



pwsa VICTORIA

prader-willi syndrome association

The benefits of connecting with Support Teams



**A comprehensive guide to explain how and why
Support Teams can make all the difference.**

DSS Department of Social Services.

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INTRODUCTION

A strong Support Team can ensure problems don't turn into a crisis.

Prader-Willi Syndrome (PWS) is complex. So it's vital that people with PWS have in place a Support Team to enable them to live a good life.

Because of its complexities, people with PWS can too easily get into difficulties which can then turn into a crisis.

This brochure has been created to be a starting point for discussions — for people with PWS, their families, support workers, NDIS and mainstream providers, advocates, life skills trainers, and others who form part of the team.

This information brochure will cover:

- ▶ Forming a Support Team, and establishing communication between support team members.
- ▶ How a Support Team helps build the capability of the person with PWS to understand their rights and responsibilities.
- ▶ Highlighting how support is given to the person with PWS in times of crisis.

**Just like everyone,
the person who has
PWS wants to:**

Belong to their community.

Have a daily purpose, like a job.

**Be able to play sports, go to the gym,
the movies and take part in leisure
and social activities and pastimes.**

Have friends and visit their friends.

Be safe and feel safe in their community.

**Be treated equally
and have a say in what
happens in their life
just like everyone else.**

**The next few pages show you how to set up your
support network, so that you can be better prepared
to live your life and achieve your goals.**

Everyone needs a Support Team.

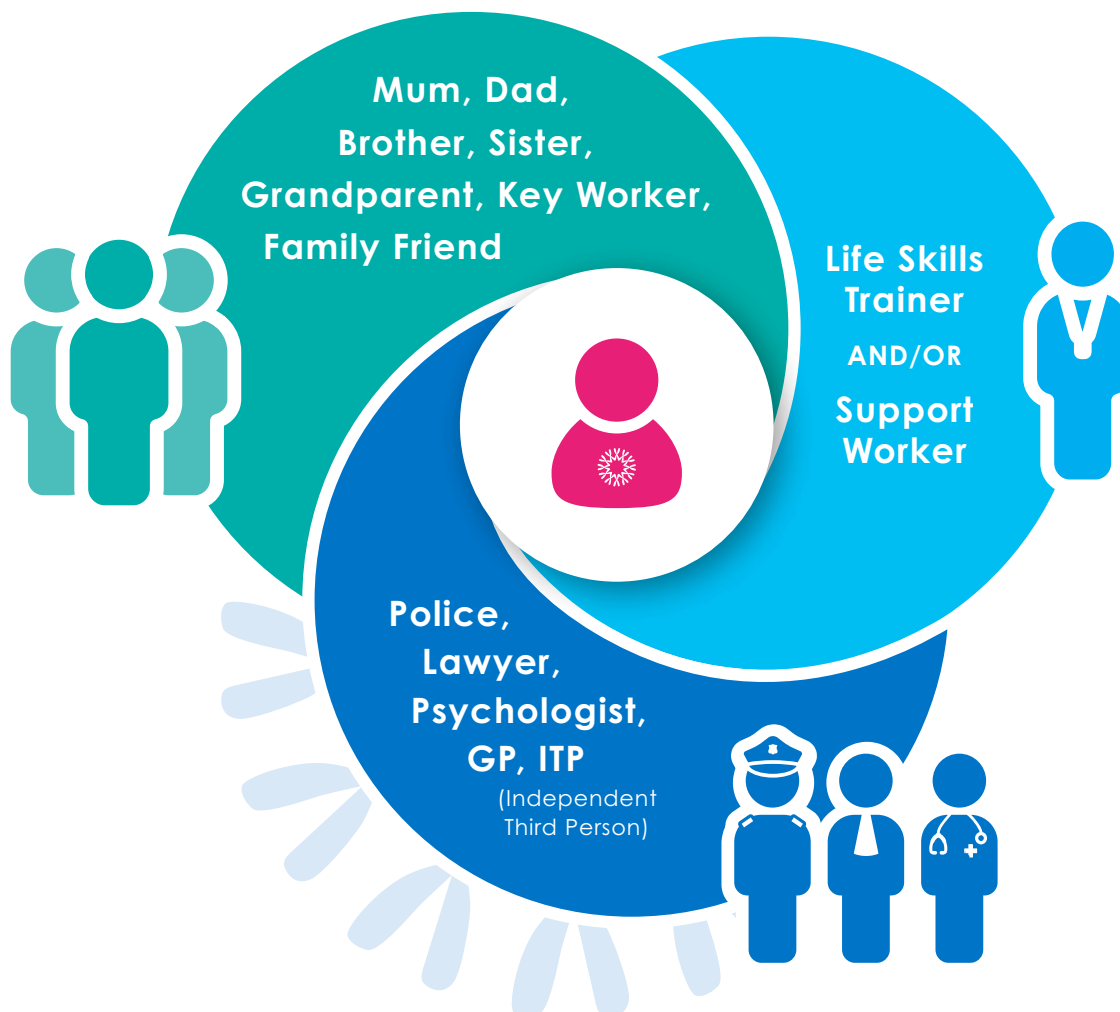
Having a group of people that understand both you and PWS is vital, in good times and bad times.

