



IPWSO
International
Prader-Willi Syndrome
Organisation

IPWSO Caregivers' ECHO abstract summary

Nov 17th, 2021: Nutrition in PWS

Please note this document is abridged from audio transcription of the Zoom session. Some errors resulting from the transcription process may be present.

IPWSO hosts: Norbert Hödebeck-Stuntebeck (NHS), Hubert Soyer (HS) and Patrice Carroll (PC)

Presenter: Constanze Lämmer (CL)

[Video link](#)

“[Nutrition in PWS](#)” Constanze Lämmer, Senior Physician, Children’s Hospital, St. Bernward Hospital, Hildesheim, Germany

PDF of the PowerPoint is available [here](#).

[Q&A Following Constanze Lämmer’s Presentation](#)

HS: In your experience, do you think Hyperphagia is influenced by the right and healthy food/nutrition? If you start with children or if you start with young adults, is there a difference? Is the situation different now than previously?

CL: If you have the chance, treat children from the early beginning, that means from the age of three or six months on. We also help the parents to understand what's going on with this hyperphagia problem. We have the parents give very structured diets to the children and the children have never had a different experience, so they accept this diet, and this nutrition management is normal for them.

So we have a lot of children at school age who are very proud of their own food which they bring to school, for example. And children learn to react in Special Situations. That means if they were offered a birthday cake, for example, they accept that they then have to give their snack which they brought from home and change it to the birthday cake, for example. And I think this is necessary because we train children and parents from early beginning, and they’re not in a situation where the child gained weight, 10kg for example, in a very short time, because we always tell them, be careful, these are signs Hyperphagia, and if this happened, you have to do this. We have a lot of children between ages of 10 and 14 in a normal weight.

I think this situation changed dramatically. If you look back 30 years or 25 years, then we had a lot of 10 year old boys and girls weighing more than 100kg and the only thing we could do was to take to make interventions to come below 100kg, and we all of us

knew that next year we would see 120kg so I think this situation changed, I think the families and their children learned.

Also, the situation you have in the group homes which came from home and had a very good nutritional management also will continue this, and other ones who never had rules, for example, and never learned, you also have big problems.

HS: Did you also notice a change in the intensity of hyperphagia?

CL: I think that that there is a change. On the other hand side we look more closely to these different types of Prader-Willi syndrome because we have some adults and where their parents say that they never had a big problem with hyperphagia, but often these adults have very hard behavioural problems in other fields or are very autistic, for example. So, I think nowadays we look more and more into detail. Families do not always say that Hyperphagia is the big problem, in the most of the families, the behaviour is the big problem, and I think the hyperphagia is in the background, but with these clear rules on how to manage the weight, in a lot of families, it's not the first problem.

Q: We support 90 people across various group home settings. We support 45 females and a third of them are aged 45 and above. On your calorie calculation, is it still appropriate to give the same user the same calorie calculation for a 20 year old as it would be for a lady in her early 50s?

CL: If you look on the slide with the energy expenditure, you see that the basal metabolic rate is influenced by age and gender. All of us have the experience that if we eat the same amount of calories then we have eaten in our 20s or 30s, then we will gain weight. Because everyone's metabolism slows down a little, and you can compensate for this this with more exercise or being more active. Yes, but of course a 50 year old woman will need less calories than the 20 year old with the same weight and height.

Q: So the calories to centimetre of height for a 50 year old would be different to a lady who is 20?

CL: I think these calories are an orientation. If you have no idea, then it's a very good orientation to start with this. But you have also seen just the difference with activity which is 20 to 40% of the daily energy expenditure, so it can vary from day to day.

And it also explains why these numbers could be in orientation, and then you have to check the weight and then to decide, OK, for this lady, maybe these calories are too much to stabilise their weight. Yes, she needs less because she's very inactive and she's 60 yes and then it could be.

But our experience is and never go under 7 kilo calories per centimetre body height because then the clients will lose lean body mass. If you lower down the energy too much they will lose weight, but they will lose lean body mass. That's the reason for the

yoyo. So in this situation you have to start to build up muscles and offer more activities and stay with these calories. And, of course look for undetected calories.

Q: And broadly the same approach for males as with females? (**CL:** Yes) We have our doctor, when we were trying to give him advice on the calories to centimetre he thought for one particular female, this was almost cruel. He used the word cruel and we were saying, but her mobility is deteriorating and she's moving less and she's only aged 50. That's not normal for a 50 year old. So that will be really useful. I can't wait to share your presentation with my other colleagues.

