

PWS First Response Kit



pwsa

VICTORIA

prader-willi syndrome association



Background

- In **times of crisis** for a person with PWS, experience tells that a positive outcome can be obtained if they are supported by a trusted adult who understands PWS.
- Via the PWS support phone line & through an increasing number of incidents where adults with PWS were not supported, a gap was identified in the unmet need for information and resources when supporting someone with PWS in times of crisis.
- Further research was undertaken to address the information gap and develop resources that:
 - Establish the importance of effective support teams
 - Educate support team members how best to support the person with PWS
 - Introduce ideas to improve communication between the person with PWS and their support team members
 - Create assets that can be used and accessed in moments that matter ie: at the time of crisis



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Kit Development

In 2019 PWSA Vic was granted a DSS ILC grant and the task of writing the First Responders Kit was started.

PWSA Vic Joined forces with Monash University IT team to:

- ❖ Develop the PWS First Response Kit resources
- ❖ Research the development of a technological solution to help improve communication between the person with PWS and their support team, together with Queensland Health.

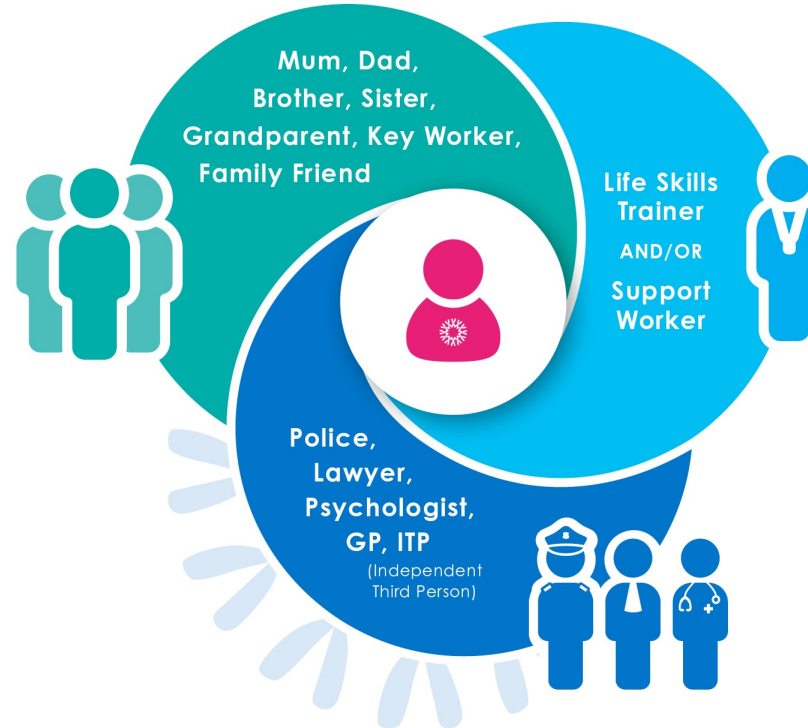
Principles that guided the Kit development

- It would be an **evolving** resource that will be updated and reviewed regularly
- It would fill **information gaps** in the PWS information resources that are already available
- The PWS First Response Kit will be required to address the needs of a wide target audience, including :
 - Recognizing PWS as a spectrum disorder and there are a wide range of ability groups in the PWS community
 - PWS is a multistage disability and each stage of PWS has its own unique needs
- The kit would include:
 - Easy to read brochures to complement the standard brochures
 - The use of graphics and photos throughout the kit, to assist in explaining the text and to use as a starting point for discussion with a person PWS.



Who will use the kit

- People with PWS
- Families who support someone with PWS
- Disability support workers
- Disability advocates
- Life skills trainers
- Other members of the support team.

