

# Caregivers' Forum

Meeting Notes | Thursday 23 January 2025, 7pm UK time

## Meeting 02.

### Attended

**From IPWSO:** Shelly Cordner (UK), Nora McNairney (UK)

**From IPWSO's PPC Board:** Neil Gumley (Australia), Patrice Carroll (USA), Lynn Garrick (USA)

**Caregiver Delegates:** Bastian Bühler (Switzerland), Kim Herivel (Australia), Myles Kelly (UK), Lynsey Moorehouse (Ireland), Julie-Anne Quinney (New Zealand), Jannik Sayoudi (Denmark)

Other Forum Members attending the meeting represented Australia, Austria, Denmark, India, Ireland, United Arab Emirates, UK, USA

33 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

### 7pm: Welcome to the Forum

Shelly gave a short welcome and housekeeping introduction. Topic of ***The Experience of Grief for Residents and Staff in a PWS Residential Setting***. Speakers were introduced to frame the topic.

**Barbara (BJ) Goff**, Ed.D, Prader-Willi Specialist, Professor Emeritus, Westfield State University, MA, USA and **Larry Genstil**, Ph.D, Psychologist, Prader-Willi Specialist, Sha'are Zedek Medical Center, Jerusalem, Israel, attended to give a brief overview of their plans for a survey, presentation and workshop on this important topic at the [United in Hope: International PWS Conference](#) taking place in June.

### 7:05pm: BJ Goff and Larry Genstil

BJ and Larry have been focussing on the experience of grief in PWS in 2 ways.

1. For someone with PWS who is living in a residential setting, their grief over a very close loved one – typically a parent. How are caregivers supporting them through that? And what needs to be done to make this a better experience for the individual and the staff?
2. The experience of a staff person working in a residential setting, losing one of their residents. BJ shared that she had been through this recently with some staff and in that example there was very little support.

These experiences are ongoing. For individuals with PWS, as they are aging, so too are their parents and they are more likely to lose them. It's the direct service staff who are frontline supporters for them, and so we want these staff to describe what that experience is like, whether they feel qualified to do it, and what they need more of to support those individuals.

We suspect that agencies do not provide training, do not provide a whole lot of support to the caregivers or the individual – BJ clarified this was from her experience. (And she hopes she's wrong!)

The other area that BJ mentioned was staff grieving over losing a resident. What do they get from the agency, if anything? Do they get any counselling? Do they get any time off? Do they get any acknowledgement, or is it get back to work as usual?

So, BJ and Larry are developing a 2-Part survey. Part 1 is about supporting the individuals Part 2 is about the staff and what they need.

They want to come out of this with a deeper understanding of that experience and hopefully generate some recommendations to agencies. (Note: This survey will be sent to all Forum Members as soon as it is open.)

**Languages:** Larry will translate to Hebrew. Verena kindly volunteered to translate to German. If anyone would like to request translation into a different language, please let BJ and Larry know.

**Emails:** BJ: [bjgoff13@gmail.com](mailto:bjgoff13@gmail.com) Larry: [genstil@gmail.com](mailto:genstil@gmail.com)

Survey will close mid-April to allow time for analysis before the conference.

**Conference details:** Conference website: <https://ipwso.org/news-events/conference-2025/>

The presentation on this topic at the conference will be in a workshop format So, we'll get to hear from you from all over the world, your experiences, and be able to look at them in relation to what the data shows.

**For discussion:** We would love to hear if there's any specific questions that you think should be addressed in such a survey.

Do you have relevant documents that outline your organisations' strategies, advice, plans, on what to do when someone dies? Please share and it will help with recommendations from the study.

### 7:15pm: Open Forum Discussion (on grief)

- Q: Could you include the impact on the person living with PWS when a housemate also with PWS passes away?

A: Yes, this is something we've thought about incorporating so let's see if we can include it. A loved one could certainly be a housemate.

- Neil notes that for many years the life expectancy for people with PWS wasn't as long as it is now, because we have learned so much about better care for people with PWS. People are getting into their old age and it's a really new time where we're getting to understand ageing in PWS. Therefore carers are spending more time with people with PWS. His first experience with grief was someone with PWS who had a very close family member pass away while they were living in a group home. Lots of questions were around "What time will I be home?" "What time will I have dinner?" He felt the person perhaps wasn't able to fully understand the grief, but focused on what was important to them.

