



Ontario Prader-Willi Syndrome Association



# Adult Family Session

**PWS National Conference**

**October 27, 2025**



Ontario Prader-Willi Syndrome Association



Working Toward an Independent Future

# Aging and PWS:

## Lynn Garrick



Ontario Prader-Willi Syndrome Association



Working Toward an Independent Future

# Update

## Cathy Mallove

# OPWSA Adult Family Support Network

Since 2017, we've focused on housing for adults with PWS: actively connecting with families, reaching out to service providers and decisionmakers, researching other jurisdictions, learning from PWS experts. Key priorities:

## 1. Parent and community connections

- Webinars on key topics including funding, accessing services, dealing with transition to adult services
- WhatsApp group  
<https://chat.whatsapp.com/LwLCXWzb0Ra9Tb749GM2Go> and GoogleGroups email list
- Gathering information to support planning and advocacy
- Individual/Peer-to-Peer coaching and support

## 2. Identifying and exploring potential opportunities / projects / partners

- Toronto PWS condo project
- Community Living Central York project
- Connecting with local agencies
- Support for individual ideas and projects across Ontario
- Researching best practices in PWS housing across the world

## 3. Advocacy with politicians / decisionmakers / funders

# Some recent progress

- Funding
  - in last 2 years, over 10 PWS families have gotten an increase in DSO Passport funding
- Housing
  - Collingwood: Supported Independent Living - family purchased home, government-funding support provided by local agency (partial in-person, partial virtual, technology-supported)
  - Toronto: Supported Living in PWS home owned and staffed by Community Living Toronto – government-funded
  - Toronto: Supported Independent Living – family rented apartment, family-managed staffing and supports, funded using Passport, Ontario Health @Home Family Managed Care, Lights funding (Community Living Toronto) - Microboard to manage
  - Toronto: condo development moving along, OPWSA is working with Reena to develop a plan and approach, including visiting GTA housing projects
  - Multiple supported independent living arrangements (condo, secondary suite/basement) . Other families are working on solutions across the province

# CLCY Water Street Project

- ▶ 17-unit (unfunded) intentional community housing project launching in early 2026
- ▶ Renovation of existing 2-storey building to create safe, stable, and supportive housing.
- ▶ Partnerships: Ontario Prader-Willi Syndrome Association & Your Support Services Network.
- ▶ Focused on individuals with diverse abilities and those requiring specialized supports.

<https://www.linkedin.com/feed/update/urn:li:activity:7370063257400766464/>



- ▶ **Ground Floor**| 6 transitional-age youth
- ▶ **First Floor**| 5-bedroom self-contained living area with kitchen, laundry, and fitness room for individuals with Prader-Willi Syndrome. All entrance points and the kitchen feature magnetic locks for enhanced safety and controlled access
- ▶ **Second Floor**| 6 bachelor apartments for Supported Independent Living
- ▶ **Outdoor**| Landscaped gardens, surface parking, outdoor amenity space, and outdoor exercise equipment, close to amenities and park | trails

# First Floor

5-bedroom self-contained living area featuring a full kitchen, laundry, and fitness room designed for individuals with Prader-Willi Syndrome. All entrance points and the kitchen are equipped with magnetic locks to enhance safety and provide controlled access.



# Parent Resource Database

- Doctors familiar with PWS
- Behaviour consultants, system navigators
- Day Programs, Camps
- Recreation Programs
- Schools

*Looking for  
volunteers to help  
test and develop!*

OPWSA Parent Resource Database

cmallove@gmail.com [Switch account](#) 

\* Indicates required question

Type of Resource

Type of Resource \*

Choose

Healthcare & Medical Supports

Programs & Respite Services

Professional Services (Lawyer, Finance, Estate, etc.)