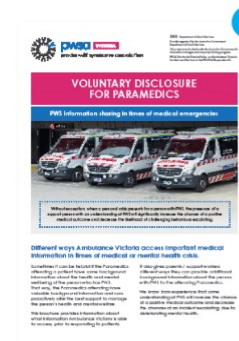
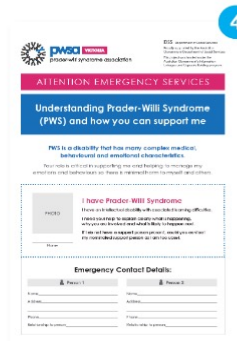
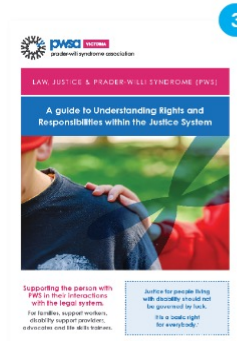


What the Kit includes

PWS First Response Kit FOR PARENTS, PROVIDERS & ADVOCATES

Brochures & Items Included:

1. Connecting with Support Teams
- Easy Read Version
2. Connecting with Support Teams
3. Law, Justice and PWS
and how you can support me
4. Understanding PWS
and how you can support me
5. Voluntary Disclosure for Paramedics
6. Voluntary Disclosure for Police
7. Wallet Card



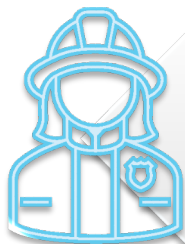
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Key areas of use



Building capacity to deal with personal crisis

- Guidance to deal with day-to-day management
- Connecting with your support team – Easy to read Booklet
- The benefits of connecting with your support team



Telling others about PWS at time of crisis

- PWS Information **Wallet card**
- **Attention Emergency Services:** Understanding PWS and how you can support me
- **Voluntary Disclosure** for paramedics /police



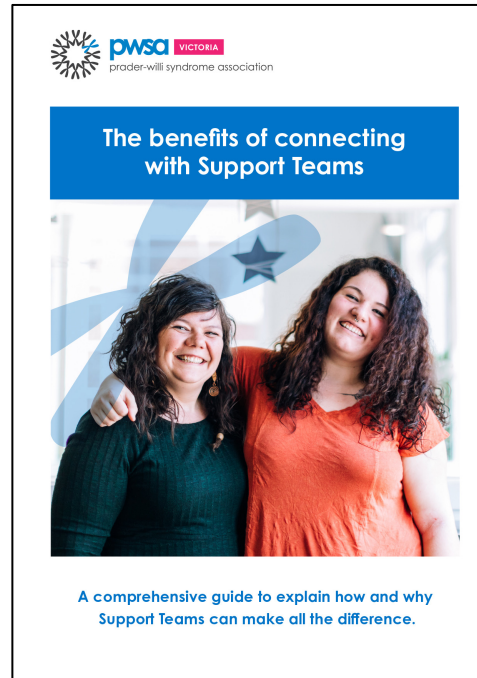
Dealing with the Victorian Justice System

- Critical resource to support and understand PWS rights within the Justice System (Victoria)
- Examples may include: Police, Jail, Lawyers



Support Teams

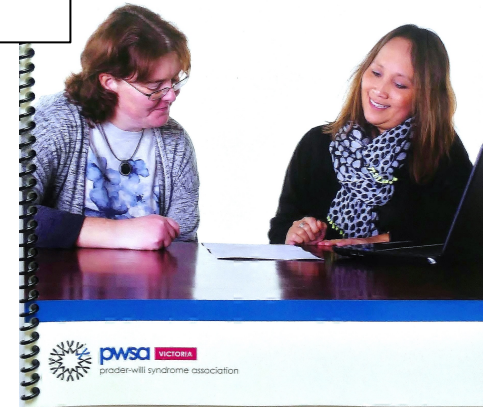
- A comprehensive guide for Support Teams
- Strategies for dealing with PWS in times of personal crisis.
- It explains how preplanning and real time support can make a difference to the outcome in times of crisis



Connecting with your support team

What you need to know

Easy Read booklet



Voluntary Disclosure

This brochure provides information about what information Ambulance Victoria and Victorian Police are able to access, prior to responding to patients.

