

Caregivers' Forum

Meeting Notes | Thursday 21 May 2026, 8pm UK time

Meeting 06.

Attended

From IPWSO: Shelly Cordner (UK), Tony Holland (UK)

From IPWSO's PPC Board: Patrice Carroll (USA), Myles Kelly (UK), Lynsey Moorehouse (Ireland)

Caregiver Delegates: Bastian Bühler (Switzerland), Kim Herivel (Australia), Julie-Anne Quinney (New Zealand), Jannik Sayoudi (Denmark)

Other Forum Members attending the meeting represented Australia, Canada, Chile, Colombia, Denmark, France, Ireland, Netherlands, New Zealand, Spain, Sweden, Switzerland, UK, USA

51 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 in the first instance if they wish to connect with specific Forum Members over email.

Agenda

8pm: Welcome to the Forum

Shelly gave a brief welcome and introduced Ingrid. The topic was ***Nutrition, structure, and safety in PWS residential care settings.***

8:05pm: Ingrid Hutchinson, RD CORU, Clinical Specialist Dietitian, Resilience, Ireland

[Ingrid's presentation, *Nutrition, structure, and safety in PWS residential care settings* is available to watch here.](#)

[A PDF of the slides can be downloaded here.](#)

Overview:

- Structured and consistent nutrition is essential in PWS
- Food security (predictable meals and routines) reduces anxiety
- Care is person-centred and trauma-informed
- Individualised nutrition plans guide support
- Safety and risk management are a priority
- Multidisciplinary teamwork supports best outcomes

8:15pm: Open Forum Discussion

What types of "pace and chase" methods are you finding successful in Ireland?

This was described as the pace at which the individual is eating, what are the bite size approaches? And then chase is allowing that time to ensure proper swallow after. So, it can be counting to a certain measure or using different techniques that the caregiver utilises to prevent choking and ensure a proper swallow.

Ingrid explained that in Ireland this kind of support isn't led by dietitians, but by speech and language therapists. If there are concerns about pacing or swallowing, the person gets referred for an assessment. The strategies are then tailored to the individual, for example things like changing portion sizes, pre-cutting food, or using hand-over-hand guidance. Dietitians still work alongside them, especially when it comes to textures or consistencies, but it's a shared, multidisciplinary approach.

From the chat: A Forum Member in Australia mentioned that what was being described sounded very similar to their own service, which shows there's a bit of shared practice across countries, and that speech and language therapists are referred to as "speechies" in Australia.

What is best practice staff training and induction for PWS houses?

Staff training is quite detailed and covers several areas. Staff are taught the basics of nutrition and how PWS affects dietary needs, including why portion sizes are smaller and why strict measuring is important. Food security is a key topic too, along with the idea that people in these services have agreed to a structured model of care.

Staff are also trained on practical things like following recipes exactly, avoiding talking about food in front of residents, and understanding how hyperphagia affects behaviour. Consistency is key. Everyone needs to follow the same plans, almost like they would with medication.

Are there any medications available that have been explored or used to help suppress appetite and reduce hyperphagia in individuals with PWS? If so, how effective are they?

Patrice and Tony explained that there is currently one medication approved in the United States (VYKAT), but opinions on how well it works are mixed. Some people find it helpful, others don't.

The general feeling was that even if it helps a bit, it won't replace proper dietetic support or food security. There were also concerns that families or staff might relax too much if they think medication will "solve" the problem, which could be risky.

How do levels of food control in PWS settings vary globally - from fully locked kitchens to more open environments?

A big discussion focused on how different countries manage access to food.

In the USA and Ireland, the typical approach is very strict - locked kitchens, cupboards, and fridges. In France, they also restrict access but emphasise involving the person and explaining why.

In contrast, one example from Scotland described a less restrictive approach, where individuals help prepare meals and have some access to food, with support. Others, like in

Canada, combine strict locking with giving the person structured choices (for example choosing meals or preparing certain foods themselves).

Practices vary a lot, but most people agreed that some level of food security is usually needed, even if how it's done differs.

From the chat: In New Zealand they lock fridges, cupboards, and even rubbish bins with formal approval in place.

In Ontario, Canada, someone said everything in their setting is locked and approved through care plans, again showing a structured, regulated approach.

Others pointed out legal challenges. In Denmark, it is classified as a use of force to lock the kitchen. They have to make declaration of consent with each person with PWS, but it can be withdrawn by the individual at any time. In California, USA, locking food can be seen as violating human rights under certain rules.

