may also want to include the things that you and your family member definitely DO NOT want to happen in their life.

e.g.

- Your family member may not want to spend their days only in services or segregated settings.
- You may want to make it clear the type of situation you do not want your family member to be living in such as an institution or group home.

Record Keeping/Emergency Information

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

Also, parents are asked over and over to repeat the history of their family member with a disability to the numerous people who come into their lives – e.g. doctors, teachers, therapists, 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:

Address	Telephone Numbers	Date of Birth
Blood Type	Current Height	Current Weight
Eye Colour	Hair Colour	Citizenship
Passport Number	Disability Pension Number	Tax File Number
Medicare Number	Private Health Cover	Birth Certificate
Solicitor	Accountant	Pharmacy
Power of Attorney	Health Care Directive	Bank Account Details
Health Care Card Number	18 Plus Card	

Medical information

When a child is born with a disability, the family has a lot to cope with and at times it all seems overwhelming, especially if there are significant medical issues to deal with. Documenting procedures is the last thing on most parents' minds as they try to cope with the emotional turmoil and the physical demands that having a sick child entails. However, later it can become apparent that documenting each medical procedure would have been very worthwhile and would make life much easier in the future.

Robert was born 9 weeks premature and weighed only 940 grams. He was put straight on a ventilator when it was discovered that he had a medical condition that meant he had no opening in both nostrils. He was first operated on at 2 days old and in his first 2 years, all of which he spent in hospital, he had numerous operations and medical interventions. At the time, his parents were only concerned with his survival and were also trying to cope with their grief as it was discovered that there were many other medical complications. In subsequent years he continued to require many surgical procedures and frequent hospitalisation. His parents were repeatedly asked by the many doctors who were involved with Robert, about the various medical procedures that had taken place. They could not remember them all and felt quite inadequate that they did not have a complete record of his medical situation. With the freedom of information act that is now in place, his parents could legitimately seek out this information from the hospital if it is still available 22 years later, but this is a daunting proposition and one which they feel some reluctance to do.

It can be quite emotionally draining for parents to have to continually explain to people, including health care professionals, the details of their child's disability and how this impacts upon them. If all this information is well documented, this information can be handed to the doctor/occupational therapist/physiotherapist etc and then all the parent has 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:

- 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
- Medications used in the past – this is sometimes helpful for doctors when deciding on a course of treatment
- Reactions to medications/allergies/any medications that MUST NOT be taken
- Medical appointments
- Medical history/medical records/hospitalisations
- Past doctors
- Preferred hospital
- Health precautions/health alerts.

It is very useful to have the details of any medical issues well documented.

Daily routines

All parents worry about what will happen to their children if they are not there to look after them. They realise the need to put procedures into place to ensure their children's safety and well being in the worst case scenario that something should happen to them. Many people feel that they can rely on their extended family and friends to step in and often they include their wishes about who they would like to look after their children, when they are writing their wills. This concern is magnified for parents who have sons and daughters with a disability as the care needs are often highly complex. Also, to add to the difficulty, their family member with a disability may not be able to easily communicate their wishes.

Emma did a wonderful job looking after her son, 8 year old Jake, who had a highly complex weekly routine. Because Emma was so familiar with all of the routines that she had set in place for her son, even her husband was not fully aware of all of the information because Emma had it all in her head e.g. If the taxi didn't turn up on time to take him to school, she knew who to ring; she knew which medications to give him each day etc but if she wasn't there, no-one else really knew the full extent of what to do. Whenever Emma had to go away for a few days, she left detailed notes for the rest of the family outlining exactly what to do each day, even details such as what needed to be packed into his bag for school. These notes were then destroyed when she returned home and she once again picked up the full responsibility of Jake's daily routines. When the family started a support circle, they said that the first thing she needed to do was to document in detail what was needed to support Jake on a daily basis, so that others could step in if she was not around. Although this task was quite onerous for her, once completed it actually took a great weight from Emma's mind as she knew that others would now know what the daily routines were, including what medications to give her son.

Think about what a typical week looks like. 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.)

It is very useful to have the details of daily routines set out clearly.

Contacts for daily activities

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.

Personal care information:

Diet	Likes/Dislikes/Food allergies
Eating	Is assistance needed?/Food preferences/Any special equipment needed?
Drinking	Is assistance needed?/Any special equipment needed?
Toileting	Is assistance needed?/Timing?/Are pads required?
Safety	At home – in the kitchen, bathroom etc In the community – road sense, awareness of danger, strangers etc
Personal Hygiene	How much and what type of assistance is needed with this? (e.g. bathing, teeth cleaning, toileting, dressing.)
Sleeping	Routines?
Mobility	What support is needed?
Daily Health care	Any special needs?