CL: We had some young men who need 2000 calories to stay with their weight but then they are much more active, and of course maybe they have had growth hormone over years and then came to the group home with a better body composition, if you have the chance to look to the body composition, maybe it will explain the difference?

If there's someone with muscle mass close to normal, of course then these two third of the caloric energy expenditure are not two thirds. That's on maybe 90% because you have a muscle mass close to normal. But over time it will be necessary to be active to maintain this muscle mass and not to lose it, and then of course he maybe needs 2000 calories, but that's not a rule.

Q: We support a young man and he appears healthy and fit and well. He has about 2000 calories today, but his BMI is about 23. Does that sound OK for you?

CL: That sounds really good. And that's why these numbers are an orientation. And then it's always necessary to check the result. But if the result is the result you expected, that's fine. If someone is losing weight or you expect him to gain weight, of course you add calories, and then I would do it by 100K calories steps. And if someone does not lose weight, and with the calories they should, then the first thing is check the environment and then rise the activity and stay with him.

NHS: In our group homes we are more and more orientated on the real weight and we start as you said with an orientation of calories, but then we define with the client together, a weight which is good for him and good for the doctor and good for parents and so on. If this is the vision, then in the future, these people could be not orientated on calories but only orientated on variety and good quality of food, but not on calories and only on their own weight.

And so they coordinate, their meals more and more by themselves if they are in a good weight situation. This is a change from what we saw in previous years, that we must not be so focused on calories and we can more focus on the real situation and we can be more flexible with food and the person with PWS by himself can be more flexible when he is a good weight.

CL: I think what you mean is the red, yellow and green zone. At first you need a frame and you have to be close to an acceptable weight. We speak about this client, not with someone with 60 kilogramme per 160 centimetre, we speak about the clients which are

in a in a good situation of the BMI, as well. Not everyone has to be in BMI of 21 kilogramme per square metre that could be individual. That's not a problem. We will help them to stay healthy, overall. If you are in this region and this can be in the individual level for someone, maybe it's at BMI of 27, then there is a chance to have more interaction in the frame and we will learn together with the client this to understand the system - if I'm more active, my body needs more energy and I have more possibilities to eat something, to add something.

And on the other hand side, if I gain weight and come over my individual level, then I have to change something and then of course we can discuss with him, Would you like to change your meals or would you like to change activity. We have the chance to discuss it together. I think that's the new vision on this, and therefore I think the client need a frame. We can't say OK, it's only on you and if you have 160 kilogramme again it doesn't matter. We have a frame and we can discuss what happens and we define together. What can you do and where we can help you? And so on.

And of course, that's not only a focus on meals and on calories. But I think we can act in this way because we have this knowledge, how many calories someone needs and have this in mind.

NHS: Do the others have experience with this, that people with PWS handle these by themselves, orientated on their weight or do we have these experience which we have over many years? - We structure these things for them. We've started in some of our group homes people with PWS are more orientated on their own competence in this.

Comment: The 90 people we support, over the years we've increased their input and their autonomy around food choices, but the daily meals are still very much managed by the caregivers. We subscribe to the view to discuss foods too much with some people with PWS it's just stressful for them. So, we still plan on their behalf, but with their input and with their agreement. We've tried to become less restrictive in certain situations, so giving people a bit more control, a bit more access to the kitchen. For example, in some cases unsupervised access to the kitchen, which I'm told in some instances does work. So we have tried. Relax is probably the wrong word, but we've tried to become a bit more relaxed around the food management and sometimes it works and sometimes it doesn't.

Our company at the moment is very hot. Some individuals thinks we're being too restrictive around, PWS, and we're trying to make the case that if we're not too restrictive then it can lead to weight gain, in some cases very rapidly.

HS: Yes, I understand it depends on how much the people with PWS can involve by themselves to manage, and it's always in the frame as Constanze told us, but in this frame there are a lot of possibilities. And I think that's key to get a positive behaviour development.

Comment: Yeah, I'm always interested to listen to how others do it. Because I think sometimes it sounds and feels like there's a more subtle, more nuanced approach to managing the food.

Comment/Q: In Switzerland we do it in a similar way like you explain. We have one group home in my institution and there are only five people with Prader Willi and they have a range with their weight of plus/minus 2 kilogrammes. And when they are in the range they feel comfortable and free with their food. But when they are too low, when they when they lose weight, then they make their portions bigger by themselves. For example, the breakfast or the snacks between the main dishes, they make it bigger by themselves. And it's the same when they gain too much weight, then they make the portion smaller by themselves.