VOLUNTARY DISCLOSURE FOR POLICE

Sharing Information to help and support people with Prader-Willi Syndrome



Victoria Police are in the process of developing a Voluntary Disclosure program. On completion, the document will be added to the PWS First Response Kit and available for download on our website: pwsavic.org.au



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VOLUNTARY DISCLOSURE FOR PARAMEDICS

PWS information sharing in times of medical emergencies



Without exception, when a personal crisis presents for a person with PWS, the presence of a support person with an understanding of PWS will significantly increase the chance of a positive medical outcome and decrease the likelihood of challenging behaviours escalating.

Different ways Ambulance Victoria access important medical information in times of medical or mental health crisis.

Sometimes it can be helpful if the paramedics attending a patient have some background information about the health and mental wellbeing of the person who has PWS. That way, the paramedics attending have valuable background information and can proactively offer the best support to manage the person's health and mental welfare.

This brochure provides information about what information Ambulance Victoria is able to access, prior to responding to patients.

It also gives parents/support workers different ways they can provide additional background information about the person with PWS to the attending paramedics.

We know from experience that some understanding of PWS will increase the chance of a positive medical outcome and decrease the chances of an incident escalating, due to deteriorating mental health.

DSS Department of Social Services.
Privately supported by the Australian Government Department of Social Services.
This project was funded under the Australian Government's Information Literacy and Capacity Building program.
PWSA Vic thanks Victorian Police and Ambulance Victoria for their contributions to the PWS First Responders Kit.



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Law, Justice and PWS

A comprehensive guide to help the support team understand the rights and responsibilities and processes of the Victorian Justice system.

It also gives a valuable list of services and programs available in Victoria to assist the support team when the person with PWS is in contact with the justice system



LAW, JUSTICE & PRADER-WILLI SYNDROME (PWS)

A guide to understanding rights and responsibilities within the Justice System



Supporting the person with PWS in their interactions with the legal system.

For families, support workers, disability support providers, advocates and life skills trainers.

Justice for people living with disability should not be governed by luck.

It is a basic right for everybody.¹

Alert Card

A wallet sized alert card and a fold out PWS information brochure for PWS individuals, to use in times of emergency or personal crisis to telling emergency services about PWS



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Proudly supported by the Australian
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This project was funded under the
Australian Government's Information
Linkages and Capacity Building program.

ATTENTION EMERGENCY SERVICES

**Understanding Prader-Willi Syndrome
(PWS) and how you can support me**



**The person you are
dealing with has PWS
(Prader-Willi Syndrome)**

Check if a "Voluntary Disclosure"
has been registered

Information for Police & Emergency Services



Ways to use the PWS First Response Kit

- Discussion starter for young PWS adults, focusing on life skill and equipping them for life after school.
- Provides a starting point for use in social stories*, which is an effective communication method to drive desired behaviours.
- Planning tool connecting a person the PWS with their support team in times of personal crisis.
- A way to quickly share important information about PWS
- Checklist of procedures to navigate your way around our Victorian Justice System

Accessing Kit

The kit is designed as a dip in and dip out resource - to be used as the needs arises.

Each person with PWS will have their own support needs and these support needs change over time

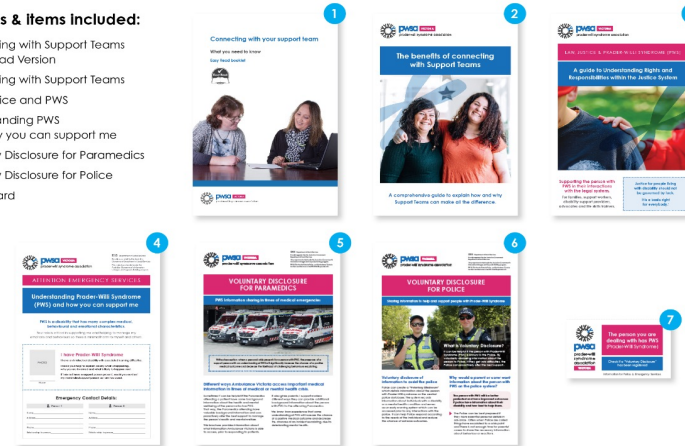
The PWS First Response Kit is available to download from the PWSA Vic website.

www.pwsavic.org.au

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