Volunteering & Employment

Tools, Technology & Resources

Other

[Clear form](#)

# We are stronger together!

- WhatsApp group

<https://chat.whatsapp.com/LwLCXWzb0Ra9Tb749GM2Go>

- Individual/Peer-to-Peer coaching and support – connect with others who have similar issues
- Email [cmallove@gmail.com](mailto:cmallove@gmail.com)



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# Maximizing Resources

**Kelly Casey**

# MAXIMIZING RESOURCES

## **MCCSS**

- Ontario Disability Support Program / PWS Food Allowance
- Passport (Caregiver and Urgent Need)
- Individualized Residential

## **Ministry of Health (Ontario)**

- Ontario Drug Benefit Program
- Ontario Health at Home
- Assistive Devices Program

## **Housing Grants**

- Municipal
- COHB
- CMHC

## **Federal Programs**

- Disability Tax Credit
- Registered Disability Savings Plan
- Canada Disability Benefit
- Canada Dental Plan

## **Other**

- Local agencies, programs and services
- Informal supports



MCCSS:  
ONTARIO  
DISABILITY  
SUPPORT  
PROGRAM

## Income Support ODSP Tip Sheet

- Room and Board: Lower \$\$. When Room and Board are provided by the same person.
- Tenant: Higher \$\$. When there is a Tenant contract and board is being supported by someone other than the landlord. **Tool:** [Cost Sharing Agreement](#)

## \$200 PWS Special Diet Allowance

- Request the "Application for Special Diet Allowance" from your local ODSP office (to be signed by health professional)



MCCSS:  
DEVELOPMENTAL  
SERVICES  
ONTARIO (DSO)

## Update your DSO up to every 3 months

- Tool: [DSO Tip Sheet](#)
- Provide an update of the **person** and their needs.
- Provide an update of the **caregiver needs**, physical health and mental health.
- Provide an update on **any changes in the home**, for example- siblings moving out, grandparents moving in and requiring care, etc.
- If you are only getting the \$5500 Passport funding, ***ensure you are still being considered for the full passport allocation*** based on the person's SIS/ADSS.
- Ask for **Individualized Housing Support** if you are hoping to create a home of your own.
- We can help coach you – contact Jen or Cathy if you want help to prepare



## MINISTRY OF HEALTH: ONTARIO HEALTH AT HOME PROGRAM

### Personal Support Worker:

- Hygiene routines (hair, shower, teeth, etc.)
- Light meals preparation
- Light Housekeeping
- Other Health Supports

<https://ontariohealthathome.ca/>



## ACCESSING ONTARIO HEALTH AT HOME

1. **Call** your area Ontario Health at Home office
2. **Tell** the case manager you need personal support worker for your son/daughter (we can provide a list of support required)
3. **Arrange** a home visit to complete the Assessment.
4. **Apply** for care:
  - Traditional PSW (agency provides staffing)
  - Cluster Supports (shared PSWs)
  - Family Managed Home Care (family gets funding to hire staff directly)

**Tool:** [Family Managed Home Care Tip Sheet](#)

***Contact Jen or Cathy if you want help to prepare***



LOCAL  
AGENCIES  
AND  
SERVICE  
PROVIDERS

1. Think of them as PARTNERS
2. Educate and inform them about PWS
3. Get involved – committees, board positions, community events, fundraisers
4. Ask for an OPWSA introduction to senior staff



## PLANNING

1. ***Person-directed planning*** is important to lead their best lives, today and in the future
2. Financial planning
3. Legal considerations
  1. Guardian/substitute decisionmaker
  2. Estate planning – for you and for them
4. Siblings – involve them
5. Circle of Care – ask for the help

# PLANNING



What is DSO   How to access services   Funded services   **Housing**   Resources   Find your area DSO

## Step 1

Exploring and understanding housing needs and wants, and creating your housing plan



## Step 2

Reviewing housing options and locations



## Step 3

Financing the plan



## Step 4

Managing housing supports



## Step 5

Building a plan that will support change



## Step 6

Learning from others



<https://www.dsontario.ca/housing/welcome-to-the-dso-housing-toolkit>



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# **FAMCARE**

# **International Prader-Willi**

# **Syndrome Association**

<https://ipwso.org/information-for-families/>



4 weeks

## FAMCARE's mission

Education and support **for** parents, family members, carers, persons dealing with people living with PWS **from** parents and experts well-experienced with PWS – all over the world.