- Lynsey says they are supporting a young man who lost his mum. He lost her before he moved into a residential service. 6-7 years have passed, but it is still a huge thing for him. It affects him differently throughout the year. If his birthday or another special day is upcoming, it hits harder. (As it would for any of us.) They have observed there is a buildup of challenging behaviour. They try to find little ways – they have a rose garden that he planted so anytime he’s thinking of his mum he can go outside and think of her in the garden that he made for her. The place where mum is laid to rest is 2.5 hours away and while they do visit it, having the garden means he can have a place to grieve at home. So they find ways to bring her into the residential service, to allow him to talk about her whenever he needs to, to recognise that the grief is still there and to be sensitive to that.
- Neil notes we might grieve in different ways and expect someone to grieve in a “normal” way so it’s important to put yourself in someone else’s position and understand what they are going through. There is always a lingering effect of a loss.
- Lynsey also notes that staff teams tend to be quite young. They are having to deal with very complex issues at a young age. They may not yet have experience of grief in their personal lives. She gave an example of a child in one of their other services who passed away and the staff team were really devastated. It had a great impact on them. As a manager it’s really important to acknowledge that if a resident passes away it has a big impact – we spend more time with residents than we do our own families.
- So the age and life experience is very relevant and an agency really needs to recognise that and offer support.
- Neil asks what do agencies or providers offer in terms of education around grief? Even knowing how to participate in a funeral or speak at a funeral is not something he knew about when he was in his 20s. Families know that the carer has spent so much time with their child and might ask them to speak at a funeral.
- Kim gave an example of where in one of their houses a staff member passed away. They worked with the residents in the house to help them understand what it meant – there was education for both the residents and staff. One of her colleagues drew up a grief plan – a psychoeducation tool which tapped into how the egocentrism is going to impact on how the participants respond to grief. For example, they might look like they’re coping well but then a few weeks down the track, they’ll start to see some of the more standard signs of grief. The plan also tapped into some guidance for staff about what they can do for themselves as well. So, it’s kind of a bit of a dual-purpose plan about supporting the participants, but then also supporting the staff as well with their own grief as well as while they’re supporting the people in the house.

Kim has kindly de-identified and shared this document. [You can read it here.](#)

Via email Kim has also shared an additional document. In their team, one of the main resources regarding grief used is one that has been developed by Scope in Victoria for supporting people with a disability with grief. [We have made it available here.](#) This is from the website [www.easyhealth.org.uk](http://www.easyhealth.org.uk) where you can sign up for a free membership to be able to access many downloadable resources.

- Brett who also works at Interaction with Kim says that they also have a Professional Employee Assistance Programme which is funded by the organisation where staff can access, either face-to-face or remotely, supports from professionals, if they feel they need it. Interaction is not aware if they staff member uses the programme, it’s all confidential. In terms of pre-emptive planning, they do tend to be reactive if something

happens unless, someone is in palliative care in which case they do try and put a plan in place. They do wish to think about how they can improve.