I have a question on the work or to the to the way we go with the people. Because five years ago we have no sugars at all in our group home. All meals were without sugar. Now we think about to make, especially for small snacks, that they can have cereal bars, normal cereal bars with sugar, and so this is my question. Do you think it's a problem when people are healthy when they have a good weight and when there is no sugar in all the meals that they can have cereal bars with sugar, as I might?

CL: I think if you look at the nutritional advice, we all have too much sugar and you have sugar even if you do not add it to your coffee. For example in fruits. That's one reason that we say we can't change fruits for vegetables. We have this part of sweets on the top of the pyramid and the idea is sweets should be less than 10% of the daily calories, and that's for healthy food not only for Prader Willi, and if you for example stay with 1,500 calories you can give 150 kilo calories as sweets. It's contained in marmalade, in Muesli, for example, or the sugar Muesli bar. And I think in this amount it's not a problem.

Now some parents say to us they can see it in the behaviour when their children get, for example sugar containing Muesli bars rather than sugar free Muesli bars, and they are much more aggressive after sugar, but that's interesting. I have no study about this, but some parents told us.

Chat: I see that many when they are learning about managing food they have this as their only activity and interest, and many become stressed, and they become very self centered and less interested in other activities, with which they were happy before.

NHS: About this experience, that if they are too much involved in managing food that there are not so many space for other things and that they are so focused on this and this makes stress for them. So what are other experiences with this?

Comment: I would agree. Everyone is so individual, so some of our folks, we know the more freedom that we give as far as food choices, that occupies their entire thoughts for the entire day. What is my meal plan for the day? How am I gonna get it? How much does it cost? And they can't attend to any other things. But then there are some

people that can help plan and prepare meals without any difficulties whatsoever. So it really is individual for us here.

PC: We have the same experience. What do you do when you have both kinds of people in the same home? Do you allow the person who can be OK around food to do some food prep and not allow the other person? What we've experienced is that if there are people in the house that experience that level of anxiety, then nobody is cooking, nobody is doing food prep.

Comment: We do both ways. In some of our homes if only one person was allowed to do it, there would be fists flying. But then some of our other homes it's just understood that when we talk about starting them cooking if it doesn't work, then we'll have to dial some things back. So the more preplanning you do with. we might have to change some things along the way if you get too anxious, that that does work for some of our folks. But the other people, if one person did it there would be lots of fighting going on so it all boils down to knowing your individuals and how they could respond.

CL: You have to qualify for this more self-controlled living and then bring together clients with PWS which can do this properly, and on the other hand side let clients together who needs more help and more control live together.

NHS: I think this is a good idea, but this is often not possible. We cannot change people from one situation to another, so they live there as a group. But the other question is how can we train them? I think this is an important question, I think if they are together and if we have a chance to train them to handle food or to understand all these things constantly present.

If we can transfer this knowledge to people with Prader Willi in a way that they understand, then they are more able to do this by their own and they are less fearful if they know more. Are there programmes, training, information?

PC: I'm wondering if even with all the training and all the understanding, is it possible? I mean, they may understand what they're being taught, but doesn't their impulse control then override that and put them in a dangerous situation, even if they have an understanding of it?

Comment: I've arranged the call in a couple weeks with Dr Tony Goldstone to try and explain to my colleagues the science and the biology and the physiology around the eating behaviours. If we're going to educate people on one level, how do we take that into account? The biology behind the eating behaviours and satiety cues, and all those kind of things?

HS: I think that's a really important question but I think we always can learn from our own body. If someone has the feeling this set amount of food is for me the amount I'm satisfied with, it's enough for me, and he can learn to switch always to these feelings and I think these are the programmes we have to give them to learn from her own body. What are the signs in your belly, what are the signs if you are getting stressed,

and teach them to have coping strategies. It needs a long time and it's an individual onset and therefore often we don't have the resources for that. That's our problem.

Comment: We've got so this data from two group homes. 8 people live in one service, male and female and one would argue that the control around food management and exercise is very well managed. The average BMI for the eight people there is 25. The average age is 35.

In the other 8 bed service, 8 males living together, where they seem to be a little bit more relaxed, the average BMI is 27 and the average age 39. So actually, although we have 2 slightly different approaches, the BMIs are still in a very healthy range.