By creating a trusted, responsible support network, who have a good knowledge of PWS, you have the support to get you through every step of a crisis.

Who can be part of the Support Team?

Everyone's Support Team will be different, but here are some ideas to help you decide who will be in your Support Team.

You can ask family, family friends, support workers, psychologists, your group home supervisor, or medical professionals to help you make difficult decisions.



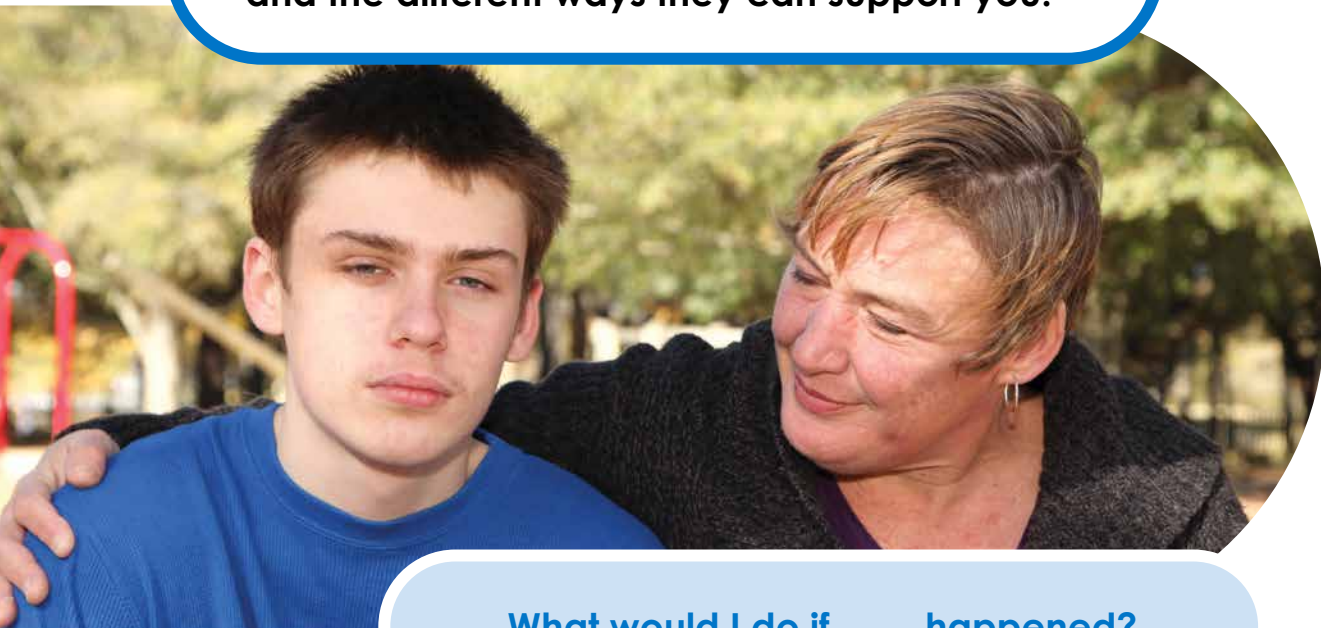
Deciding who will be in your support network.