Thank you for your attention!



34 years

# Most Stressful PWS Traits

Food related



Anger



Arguments

Temper tantrums

Inability to cope with change



Skin picking

Perseveration



Excessive Talking

# Families' Desires

Residential services

Professional information & advice

Education from other parents

Availability of PWS knowledgeable professionals

Job / activity centres

Respite centres

Support for families

Improved societal & government awareness of PWS

???



Nutrition Workshop



BIRD Institute - PWS diagnostic laboratory Italy

# Topics

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- Coping with Change
- Duty of Care
- Exercise
- Health Checklist
- Healthy Adult Life
- I Want the Same
- Law Enforcement Matters
- Life Plan
- Managing a Meltdown
- Motivation
- Personal Care
- Preparing for When Parents are Gone
- Promoting Positive Behaviour Throughout Life
- PWS Awareness for Professionals
- Skin Picking
- Story Telling
- Strength in Boundaries
- Support Through COVID19
- The Importance of Planned Purposeful Days
- Too Hot Too Cold
- Transitional Years
- When Rituals Become a Problem

# Guide to Me



This document is to be completed through the cooperation of the person with PWS and his/her trusted family member or caregiver. It contains sensitive and private information to be used confidentially to attain or maintain the best quality of life for the person with PWS. All of the information may not be relevant to all people with PWS, so chapters of this document can be selectively omitted. This document has been adapted from the original by Kate Beaver (PWSA USA) for IPWSO use.

*Please download as many chapters as needed and make your own Personal History folder.*

## INDEX

Chapter 1	About Me	p.2
Chapter 2	My Possessions & Interests	p.8
Chapter 3	Home	p.12
Chapter 4	Current Education or Employment Status	p.14
Chapter 5	Healthcare History, Needs & Current Services	p.17
Chapter 6	Personal Care	p.21
Chapter 7	Financial Information	p.23
Chapter 8	People who assist Me	p.25
Chapter 9	Some Final Thoughts	p.29
Chapter 10	Religion/Spiritual	p.30

## Information For Families

Information for families

by IPWSO

Playlist • 18 videos • 79 views

Information and advice for families about Prader-Willi syndrome. These presentations were recorded at ...more

▶ Play all

14 only care home for PWS adults in South Africa

15 When PWS moves out: Our family's transition...

16 Friendships and Beyond: Navigating Relationships and Sexualit...

17 Responsible parental care during transition to adulthood in...

18 PWS 10 years out of the family home: Self...

### Adult Life

In this section we link to various guides which may help when you are supporting an adult with PWS.

Guide to: Meeting with professionals

Guide to: Prader-Willi syndrome and Duty of Care

When someone with Prader-Willi syndrome is in trouble with the law

Read more

Read more

Read more

Guide to: The importance of planned, purposeful days

Guide to: Too hot, Too cold: Abnormal temperature sensation

Guide to: Preparing for the future: When parents die

Read more

Read more

Read more

### A Guide to Me

This 30 page document is in 10 chapters and makes up a "personal history" of the person with PWS. Available for caregivers, support workers, teachers and service providers. The document has been adapted from the original by Kate Beaver (PWSA USA) for IPWSO use. It is a generic document and can be changed and altered according to individual needs.

Download PDF

<https://ipwso.org/information-for-families/adult-life/>





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Working Toward an Independent Future

- **Breakout #1**
  - Group A – Under 25
  - Group B – Over 25
- **Breakout #2 - Planning and Supporting Community Involvement and Engagement**
- **Breakout #3 – Local Connections**