HS: I think that's interesting. Even if there is an individual onset, I think you will always have effects. And so it's necessary to observe these things very closely as you did with your groups.

NHS: Can I ask about your talk with Tony Goldstone. Is the instinct that it is not possible for them to handle these things?

Comment: So Consensus is a very large group and roughly 15% of the whole of the Consensus population who have learning disabilities have Prader Willi syndrome. There are two or three people new to Consensus who think we're too restrictive and that people with Prader Willi should have more autonomy around their food and access to money. Now our initial response to that is to be careful because this is a highly successful model which has saved people's lives and extended their lives. If you start to tinker with that, for example if we said to 2 people who are deemed to have capacity in an 8 bed service, you now have access to the kitchen and greater access to money, we think that would have ramifications for the other 6 people who live there. Because we know a lot of people with PWS have that burning sense of injustice and we think they would respond negatively, some more than others, behaviourally

HS: I think that's important. We also have to look, if the person is changing, maybe all those structures around the environment have to change. If you don't need the same frame as someone else, I think it's our task to look at how we can build up an environment that's fitting to them and that's often not easy.

Comment: Of course we look at the data. Of the 90 people we support, say 50 go home throughout the year. Of those 50, 49 will categorically put weight on, and in some cases a lot of weight. So whatever controls we might have been able to teach them whilst living in a group home, the evidence is usually when they go home all those thoughts and all that learning has gone out the window because they don't then carry it into the family home.

Comment: We see that all the time and sometimes people will gain 9 kilogrammes in 2 days after a home visit. They know the routine in the structured environment but get outside of that structured routine environment, then that learning goes out the window, and it's a free for all.

Comment: That's our experience. I once went to Dr Nick Finer and actually gave him the data similar to what Lynn's just said, and he actually came back to me and said that's not possible, for someone to put that amount of weight on in that period of time. And we're thinking well, the weighing scales weren't lying, and he did put that amount of weight on.

Chat: The parents see how happy their child is when they get extra food, and next time it is expected, and some with PWS get stressed more days before a home visit because they are only thinking of the extra food. A great problem in many PWS homes, I am told.

Chat: You are correct, we have increased behaviors before home visits and after as well with the stress of returning.

CL: I think this weight gain over the weekend has 2 aspects. One is that there's not the structure you have in the group home. I think the other aspect is that the parents changed their situation. They were responsible for the weight over 18 years or 20 years, and most of them say OK, now we are in the other position. We are the ones which have only the weekend, the group home has to care for the weight and this is what I call nutritional Sunday and then it's not only nutritional Sunday, it's out of control. And I think these two things come together when we have these extremely high weight gain over a weekend. It would be better if the parents would be able to also to give a frame at the weekend.

I like the idea to start in a comfortable weight range because we all know on the one hand side we'll be responsible for the weight development because on the other hand side we came back to the situation where people die because of their obesity, that's one thing, and we have the structure to reach a comfortable BMI zone, and I think we should offer all clients a possibility to learn to understand activity and sports are the thing where I spend energy and food is the thing where I get energy and these have to be balanced and I think it's a project over a long time and not everybody will manage this at the end with the same success. I think the big problem is this individual support and of course, that's a problem of capacity of people which can give help in this way.

NHS: This is often the situation that we ends at this point that we say we have no resources for this. We haven't, but the question is, is this the right way to go on in this way? So if we know we are on the right way, then it's a problem of resources, but in my mind it's too close to think only about being self controlled about nutrition. If we try to support them in the way that they are able to handle different things, not only meals and nutrition, not only money, but also social interaction, and we involve them more and more, then they are more and more able to transfer this knowledge to home. This is what we also see, very often, that they go home and they get bring back over the weekend 5, 6 or 10 kilogrammes more with them. But if they do not learn to be more and more self controlled then we have to support them over their whole lifespan. I

think the ways that we train, support and develop their competencies in different areas, not only in nutrition.

HS: A short example of a young man who is not really on a high cognitive level, but he has learned his daily routines for himself and what he is responsible for. If he comes home, he told his parents how to manage his food at home. He told them, please lock, please look at me, I can't eat so much. He instructs his parents and now he come back only with 1K or half a kilo more. And that's really a success for him and he's proud of it.

Comment: What I think I hear you're saying is that most of our individuals have that executive functioning difficulty, and so in lieu of that, we make up for that with the structure that they thrive on. You know your structure, they stick to it religiously. If that structure then is taught and ingrained, that almost can take the place of some of that higher functioning in a home situation where no, I must follow my routine.