As well as family members, a Support Team should be 'balanced' and also include people outside the immediate family. Remember, not everyone in your Support Team is available all the time, and you never know when they might need to be contacted.

Ask Support Team members for contact details so you can reach them easily if you need them to help you, and if possible (and you get permission) have the Support Team members share contact details with each other.

Make sure their details are in your phone contact list.

Talk to them about being your support contact and the different ways they can support you:



What would I do if happened?

When do I call on my Support Team?

Who do I call when I need support?

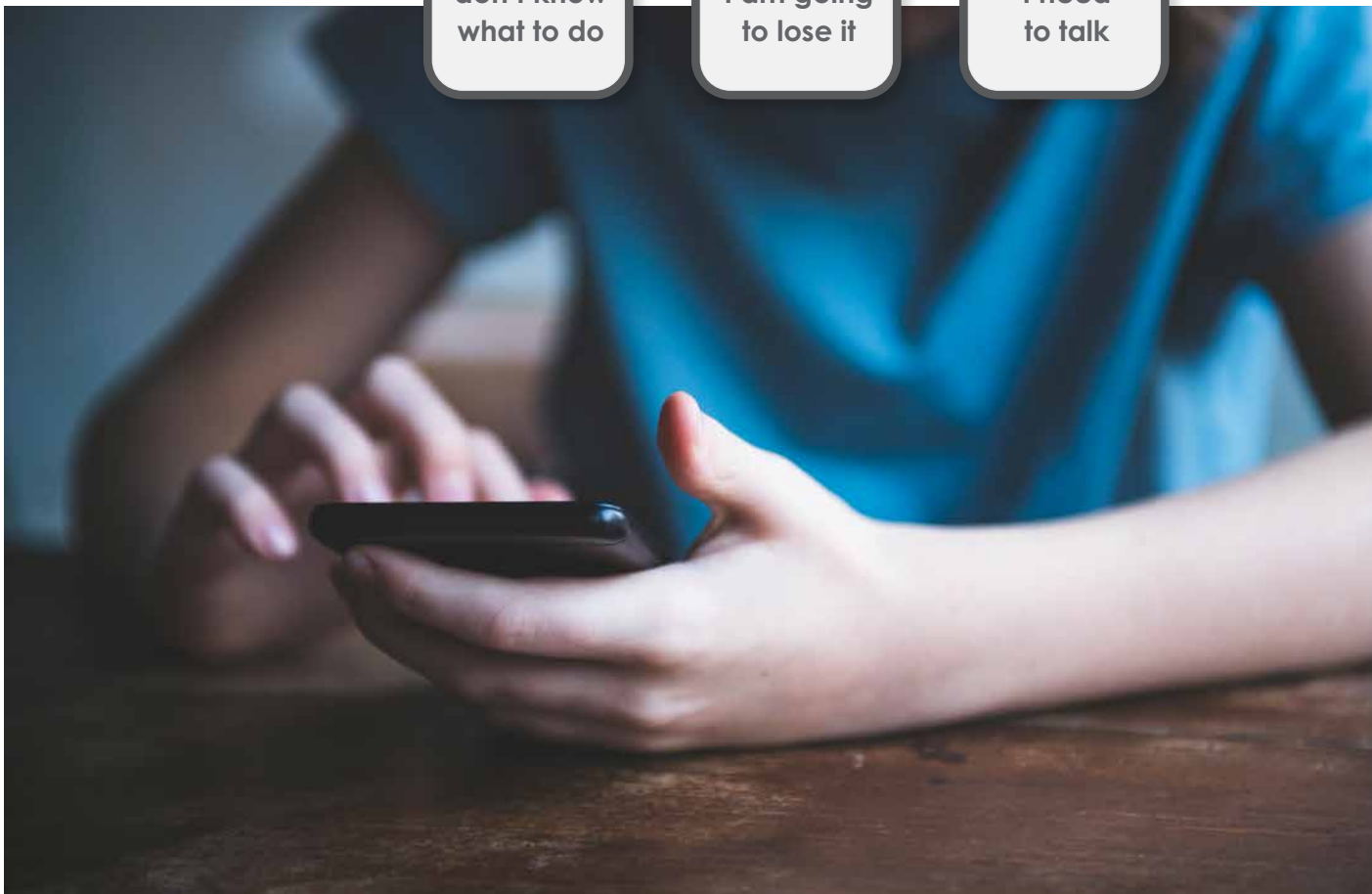
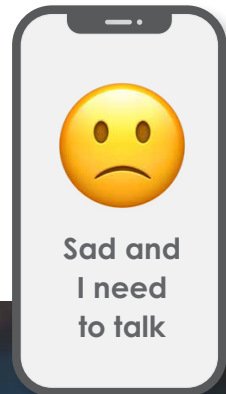
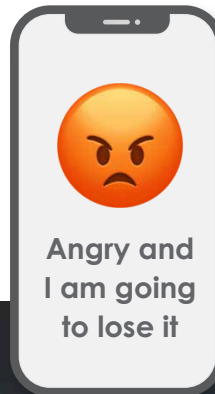
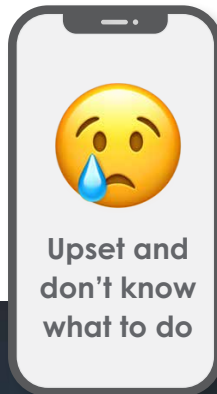
How would I contact my Support Team?