- Neil asks if we do need to be more pre-emptive. We do staff training in lots of different areas but this topic is not typically included in staff training.
- BJ wonders if the frequency of occurrence really warrants pre-emptive training. Oftentimes training opportunities are scarce and so organisations really put a lot of focus on behaviour management. But it would be lovely to hear of where it is part of the training programme, particularly where the home has older residents it may be more relevant.
- Jessica (also at Interaction) shared that she is quite new to PWS with a background in Mental Health. Because in Australia there are a lot of legislative requirements, in previous roles where there has been the loss of someone they supported, there was a training programme for this and she hopes they can bring that to Interaction. They will go through expectations with staff, what it might look like if a participant passes away, the legal aspects, but also preparing them emotionally and making sure they know there are systems in place, debriefing, clinical supervision, regular check-ins, what reporting might look like, what they might be asked, and working with them to navigate any feelings of blame or guilt. End of life is a part of the process and most of their participants are with them until the end of life, especially in a residential setting so it is really important to be prepared, and also to make sure that as management they are providing staff with comprehensive support, access to services, time off if they require. Also encouraging them to be able to say goodbye, have contact with family, attend the funeral. Sometimes in disability it falls on the organisation to plan the funeral so also preparing staff and making sure there are policies in place around what that looks like and what the company's obligation is. It's a comprehensive process and there are programmes that do have these pre-emptive plans it's just a question of how it is shared across the sector so that everyone is doing the right thing. Not only for the person with PWS and staff, but organisations as well - there is a lot of legislative work and reporting that is required – a lot of time staff really struggle with that. When questions are being asked of them it can be quite emotional for them so they need to be supported through that process as well.
- Brett also shared about a resident who passed away last year and lived in a group home for a very long period of time. But there was quite a strong connection between that participant's family and the organisation. So, there was a bit of support for the family as well, after she'd passed away, as well as for the staff and the other participants. But the family were also very keen, because they visited regularly and had a strong connection with the other residents in that house, to continue that after their loved one had passed away. They felt there was a bit of continuity in terms of the connection they had. So, there's been a maintenance process around how that works. For people with PWS, for consistency and routine, that is something that we might have to consider, about whether people would be willing to continue to visit. It's a really complex issue.
- Julie-Anne points out that, in her experience, there's a lot of grief outside of death. Recently she worked with a person who went through a heartbreak, and it was devastating for them. She didn't feel well equipped to help. There's lots of things that happen, not being accepted, losing jobs because of things changing, because of their PWS. Quite a lot of grief outside of death.

- Neil agrees that not feeling accepted is a really big issue. There are many different faces of grief and how it looks and how people understand it and look at it. Also to Brett's point, the PWS community is close knit, so families grow together. It can be very difficult when a person passes away and suddenly the people in the residence with PWS no longer see that person's family. When someone does pass, how do we navigate what used to be a norm that is now no longer happening?
- Larry (who had to join the meeting late) explained that he ran a group home for people with PWS from 1991 until 2000. He is still the psychologist there. In the late 90s they had a couple of parents die, and the families did not allow the PWS residents to participate in the funerals, the grieving process. They thought that was horrible and also saw reflections the grief in their behaviours. Around 2001, their psychiatrist at that time suggested they do a bereavement group. 12 or 13 residents that had lost first degree relatives over the last several years, none of whom had participated in the funeral or the grieving process.
- In the Jewish religion, after the funeral you sit (shiva) for seven days and people come and visit you and console you, and then you go back and set up a headstone and then for the first 30 days, you also are more grieving and then after that for the next 11 months. So, it's a process in the Jewish religion, that I think is very healthy because it's gradual and you're grieving heavily in the beginning and less and less and less.
- With our PWS residents, that wasn't really viable and in our group we met once every two weeks for a year and a half. We had them bring led pictures of the person they lost. We had them write letters of farewell because they had never really said goodbye to them. We had them visit the gravesite with family members or with staff members, whoever was available, and we had them talk about how they felt, and we emphasised the feelings.
- We discovered that our people did not go through Elisabeth Kübler-Ross's [stages of grief](#), they were very different. They were in shock, and then very, very sad and missing (the person). But we didn't see the "why me" level, we didn't see the anger. We did see gratitude that they were allowed to participate finally and start expressing the feelings, and then we made it clear to all of our parents. That they have to be full participants in any grieving process. So that's what we've done ever since and since then, I still don't see Elisabeth Kübler-Ross's stages of grief in our people. But we do see shock and pain and missing, and they talk about a lot. And we try to encourage that. We talk a lot, a lot about mourning and morning rituals.
- Neil says Larry has touched on not yet mentioned which is the cultural aspect, different ceremonies, different kinds of memorials and funerals. There is often food attached to these services and it's important to navigate through that in a safe environment for everyone.
- Larry notes that in the Jewish religion, the funeral is almost immediately after, within 24 hours after the death, if it can be done. So, the grieving process can start. Elsewhere people sometimes have the funerals more days or weeks after the death, and so there's a different kind of grieving process. With their residents they are offering a lot of support, a lot of talking about it. The staff don't really know how to react, so there's some talking about it with the staff, but it's a very cultural kind of thing too, because a lot of the staff are Muslims and they have a different process, but all are aware of the other cultures and all participate in the different processes. Everyone tries to be as helpful and empathic as they can.

