

# Caregivers' Forum

Meeting Notes | Thursday 22 January 2026, 1pm UK time

## Meeting 05.

### Attended

**From IPWSO:** Shelly Cordner (UK), Farisha Colbourne (UK), Tony Holland (UK)

**From IPWSO's PPC Board:** Neil Gumley (Australia), Myles Kelly (UK), Lynsey Moorehouse (Ireland)

**Caregiver Delegates:** Bastian Bühler (Switzerland), Kim Herivel (Australia), Mark Lister (USA), Mariam Muritala (Ireland), Jannik Sayoudi (Denmark)

Other Forum Members attending the meeting represented Australia, Canada, Chile, Colombia, Denmark, Ireland, Norway, Switzerland, UK, USA

47 people in total attended.

**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

#### 8pm: Welcome to the Forum

Shelly and Neil gave a brief welcome and introduced Susanne. Topic of ***Ageing in PWS***.

#### 8:05pm: Susanne Blichfeldt, MD, The Danish Prader-Willi Association, IPWSO Clinical and Scientific Advisory Board (CSAB), Denmark.

Susanne's Presentation, AGEING IN PRADER-WILLI SYNDROME What do we know. What can we do to avoid too early aging is available to watch here.

A PDF of the slides can be downloaded here.

A copy of the Aging signs in PWS checklist which was included in the presentation is available here.

#### Overview:

- To tell that early physical ageing is not a rule for all with PWS
- To give information about medical facts and possible treatments (PWS.)
- To avoid too early ageing, because of lack of knowledge about medical needs
- To secure a focus always on individual needs, also with changes and ageing
- We still need to learn more, more research is needed about PWS and ageing

- We must avoid false expectations, that can arise without documentation
- And you to day are the experts, so we look forward to learn from each other

### 8:35pm: Open Forum Discussion

The Forum Members talked about how aging in people with PWS is still very new territory, mainly because many people with PWS are now living much longer than they used to. This is a good thing, but it also means caregivers and professionals are figuring things out as they go. People shared that aging looks very different from one person to another. Some individuals seem to age earlier, physically or mentally, even when their weight is well controlled, while others in their 60s or even 70s are still active and doing well. Genetics were mentioned as a possible factor, including whether certain genetic subtypes might be linked to earlier aging, but there isn't enough evidence yet to say for sure.

Weight came up often as a major influence on health as people age. Examples were shared of people who did much better once they moved into structured homes where diet was managed properly. At the same time, it was clear that weight doesn't explain everything, since some people who were never very overweight still showed signs of decline, while others stayed healthy. Swallowing problems were mentioned as something seen in some older adults, possibly related to muscle aging, and in some cases severe enough to require feeding tubes.

There was discussion about bone health after a parent shared concerns about their young adult daughter having multiple fractures after simple falls. Susanne agreed that osteoporosis should be checked for, even in younger adults, and that growth hormone deficiency can play a role in bone weakness. Growth hormone treatment in adulthood was talked about, with big differences between countries. Some places allow or even encourage adult growth hormone, while others do not. Testing and ongoing conversations with endocrinologists were encouraged, especially as research and advocacy in this area continue.

Behaviour changes with aging were also mentioned. Many people felt that behaviour often stays fairly stable when care is consistent and staff understand the person well. When behaviour gets worse, it is often because something in the environment has changed, such as staff turnover, loss of routine, or changes in living arrangements, rather than because the person themselves is declining. Dementia was discussed, but carefully, since there are still not many older adults with PWS and not enough data. It was noted that grief, depression, or long-standing mental health issues can look like dementia and need to be considered.

A strong theme was the importance of noticing changes over time. Medical and behavioural issues are easier to catch when someone has known the person for years, but that is harder when staff change frequently. Keeping good records and doing regular check-ins was seen as very important. Some programs use regular functional assessments to track things like daily skills, how long tasks take, interests, and independence. These help spot small changes early so they don't get missed or blamed on the wrong cause.

Loss and grief were talked about, especially the loss of parents or long-term caregivers. These losses can deeply affect people with PWS and may lead to depression or behaviour changes. Planning ahead for who will advocate and stay connected as parents age was described as difficult but necessary. In many cases, staff end up becoming the main long-term support, which makes consistency and emotional awareness even more important.

Exercise and staying active was discussed. Walking was mentioned as one of the easiest and most useful activities, especially when done with staff, since it also allows time to talk and

connect. Keeping both the body and mind active was seen as important at all ages, even if activities need to be adapted over time. Physical therapy was recommended, especially to help with posture, back and joint problems, and pain that people may not be able to explain well. Yearly physical therapy assessments were suggested as a good standard.

Overall, the group came back to the idea that people with PWS living longer is a positive outcome, even though it brings new challenges. Caregivers were recognised as being central to successful aging, with consistency, observation, routine, and understanding often mattering as much as medical treatment.

### Notes from the Zoom chat

Discussion in the written chat added strong examples of how often real medical or mental health changes in adults with PWS are dismissed as “just behaviour” or learning disability, especially by professionals who don’t know PWS well. Several people shared that they regularly have to push for proper investigations, particularly when someone is seen as “too young” for conditions like osteoporosis, dementia, or cardiovascular issues.

There were practical reminders from residential providers about treating any sudden change as a change from baseline, not as laziness or refusal. One example involved dangerous blood pressure spikes and withdrawal from activity despite normal test results, highlighting the need for close monitoring, documentation, and looking beyond obvious causes.

The chat reinforced how critical consistent staff are for noticing early changes. Multiple people confirmed that long-term staff are often the first to recognise when something is medically wrong, even when tests initially appear normal.

A brief but important point was raised about hyperphagia appearing to lessen in some older adults, with the suggestion that this may be learned social behaviour rather than a true reduction in food drive.

Transitions were again flagged as a trigger for behaviour changes, especially moving from the family home to residential care. Members shared that these changes often settle when routine, communication, and relationships are actively supported.

### 8:25pm: Close and Thank you

The next meeting of the Caregiver’s Forum is scheduled for **Thursday 21 May 8pm UK**, on the topic of **Nutrition, structure, and safety in PWS residential care settings**.

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