How do I ask for support, help or advice?

There are several ways you can get in contact with your support network.

- Just ring them.
- Get someone nearby to ring them.
- Use the emojis on your phone to convey a message or emotion.
- Send a predictive text message on your phone.
- A rehearsed simple message.

These visual messages quickly and directly let your Support Team know you need help with a problem.




A support person can help you when:

- You are upset about something and need to talk about how you feel.
- Having a person, you trust in difficult times can help you calm down.
- You need help to collect information or fill in paperwork.
- You need to make a decision, but you don't know what to do or are unsure of the consequences.
- You need to tell others how you feel – if you are feeling down.
- Something in your house is worrying you and making you anxious.
- You think something is wrong, and you want to talk to someone you can trust.
- You feel someone has done something to you, it makes you feel uncomfortable and you want to tell someone you trust.
- Something serious has happened, and you need help to contact the police and report a crime. For example:
 - If you have seen something you know is breaking the law
 - If you are a victim of a crime
 - If something is upsetting you and making you feel anxious or worried.

What happens when I can't contact my Support Team?

There may be a crisis or situation when you have to rely on people you don't know to contact your Support Team for you. Work out a plan in advance about how you will ask them to do it.

Here are some examples:



Carry a PWS Wallet Card with contact details



Wear a medical emergency bracelet



Have contact details in your phone – An ICE entry (IN CASE OF EMERGENCY)

This ICE number should be included in the Wallet Card and Voluntary Disclosure Information.



We all have rights and responsibilities.