At this point in the meeting Neil highlighted an email sent by the team at Solvang ApS, Fejø, Denmark very helpfully sent ahead of time which shares their process when someone dies. Brian also described some of the tools they use which are described in the email below.

### **GRIEF PLANS AND INITIATIVES ON SOLVANG**

At Solvang we have several initiatives that help us to be as ready as possible when a resident finds themselves in times of grief.

For the staff we made a binder containing sources of inspiration and guidelines to how best to support a resident through the grief process, when another resident, next-of-kin or staff dies.

Our material treats of expected death and what to do in case of a not expected death. We gathered relevant telephone lists, general information about grief stages, sources of inspiration to making a memorial book and a memorial table, inspiration to rituals and memories, important jobs and considerations, what to be aware of regarding resident behaviour, references to relevant literature, and what to remember concerning 'last will and testament'.

If/when a resident on Solvang dies, it is our intention that the staff make a memorial table with pictures of and short stories about the deceased. We will have a physical box ready containing candles, tablecloth, pictures, and photo books to use on a memorial table. The small stories and pictures will help the remaining residents to remember the deceased's life and thereby inspire to conversations about the deceased.

Ea Nielsson and Brian Jakobsen, Bostedet Solvang ApS, Fejø, Denmark

- Bastian says in Switzerland they also do a table with a picture of the person and some simple easy to understand sentences about the person. They include something which was special to the person like a cap or article of clothing that the person might be known by, so that the other residents who maybe aren't able to read or have other context they see the article and they know who's passed away. They have had a good experience with that.
- Myles shared about an experience in 2021, he was based at a service which had 15 people with PWS living there. One man who had lived there since 1986 passed away quite suddenly. There are probably not many examples of this where so many people with PWS who had lived together long-term lost a housemate.
- Michelle who worked closely with that group explained that they do end of life training for the staff. This was a really sudden death. They arranged counselling for staff as well as for the people they support. They made the funeral arrangements – residents were given a choice over whether they would like to attend. They held a wake at the home and they did goodbye messages especially because it was sudden and they hadn't had a chance to say goodbye. They did a time capsule and planted a tree and a rosebush for him. Grief counselling was available for anyone who wanted it. They have support plans that approach the topic in a sensitive manner.
- Myles asked Michelle about the other residents in the house and what that grief looked like. For example, on the day of or the week after or the month after? Michelle responded that it's very individualised. There was shock. Some people were scared, they wondered is it going to happen to me? Some of the people they supported just carried on as usual. Some focussed on what benefits they would get from the situation. And some people, it made them have a fear as well. Is it going to happen to me? Some

were angry and were very some emotional also. Some worried about the impact on their own life and routine. They gave time for people to talk and work through it in their preferred way.

- Neil reflected on a previous experience where he worked with a person with PWS who had a close family member pass away. Initially there didn't seem to be much attachment. Their concerns were more around their own routine being disrupted. But as time grew, they expressed their grief in different ways. How their grief looks might be very different to what we'd expect so it's important to recognise the different ways it might manifest.
- BJ notes that staff, particularly without experience of PWS or grief, might mistake some behaviours, particularly if they occur months later. They might think that is just PWS rather than something triggered a memory of the deceased. A tantrum could be an expression of frustration because a friend is gone.
- Kim also picked up on different types of grief. She recounted they had a participant that was very attached to a support worker and that support worker moved on. That happens in the industry. The participant can't get wrap her head around that - she's had other support workers leave since then, but this one she still goes back to reminiscing about this support worker. And why won't this support worker talk to me? She tries to reach out on social media and the support worker doesn't respond and it's been about four years now since she's had any contact with that support worker, and even now when she starts to ruminate on that, on that person, the staff know that means there are other anxieties bubbling along for her so that has become a bit of a measuring stick of how well this young person is coping with life in general, if she starts to reflect on that relationship and the loss of that relationship.
- There was further discussion about challenging behaviour long after a person has died. Is it PWS behaviour or is it to do with the grief? Should we be recording all incidents and retrospectively considering if behaviours are normal for this person?
- There was an additional comment giving an example where the staff saw behaviours when an individual moved into the room of the person who had passed away, even though it was months later.
- Myles shared that he was browsing about the topic and came across a short document from PWSA | USA about grief in PWS. It covers possible grief reactions from a child or adult with PWS and talks about ways to provide support. It is an older document so maybe some things have changed, but it has good advice. [You can read it here.](#)

