

Connecting with your support team

What you need to know

Easy Read booklet



pwsa

VICTORIA

prader-willi syndrome association

How to use this booklet



Prader-Willi Syndrome Association (PWSA)
Victoria wrote this booklet. When you see
the word 'we', it means PWSA Victoria.



We wrote this information in an easy to
read way.

We use pictures to explain some ideas.

Bold

Not bold

We have written some words in **bold**.

This means the letters are thicker and darker.



We explain what these words mean.

There is a list of these words on page 37.



This Easy Read booklet is a summary of
another booklet. This means it only includes
the most important ideas.



You can find the other booklet on our website
at [pwsavic.org.au/get-support/connecting-
with-support-teams](https://pwsavic.org.au/get-support/connecting-with-support-teams).



You can ask for help to read this booklet.
A friend, family member or support person
may be able to:

- help you
- talk to you about how your support team can work for you.

We are proudly supported by the:

DSS



- Australian Government Department of Social Services (DSS)



- National Disability Insurance Agency (NDIA).

What's in this booklet?

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What's this booklet about?



Prader-Willi syndrome (PWS) is a disability that can make your life challenging.



For example, lots of small problems can turn into big problems very quickly.

PWS can affect lots of people in your life, like:



- you



- people who support you.



PWS can affect how you act.

PWS can affect how well you:



- learn



- take part in the community.

PWS can also affect your:



- physical health



- mental health.



Most people with PWS have a **support team**.

Your support team is all the people who support you.

The people in your support team might be:



- family members



- support workers



- disability service providers



- health care workers



- **advocates.**

Advocates are people who help you:



- have your say



- get information and advice.

Your support team can help you:



- stay healthy and happy



- make decisions



- talk to people who can help you,
like your doctor.



We made this booklet to help you understand more about your support team.

Why are support teams important?

You might want to:



- work



- do things for fun, like play sport



- make friends and do things with other people



- feel safe in the community



- have a say about what happens in your life.

Your support team can help you:



- do things you want to do



- live your life how you want.



They can also help you make decisions.

It's important for your support team to understand:



- you and your story



- what PWS is.

This will help them support you when:



- good things happen to you



- bad things happen to you.

Making your support team

When you make your support team, you should include people who are:



- from your family



- not from your family, like a friend.



This is because not everyone in your support team can help you all the time.



When you make your support team, you should ask for their contact information.

This can include their:



- phone number



- email address.

You should keep their contact information in a place that's:



- safe



- easy for you to get to.



For example, you can put their contact information in your phone.

Asking for support from your support team



There are lots of ways you can ask your support team for support.



You can call them.



You can use your phone to send them a message.



You can send them a picture or emoji.



For example, you might send them a sad face if you're upset.



You can email them.



There might be times when you need someone else to contact your support team for you.

You and your support team should work out what to do if you:



- can't contact them



- have an **emergency**.



An emergency is a dangerous situation that we don't expect to happen.



It can also put your health at risk.



You can carry a card about PWS with you when you go out.

We call this a **PWS wallet card**.

A PWS wallet card:



- explains you have PWS



- has your support team's contact information.



You can also wear a **medical emergency bracelet**.

A medical emergency bracelet:



- explains you have PWS



- has a phone number someone can call if you have an emergency.

How can your support team help you?



Your support team can help you in lots of ways.



They can help you fill out a form.

They can listen to what you have to say, such as:



- if you think something is wrong



- how you feel.

Your support team can help you talk to the police if you:



- see someone do something wrong or break the law



- are very worried about something



- experienced a **crime**.

A crime is when something bad happens to:



- you



- someone else.



For example, it's a crime if someone steals your money.

Making decisions



Your support team can help you make decisions when it is hard for you.



They can help you understand all the information you need to make your decision.

Behaviours of concern



Sometimes people with PWS show **behaviours of concern**.

Behaviours of concern are things you do that might put:



- you in danger



- other people in danger.

If you show behaviours of concern you should talk to your support team about:



- when you show behaviours of concern



- how they can support you.



When you have a problem, you should talk to your support team about what causes those problems.



This can help stop the problem happening next time.

Your rights and responsibilities



Your support team can help you understand your **rights**.



Rights are rules about how everybody should be treated fairly.



For example, you have the right to feel safe when you go out.



Your support team can help you understand your **responsibilities**.



Responsibilities are things you need to do.



For example, it's your responsibility not to hurt other people when you go out.

Your support team will help you understand your:



- rights



- responsibilities.

Knowing your rights and responsibilities will make everyone in the community feel:



- safe
- happy.

Giving your personal information



Your support team can help you understand what will happen if you can't give your information to people who want to help you.

These people can include:



- police officers



- ambulance officers



- doctors.



Your support team must have your **consent** to give your personal information to other people.



When you give your consent, you say it is ok to do something.



Your support team can also explain what it means to give your consent.

Your support plan



You and your support team should make a support plan together.

Your support plan should explain what to do when you:



- have an emergency



- have a bad experience



- need support to do something.



Everyone in your support team should know what your support plan says.

When you finish making your support plan, you should keep it in a place that's:



- safe
- easy for you to get to.



For example, you can ask someone to save your support plan on your phone.

Making your support plan

Your support team will help you:



- think of ideas to put into your support plan



- write your support plan.



We have written some questions.



Your answers can help you write your support plan.



There is a box under each question where you can write your answer.



What will you do if you have an emergency?



What will you do if you need to fill out a form that is:

- confusing?
- hard to understand?



What will you do if you need to talk to police?



What will you do if you need to go in an ambulance?



What will you do if you see something bad happen to someone else?



What will you do if:

- something bad happens to you?
- it makes you sad?



This plan was made on ____/ ____/ ____.



I will update my plan on ____/ ____/ ____.

Contact your support team



You can contact your support team when you:

- have an emergency
- need help.



Contact name



Phone (during the day)



Phone (at night)



Mobile



Email



Address

Another person on your support team



Their name



Their phone number (during the day)



Phone (at night)



Their mobile



Their email



Their address

Bold

Not bold

This list explains what the **bold** words in this document mean.

This means the letters are thicker and darker.



Advocates

Advocates are people who help you:

- have your say
- get information and advice.



Behaviours of concern

Behaviours of concern are things someone does that might put:

- themselves in danger
- other people in danger.



Consent

When you give your consent, you say it is ok to do something.



Crime

A crime is when something bad happens to:

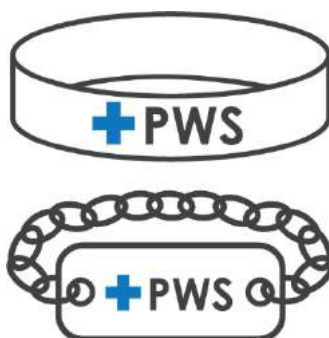
- you
- someone else.



Emergency

An emergency is a dangerous situation that we don't expect to happen.

It can also put your health at risk.



Medical emergency bracelet

A medical emergency bracelet:

- explains you have PWS
- has a phone number someone can call if you're in an emergency.



Prader-Willi syndrome (PWS)

Prader-Willi syndrome (PWS) is a disability that can make your life challenging.



PWS wallet card

A PWS wallet card:

- explains you have PWS
- has your support team's contact information.



Responsibilities

Responsibilities are things you need to do.



Rights

Rights are rules about how everybody should be treated fairly.



Support team

Your support team is all the people who support you.

Contact us



PWSA Victoria support line – **0451 797 284**



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www.pwsavic.org.au



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