Communication/behaviour

It is important for others to understand how your family member communicates their needs, particularly if they do not use standard speech. People also need to know how to interpret their 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?

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 family member's financial affairs.

Income and 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.

Budget considerations

- Can the person manage their own finances?
- What assistance do they need with this?
- Who provides this assistance?
- What safeguards have been put in place around the person's finances?

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.

One way to work this out may be to imagine that you have the opportunity to travel overseas for three months.

Who would take care of all the things you normally do?

Expectations of Support Workers

Sometimes it is difficult for parents to verbally outline all of their expectations of support workers who come into their homes or who support their son/daughter in the community. A document outlining what is expected can be a useful tool to help workers support your family member in the way you would. It can make this communication easier but it is important to be very specific about what you expect. As well as making sure they really understand your family member, 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.

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

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

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

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

Freely downloadable templates in Microsoft PowerPoint with particular reference to communication.

Appendix

The following outline is a format that families can use to develop their own personalised document about their family member. Families can contact Pave the Way for a digital version of this document. Families are encouraged to use this resource as a guide only as any personal information is more compelling when it reflects the person's own wishes, story and culture.

Deepening Understanding

Introducing me!

Personalised introductory statement

What has happened in my life so far?

My hopes and dreams

My personality/emotions

My strengths and gifts

My skills and abilities

My likes

- Activities
- Food
- Music
- Outings
- Sports

My dislikes

Things that make me anxious

Things that make me feel safe/calm

Things that make me feel valued

About my family

My connections in the community and how these can best be fostered

My learning and educational history/needs/desires

My spirituality

How I contribute (work, volunteering)

My relationships and how these can be maintained

Important people in my life

List of names, addresses, phone numbers and their relationship to your family member.

NAME	RELATIONSHIP	PHONE NUMBERS	ADDRESS	EMAIL ADDRESS
next of kin				
friends/neighbours				
support circle				
support workers				

My social networks/community organisations I am involved in

ORGANISATION	ACTIVITY	DAY & TIME	ADDRESS	PHONE CONTACT

Sharing the Vision

Vision Statement: the vision you and your family member have for them to lead a rich and meaningful life.

Where do I want my family member to be living/where do they want to live?

What kind of work will they do?

How will they spend their days?

Who are their friends likely to be?

Who will manage their money?

Who will decide on support funding and planning?

Who will assist them to buy food/clothing etc?

Who will help plan holidays and celebrations?

Who will hire paid support workers?

Record Keeping

Personal information

Address

Email Address

Telephone Numbers

Date of Birth

Birth Certificate

Blood Type

Current Height

Current Weight

Eye Colour

Hair Colour

Citizenship

Passport Number

Disability Pension Number

Tax File Number

Health Care Card number

18 Plus Card

Medicare Number

Private Health Cover

Solicitor

Accountant

Pharmacy

Power of Attorney

Health Care Directive

Medical information

Medical diagnosis

Medical issues

Allergies

Contact details for:

- GP
- Specialists
- Dentist
- Therapists
- Pharmacist

Current medications

Date started	Brand name/Generic name	Dosage/ Times	Strength	Purpose	What it looks like	How to administer
					e.g. small yellow tablet	

Medication supply (where kept)

Vaccinations

Medications used in the past

Any medications that MUST NOT be taken

Reactions to medications

Medical history/ medical records

Hospitalisations

Past doctors

Preferred hospital

Health precautions/health alerts

Medical appointments

Daily routines

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

Contacts for daily activities

NAME/ORGANISATION	ACTIVITY	ADDRESS	EMAIL ADDRESS	PHONE NUMBERS

Personal care information

Diet

- Likes
- Dislikes
- Food allergies

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 Hygiene

Assistance needed with:

- Bathing
- Teeth cleaning
- Toileting
- Dressing

Sleeping

- Waking time
- Bed time
- Routines

Mobility

- Support needed
- Equipment needed
- Transport arrangements

Daily Health care

Communication/behaviour

Preferred method of communication

How I indicate how I am feeling

How I receive communication

My literacy ability

- Reading
- Writing
- Maths
- Money
- Telling time

My telephone skills

What changes in my behaviour indicate

How I communicate if I am under stress

Financial and legal arrangements

Name and address of solicitor

Location of current will

Details of person taking responsibility for financial affairs

Executor

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

Banking details

How does the person manage their finances?

What assistance do they need with this?

Who provides this assistance?

What safeguards have been put in place around the person's finances?

Emergency Plan

Who needs to be contacted?

Where can the following be found?

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

Details of who will provide:

- Accommodation support
- Financial support
- Health care support.