### 8:10pm: What Topics Would You Like to Discuss at Future Meetings?

- BJ says she has an interest in working with PWS staff of different cultures, and how that plays out in terms of agency policy, relationship with families, relationships with the individual. And it could be everything from food to, you know, their cultural beliefs about sex, drugs, rock'n'roll. In the states, and likely lots of countries, are hiring people from all over the world that have very different backgrounds.
- Trent agrees that is a really interesting topic as a lot of support workers in Australia tend to be recent immigrants and often have different cultural beliefs based on where they are from that might not necessarily mesh in with day-to-day things in Australia and it's interesting to discuss how to work together in these circumstances.

- Larry says that from working in the United States he observed people in residential care are often miles and miles from their families and that is a different culture. In Israel, it's a very small country and so everyone goes home every other weekend and every holiday and the parents are very involved. And while sometimes it's difficult to deal with parents, the connection is so important.
- BJ notes that in terms of loss, it can also be that the parents move far away and that feels like the person has lost their family. Then often other families might step in for the person, or often staff step in and are the ones to help celebrate the holidays and special occasions.
- Neil agrees there is a topic around how the staff do sometimes act as pseudo families. And where do you need to draw the boundaries? He has worked with staff who are literally family members to the participant, or who do step in because they have no one else. And it's important that they have those connections.
- Staff retention is also a struggle because in the in the disability sector it's sometimes a stepping stone to other jobs. So, you get these wonderful staff who come in for 2-3 years and make a huge impact on someone's life, but they're at university and they're only travelling through the industry. How do we deal with that? And that's grief as well, when a staff member moves on and someone who's had a very good close connection with people and they move on to their other, their other source of employment, how do we work with that?
- Julie-Anne also points out that quite often people end up in residential care because there's been crisis at home. That can often destroy the relationship between a child and their family. And quite often there's a lot of support needed to rebuild that relationship, and make a line in the sand so that you don't take over as family, that you really support that person to rebuild that rapport as mother and daughter, or mother and son.
- Neil says in Australia parents often try to manage everything themselves for as long as they can but get to a point of burnout. This can lead to a person with PWS moving to a residential home in their 30s and they've missed formative years of preparing to leave the family home and feel very displaced which can be very sad.
- Kim says she had a similar experience where a lady she works with lived at home, but her father has stress-related health issues, so they were taking steps to change their living situation. So, the steps had to be start started towards her moving out of out of home. There was the grief of the family home being sold, and working through that, but then trying to explain that she would go to live somewhere else and mum and Dad were going to go live somewhere else, still see each other a lot.  
But there are some funny moments that come out of it, her family were really good at trying to take some lightness throughout this whole stressful period. When they were selling the family home, the young lady was telling her mum and dad that they had to list it as a three-bedroom house because she was not leaving. And so, she was going to continue to live in the family home. So, I was working through all those processes with her about social expectations and that she couldn't stay there. It can be kind of a bit of a blend sometimes.
- Myles suggests that loneliness and isolation in adults with PWS is another important topic. It's touching and frustrating and in the UK, we hear about that a lot and we see it a lot. It would be interesting to know how others try to counter that, and what else we might be able to do as a community?



- Also raising awareness is a topic that we every so often talk about. How do people do it locally in their country, locally, regionally, nationally and how successful are they and how long lasting is it?

### 8:25: Close and Thank you

The next meeting of the Caregiver's Forum is scheduled for **Thursday 22 May, 1pm London, UK time**. Topic will be announced soon.

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