There was also an interesting idea in the chat about having two kitchens - one fully locked and another "training kitchen" with no stored food - which fits with the idea of balancing safety and independence.

How might reducing food restrictions in PWS settings impact underlying anxiety levels in individuals?

Again, this comes down to the individual. Strict environments have saved lives, but there's growing interest in whether some individuals, especially younger ones, might manage with less restriction.

However, loosening things too much can lead to higher anxiety or behavioural issues. The key point repeated throughout was that everything needs to be tailored to the individual, based on their ability to manage food and their overall wellbeing.

From the chat: One of our individuals prefers all items to be securely locked, as this helps to reduce his anxiety. I agree - it needs to be individualized.

How are services responding when regulations or legal frameworks view food restriction (e.g. locked kitchens) as a violation of human rights, despite its importance for food security in PWS?

Different countries handle this in different ways. Some require formal approvals or documentation to justify restrictions as being in the person's best interest. Others use legal frameworks like guardianship or supported decision-making.

In Ireland, people usually consent to the service model, but if there are concerns about capacity, professionals can assess whether restrictions are still necessary for safety. Overall, services often have to show that any restriction is the least restrictive option possible.

From the chat: In the USA, rules vary by state and you can only lock food if everyone in the home needs that level of restriction.

Others said they have to build a full case and submit it to authorities to justify restrictions, and that the process can be long.

Overall, Members in the chat reinforced that services are constantly balancing legal expectations with safety needs.

How does consent to food security measures work in practice, and what happens if someone withdraws that consent?

In some places, people can leave the service if they no longer agree. In Ireland, there are systems to assess whether someone has the capacity to make that decision, especially if removing restrictions could cause serious harm.

It's a complicated issue, because it sits between respecting autonomy and keeping people safe.

From the chat: In Denmark, locking kitchens is classed as a use of force, so consent has to be formally recorded and can technically be withdrawn at any time.

One person said in practice none of their individuals had actually taken consent back because they understood they needed the support.

Other comments mentioned similar systems where consent is reviewed regularly or formally documented with professionals and family involved.

Trust between staff and residents plays a big role in making this work day-to-day.

What strategies can be used when individuals access food outside agreed plans or break food-related rules?

This can be really difficult. Sometimes it leads to major risks and even the person having to leave the service. Staff try to work with the individual, understand why it's happening, and adjust plans if possible.

From a dietetic point of view, it can help to tweak meal plans - adding small treats or maintaining weight instead of pushing weight loss - to reduce pressure and cravings. Understanding the reason behind the behaviour is important.

From the chat: In worst case, they cannot live in our group home, if they don't want to consent to the locking of the cabinets. It very much relies on the good relation and trust with the caregivers.

How to give people more control over food safely?

Ideas included letting people help with menu planning, offering choices between meals, preparing food with support, or choosing flavours and ingredients. Some services even involve individuals in staff training or education.

Another important point was teaching people about nutrition, so they understand their choices. This can reduce anxiety and help them make better decisions.

From the chat: One service described having separate apartments with kitchens and shared house rules, including things like not eating in front of others to avoid triggering behaviours.

There was also a question about practical details like what happens to leftover food when choices are offered?

How to manage situations where some individuals cope well around food and others don't?

The answer again came back to individualisation. Some services adapt by giving certain people more opportunities to prepare food in controlled ways, like pre-portioned ingredients.

However, it was acknowledged this is difficult, especially in shared settings where one person's freedom could affect another person's safety.

From the chat: There was an example from Switzerland, where they have different living setups in the same building. Most people live in a fully restricted group home, but one person who can manage more independence lives in a separate apartment and only uses the shared system when needed.

There was also a comment about someone who had been considered "okay" around food but later died after overeating, which highlights how risky it can be to assume someone is safe long-term.

How can environment and design help?

Towards the end, there was a more general discussion about improving support.

People suggested that the design of buildings could help, like how kitchens are positioned or how visibility is managed. Technology was also mentioned, such as fridges that only open at certain times.

9:20pm: Close and thank you

There is no one-size-fits-all approach - support must be tailored to each individual while keeping safety central, with shared challenges across countries around balancing safety, independence, and legal requirements.

The next meeting of the Caregiver's Forum is scheduled for **24 September 1pm UK time**, on the topic of **Medical and physical health needs of residents with PWS**.

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