HS: If we only look to enhance the possibilities of interaction, that's helpful for them to learn to deal with other situations. And most of it, it's stress related. And if you are in, in and food is also one of the things which are really stress related.

I see what is written in the chat that parents see how happy their children is when they get extra food and next time when they come home they always give them extra food and therefore the stress level arises into children very much. And when they come back into the group home, they're only thinking about the next extra food, and that's a problem.

Comment: We have the exact same experience as that and some of our folks look forward to something that might even be 2 months in advance and start having behavioural increases 2 months in advance of a home visit because they're so excited about the food they're going to get.

HS: I have the same experience but even it maybe other things. If you think on Christmas, they go home and at Christmas it's not only the food, it's other things that are stressful for them and two or three months before they are focused on that. That's one problem we have in Prader Willi syndrome, that they are focused on things that may be stressful for them in the future.

Comment: I can imagine pretty well that if the parents give at home some special or extra food that they become more and more stressed before the weekend or holidays. But we work very close together with the parents and we told them every time what they had to do. We feedback to the parents after the week and the weight so that they know how they manage it at home and so normally it works pretty well in our institution.

Comment: We've gone as far as to pack pre portioned foods, or give little containers that show this is how much vegetables they should get and you fill it up with vegetables. But then they just get double portions of everything somehow.

PC: We started sending home the calories and what their menu would have looked like had they stayed and that seemed to help as well. The parents actually had a visual of what they're giving them and what they would have eaten if they were still back at the residence.

Comment: One of our problems is that for many years we support people who've gone home at Christmas and Easter and for other occasions, and they put weight on, sometimes inordinately. But the parents tend to think, well, yeah, they've always done that, and when they come back to you, they lose that weight. And we're trying to explain to them, but they're getting older and it's becoming more of a struggle.

We plagiarised a letter from the Americans many years ago, which we still send home at Christmas and Easter trying to get parents' buy-in to just keep an eye on the food intake and increase the exercise, and in the vast majority of cases it falls on deaf ears, sadly.

HS: It's necessary to have well educated parents too. And you have to start at the early stage to educate them and then I think that will be a big influence on their children and how children manage food.

Comment: For us we not, some of the people we're talking about maybe arrived at 25 stones, sometimes more, and they've lost half of their body weight. So from a parents perspective, if they put a stone on or two during the home visit, they're still 10-15 stone lighter than when they arrived with us all those years ago. For the staff supporting those people, they then have to start all over again. And of course there is stress for that, some people are nervous about getting weighed because they know they've put weight on.

NHS: Sometimes we discuss this before they go home and we say, we know from the last years that you come back and you have more weight. So we start to discuss with them, what do you think? What is your goal? Maybe he said it's 5 kilos it, maybe it's one or two kilos less than last year. Then we accept this because we know that there will be more. The idea behind it is to take stress away from the one with PWS, and if there is 6 kilos and a kilo more than he wants, then we do not stress him when he's coming back, we stress the parents but we do not try to stress the one with PWS. And we know and we accept over the experience of 25 years that often we have no chance to change parents' views, ideas and thinking. They say, yes, we do but they do other things. We take away the stress from the people with PWS because when we stress them that they should transfer all these things. We have to accept that these are two settings and we have to stress more and more the parents if we have the chance.

HS: Sometimes parents get nervous when they see their children lose weight. They think it's too much if even they have a body mass index that's really good. But the parents are nervous that it's too much weight and think it might be unhealthy for them. It's often a discussion to convince them that the weight of their children is fine and it's not necessary to eat more.

CL: I think in this case it's very helpful to have these biological impedance analysis because you then can show how healthy or not healthy is the body composition, and I think that is a good instrument therefore.

Comment: I'm actually from a company that's looking at putting together a housing facility for people with Prader Willi. So, I'm very keen to hear the other people talking about this because we're going to be going through all that, diet, planning and menu planning for our customers. Just recently we've been looking at a customer who's with another company and she's 16 and she's on an extremely limited diet. My understanding is when she first went to that service she was quite overweight and is now down to reasonable weight, trending towards being underweight. So being able to hear 7 kilocalories per centimetre of height, that's a really useful limit to try and understand where those lines need to be drawn just to make sure they're maintaining their health overall. Particularly because this person is 16 so they're still growing and they're starting to show signs that they are probably not getting enough calories in.

