

# Caregivers' Forum

Meeting Notes | Wednesday 25 June 2025  
3:55pm MST time, Phoenix, Arizona, USA

**Meeting held as part of the United in Hope: 2025 International PWS Conference (Professional Providers Program.)**

## **Attended**

**Presenters:** Shelly Cordner, IPWSO (UK), Lynsey Moorehouse, Caregiver Delegate (Ireland)

**From IPWSO's PPC Board:** Lynn Garrick (USA), Patrice Carroll (USA), Mary K. Ziccardi (USA.)

Other participants attending the meeting were delegates of the conference and represented Australia, Canada, China, Egypt, Ireland, Japan, Hungary, Mexico, Netherlands, Switzerland, UK, USA

**Please note in accordance with [IPWSO's Privacy Policy](#) we do not release the Zoom recording of the meeting, or list the names of general Forum Members without their express permission.** PPCB and Caregiver Delegates have given advance permission to have their names listed in the Forum.

Members should contact Shelly Cordner [scordner@ipwso.org](mailto:scordner@ipwso.org) in the first instance if they wish to connect with specific Forum Members over email.

Agenda:

## **Overview of the IPWSO Caregivers' Forum (Shelly Cordner)**

### **1. About IPWSO**

Shelley shared that IPWSO supports families, professionals, and caregivers in PWS worldwide. It has 47 member associations and a small core staff, supported by three key boards: Clinical & Scientific, Family Care, and Professional Providers and Caregivers. These boards guide initiatives and share expertise globally.

### **2. Role of Caregiver Delegates**

Delegates link IPWSO, national associations, and local care providers. Twelve countries have appointed delegates, including (in attendance) Mark Lister (USA), Lynsey (Ireland), and Kim Herivel (Australia). Delegates are vital, especially in countries with few caregiver connections.

### **3. How the Caregivers' Forum began**

The forum began after a 2024 Berlin conference discussion. It is an online space which aims to connect and support caregivers, especially in countries with limited networks, through shared resources and community-building.

#### 4. Forum Activities

The forum hosts three online meetings and newsletters per year, offers a dedicated webpage, and invites all caregivers to join and contribute. It's designed to be inclusive, practical, and caregiver-led.

#### 5. Topics of Interest

Common discussion themes include behaviour, grief, residential options, and family dynamics. Other topics: transitions, diet, staff training, and restrictive practices. Each meeting ends with an open discussion.

#### 6. Forum Challenges

Barriers include language, time zones, limited funding, and caregiver fatigue. Despite this, the forum continues to grow, with a focus on being flexible, inclusive, and supportive.

### Live Mini-Forum Discussion: Lynsey Moorehouse

**Topic: Supporting individuals with PWS in care settings that use less restrictive approaches.**

Lynsey led a live discussion on **restrictive practices**, emphasizing the challenges faced by caregivers supporting individuals with AWS/Prader-Willi Syndrome in settings without syndrome-specific services.

#### Key Issues Raised:

- **Access to syndrome-specific environments** is limited.
- Caregivers must often adapt strategies within general services.
- **Restrictive practices** must be balanced with **human rights laws**, especially where blanket restrictions (e.g., locking kitchens) may infringe on the rights of residents without PWS.

### 1. Case Studies and Peer Sharing

#### a. Ireland Case (Lynsey)

A young woman with PWS was moved into a non-specialised service due to a crisis:

- A private upstairs apartment space was used to reduce environmental stress.
- A multidisciplinary team supported her from day one.
- Social stories, tailored routines, and staff training were implemented immediately.
- Outcomes were positive despite the environment not being ideal.

#### b. USA Case: Roommate Incompatibility

- Two incompatible residents (one with PWS, one with a personality disorder) led to escalating issues.
- Shared restrictions didn't work.

- One resident later transitioned into a customised care setting and thrived - lost weight and gained independence.

#### **c. Creative Adaptations: Garage Fridge**

- A home with shared residents installed a second fridge in a locked garage for PWS dietary needs.
- Created a buffer that respected both individuals' rights and needs.
- Use of alarms on main fridge doors helped staff monitor food access.

#### **d. Assistive Technology**

- Mentioned as a promising but underutilised support tool.
- Examples included alarmed doors, coded cupboards, food portion control systems.

#### **e. Importance of Training**

- New staff unfamiliar with PWS can cause distress or lead to manipulation by residents.
- Emphasis on comprehensive training for new hires, including online modules and clinical in-service sessions.

#### **f. Staffing Ratios and Mixed Houses**

- Homes with mixed-needs residents require carefully planned staffing ratios.
- Without the right support, restrictive practices can become ineffective or ethically problematic.

## **2. Forum Takeaways and Reflections**

- **Peer support is powerful.** Caregivers valued learning from each other's challenges and creative solutions.
- **One size doesn't fit all.** Individualized planning and empathy are essential.
- **Cross-border learning** helps identify new strategies and technologies.
- **Forum members want more collaboration**, not just within their countries but internationally.

## **3. Next Steps**

- The **next forum session is scheduled for Thursday September 25, 8pm UK time.**
- A sign-up link will be distributed after the meeting.
- Shelly encouraged everyone to participate, contribute topics, and invite colleagues.

#### 4. Closing

Shelly and Lynsey thanked all participants for their openness and shared wisdom. The discussion was praised for its depth and collaborative spirit.

Participants were encouraged to:

- Stay involved in future forums.
- Share resources via the IPWSO caregiver portal.
- Advocate for better training, funding, and support in their local systems.

To sign-up for the Forum visit: <https://ipwso.org/news-events/caregivers-forum/>

For detail on all upcoming IPWSO events visit: <https://ipwso.org/news-events/>