In Australia we think it is fair that everyone has certain rights:

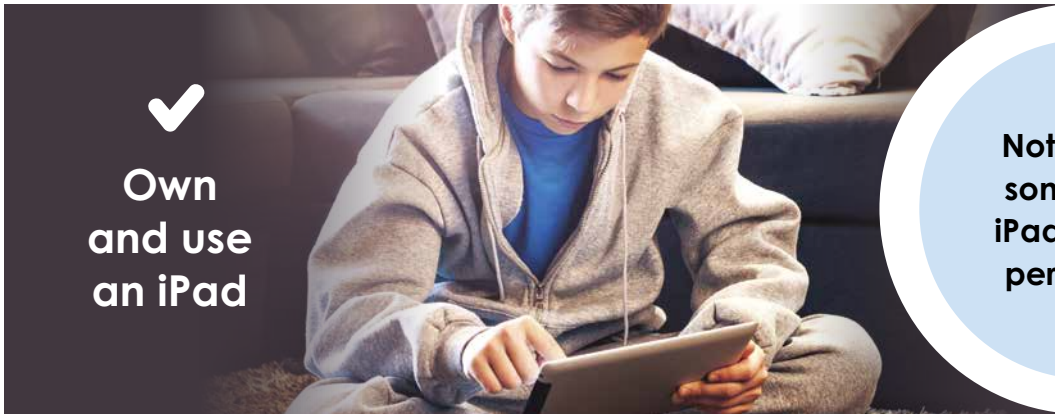
- ▶ The right to be safe.
- ▶ The right to go to school and work.
- ▶ The right to be paid a fair wage.
- ▶ The right to vote.
- ▶ The right to own belongings.
- ▶ The right to be treated equally.

Your Rights

Your Responsibilities



Own
and use
an iPad



Not to take
someone's
iPad without
permission



Listen
to music
you like



Listen to
music quietly
so it doesn't
upset people



Feel safe
when you
go out



To not hurt
other people



Share
your
opinion



Not to use
loud voices
and allow others
to have their
opinion

To be happy and safe in our community, we all have to do the right thing by each other.

- ▶ We need to have rules to keep us safe and protect our rights.
 - ▶ There are people in the government who decide what we can and cannot do.
 - ▶ The government makes rules to keep us safe.
We call these rules laws.
 - ▶ Some actions are dangerous, and may hurt people, so we follow the rules to help keep everyone safe.
 - ▶ **As well as the right to be happy and safe in our community, we also have responsibilities to make sure other people in our community are happy and safe.**
 - ▶ Everyone has the responsibility to follow the rules.
 - ▶ **If you DO NOT follow the rules you can get into trouble.**
 - ▶ You and everyone in the community must follow the rules.
-

Making good decisions and following the rules.

Sometimes you need someone to support you to help you make good decisions.

You can ask other people to help you make that tricky decision if it is too hard to do by yourself.

Talk it over with a person you trust if you are not sure about what to do.

Everyone needs people they can talk to and get advice and help.

Time to talk about problem times.

