



pwsa VICTORIA

prader-willi syndrome association

DSS Department of Social Services.

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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.

Ambulance Victoria patient sharing information process.

▶ The initial call to Triple 000 will set the process in motion.

Emergency Services Telecommunications Authority (ESTA) is Victoria's triple zero service and provides the critical link between the Victorian community and the state's emergency services agencies.

ESTA provides 24-hour emergency call-taking and dispatch services for police, fire, ambulance and VICSES.

Given the volume of calls ESTA receives, it is very important that initial caller provides as much information as possible. The information given to the operator will decide how the call will be triaged.

Clear and concise up to date information is vital. It is also important that the caller let the ESTA operator know that the person has PWS and any other information about underlying medical or mental health conditions.

▶ ESTA handles the incoming calls, and they are usually split between ambulance and police.

Incoming calls are categorized as either 1, 2, or 3. Category 3 calls include patients who have chronic disease, comorbidities, and highly complex challenging behaviours.

If the call is categorized as a Category 3 a specialist team of practitioners will provide secondary triage of the patient which could include self-care advice, referrals to your primary care provider or through the use of telemedicine experts and mental health professionals.

▶ Often this group of patients may have care plans that are stored in Ambulance Victoria's system to help paramedics with any behavioural issues.

To have a profile in this system the patient needs to have previously used the ambulance service. A carer or family can speak with their GP or specialist and discuss a care plan being added to the Ambulance Victoria database which is state-wide.

Make sure your Psychiatrist/Mental Health clinician is aware of the Victorian Mental Health database known as the CMI database. Details about this can be found at <https://www2.health.vic.gov.au/mental-health/research-and-reporting/reporting-requirements-for-clinical-mental-health-services/cmi-ods>

One key purpose of this database is to support the identification of registered clients through the allocation of a unique state-wide identifier for new clients.

NOTE Ambulance Victoria do not access the police "Voluntary Disclosure" information that is stored on the Victorian Police computer base.

▶ It is also important that when the paramedics arrive onsite that the person with PWS has a member of their support team present to support them throughout the process:

Every effort should be made to make sure there is a trusted, responsible adult from the person's support network, with a good knowledge of PWS, present through every step of the medical transfer to hospital or follow up medical treatment.

Supporting the person with PWS when the paramedics arrive:

- ▶ Help them understand any questions the paramedics may ask.
- ▶ Clarify any details by providing up to date information about medical history and prior treatments.
- ▶ Contact the legal guardian if they are not present so that legal and community support can be organised, as required.
- ▶ To give the paramedics more information about PWS and to support the paramedics to understand the often complex behaviours of PWS.
- ▶ To reassure the person with PWS what is happening and try to deescalate concerns.



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Voluntary Disclosure to share with Paramedics

PHOTO	Name: _____ Address: _____ _____ State: _____ Date of Birth: _____ NDIS Ref: _____
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Tick behaviours that apply:

- | | |
|--|---|
| <input type="checkbox"/> May become agitated if approached | <input type="checkbox"/> Confabulation and fantasizing common |
| <input type="checkbox"/> Abnormal food-seeking activity | <input type="checkbox"/> Intellectual disability |
| <input type="checkbox"/> High anxiety levels | <input type="checkbox"/> Self-injurious behaviours |
| <input type="checkbox"/> Limited sense of danger | <input type="checkbox"/> Limited independence skills |
| <input type="checkbox"/> Poor communication skills | <input type="checkbox"/> Cries and gets confused |
| <input type="checkbox"/> Over-estimates capability | <input type="checkbox"/> Cannot explain, when under pressure |

Relevant medical Information: _____

Mental Health diagnosis: _____

Things that calm the person/best way to approach:

(interventions, word phrases, breathing strategies/counting) _____

Interests/favourite place/favourite sports: _____

Any visual/hearing issues: _____

Communication Skills – receptive and expressive language skills: _____

Triggers that increase anxiety or stress levels: _____

Triggers for harm to self or others: _____

Other important information: _____

Emergency Contact Details:

 Person 1

Name _____

Address _____

Phone _____

Relationship to person _____

 Person 2

Name _____

Address _____

Phone _____

Relationship to person _____