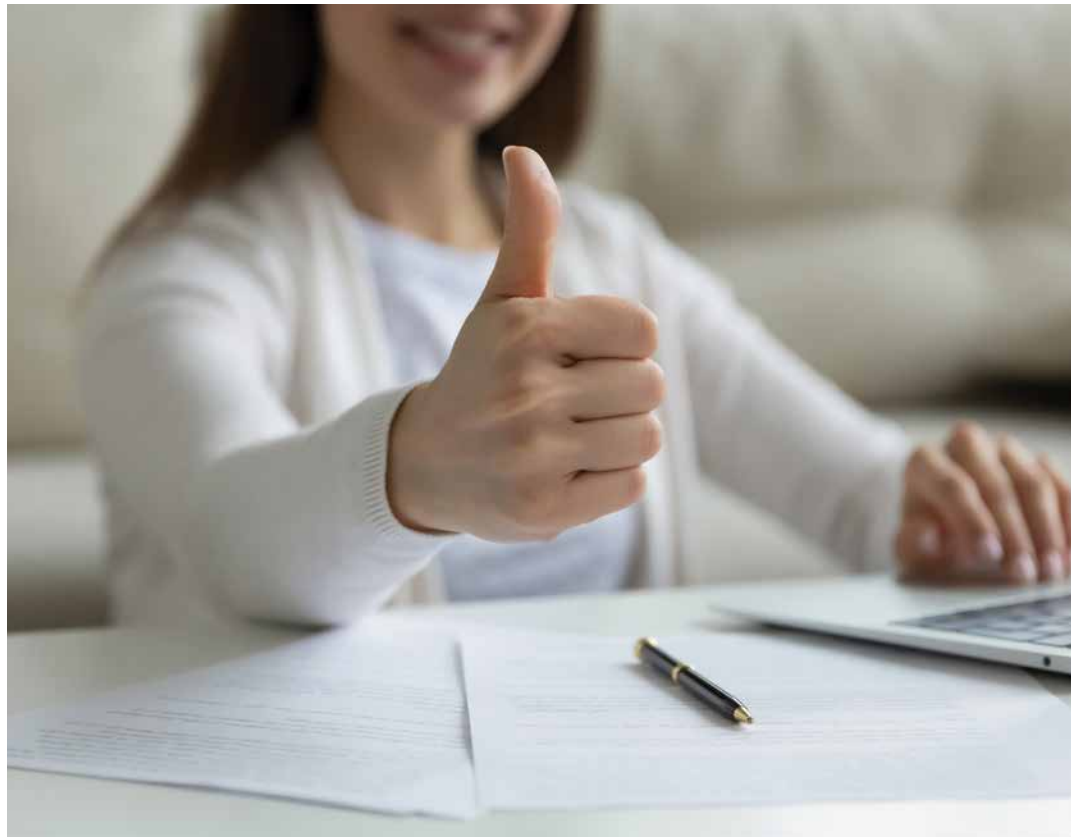
It is only a 'Behaviour of Concern' for you and those around you when it is causing problems for you or those around you.

A "Behaviour of Concern" is when something bad happens that can get you into trouble.

It makes you and others around you feel unsafe and unhappy.

To help minimise "Behaviour of Concern" situations from happening, use these ideas:

- Talk with your Support Team about what causes most of the problems for you and others around you.
- Talk with your Support Team about when the behaviours of concern occur.
- Talk with your Support Team about ways to support you when behaviours of concern occur.
- Talk about what you should do if you are not able to tell the paramedic/ ambulance/police about important personal information relating to PWS.
- Your Support Team must have your permission to tell the police, doctor, or paramedic about important personal information.
- Talk about what giving permission or consent will mean.
- Work with your Support Team to develop a plan.
- Make sure everyone in your Support Team knows the plan.
- Keep it simple.



Building your Support Plan in a few simple steps.

- ▶ Think of some difficult situations and then think of what you could do to make them better.
- ▶ Discuss your ideas with one or more of your Support Team.
- ▶ Then fill out the **Support Plan** with what you agree are the best ideas and solutions. (Support Plan is on the next page).
- ▶ Share the information with your Support Team members.
- ▶ Once completed, keep the Support Plan with you. Alternatively, ask someone to help you save it in the 'notes' section of your mobile phone.



Support Plan

1 In an emergency I will...

2 If a form is confusing or hard to fill in, I will...

3 If the police want to talk to me, I will....

4 If I have to go in an ambulance, I will...

5 If I see something bad happen involving someone else, I will...

6 If something bad and upsetting has happened to me, I will...

REFERENCES

Support for Justice - A guide for people with disability, their support professionals, family carers, friends, and advocates <https://inclusionmelbourne.org.au/projects/support-for-justice/>

Reporting Crimes: Your Rights. www.police.vic.gov.au

Facilitating Independence - strategies for staying safe in the community, Nolan, L, 2015
<http://www.bulleenheights.vic.edu.au/wp-content/uploads/2015/08/2015-Lucinda-Nolan-Facilitating-Independence.pdf>


The Bridging Project Scope – Fact Sheet Behaviours of Concern www.scopevic.org.au

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Your Rights and Legal Information
www.banyuleyouth.com/your-rights-legalinformation

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