A lot of the material I've been looking at is that no doubt, no hope school of thinking and thinking of that in terms of Australia's legal structure around the NDIS and thinking in terms of freedom of choice for people with disabilities and how restrictive practises work and that sort of thing. So fitting that no doubt, no hope into a restrictive practises framework, it does offer a limited choice. I've been think where are the avenues where we can give people choice and can give them some flexibility in what they can do?

I know from the conference the other weekend where they were talking about the traffic light system where that idea was you're all right within a certain range. So you've actually got a bit more flexibility as far as your food choices go, and you'll know that where it's gotten over a certain point, maybe it's time to start tapering off those choices and start looking at some restrictions until we get you back to where you're more healthy. And how that might serve, that system might vary depending on the level of function for the individual.

The other interesting thing to hear about is you know how hyperphagia can vary in individual presentation and some people can handle a certain amount of choice and be flexible where for other people that can be problematic.

HS: From the experiences we heard already, we are really on developing ways to get more involvement of people with Prader Willi syndrome and I think that's a key point for us - how to find out what the capacity of the individual is and how to use the individual's resources? It depends on resources, but that's a second question. First of all, we have to look at how we help every individual with Prader Willi syndrome to get the best development for themselves and then we have to look how to we can find the resource for it.

NHS: I hope that one of the next echoes could be that we present, or some of us presents, a training or idea for training programmes to involve people with Prader Willi and we can discuss this.

Q: Yes, one question about the free caloric drinks, you said that when they drink more than 10 litres per day, it's too much because the minerals. And what do you think about 5 liters?

CL: Usually two to three litres would be good but there are special situations, for example, big activities, a long walk in a hot summer where you need more fluid, or if they have a fever, for example, but I think it comes up maybe to four or five litre, but five litre is a lot and they actually should make a cut.

HS: It's dangerous for sometimes for hyponatremia. We have had one case and that's really problematic and you have to get to hospital at once as it's life threatening. We have to look at how much fluid they are drinking.

CL: At the end 5 litre is a mark. For example, there might be a woman with 150 centimetres height and 40 kilogramme. Of course for her even four litres are too much. And it always depends if you have a tap water, that means you have no level of minerals, or if you have a special water which maybe has much more minerals, but I think all around more than five litres is too much.

Patrice Carroll Summary

PC: We started with a wonderful presentation. We reviewed energy intake and metabolism; the energy expenditure and the basal metabolic rate. People with PWS have a reduced metabolic rate and if we reduce calorie intake too much they will lose muscle mass. They need about 60 to 80% of their typical peers' recommendations for energy intake. Start with 2/3 of the calorie of their typical peers and increase energy expenditure as needed.

We went over the diet, the makeup of carb, sugar, fat and fluids and vitamin D. Went over the food groups, reviewed caloric makeup of different foods, vegetables versus chocolate. We reviewed the food pyramid. Two to three litres per day of sugar free fluids, 3 servings of vegetables, 2 servings of fruit, etc. Avoid bananas and grapes and serve potatoes over pasta when possible.

Insulin role in metabolism, build-up of fat reserve. Low glycemic index carbs prevent hyperinsulinemia. We reviewed meat, fish, eggs - try to serve fish at least once a week. Less than 10% of energy intake should be from sweets and we saw visuals of what a plate should look like. We went over how to calculate and write a nutritional plan, the rules of healthy food. Fresh food that tastes good. Avoid fried foods and sugar. Encourage slow eating.

Psychological aspects of nutrition - My plate, my meal, plates will look different depending on the need of the client. Drink water before meals. Food security, and involve the person in the meal planning when possible. Everyday nutrition versus Sunday nutrition, clear eating rules, explain expectations in advance and caregivers have to be in control of the diet. Weigh daily or weekly. Nutrition and exercise can prevent loss of muscle mass.

Then we went into our open discussion. We had a discussion regarding hyperphagia, the need to start from a young age to train kids and parents and the need for proper nutrition. We spoke about how the metabolic rate is dependent on age, activity and height. Pay attention to weight loss and gain and add decreased calories as needed. Involving the client and discuss the correlation between calories and activity levels.

Can individuals with PWS be in control of their diet to any extent? And then we had a follow up discussion. Some places allowed food prep and give more independence around food. Others noticed an increase in anxiety when they have more freedom, and know your individuals and how they respond.

Can a person with PWS be taught and trained to become more independent around food? Weight gain outside of the home in a structured setting and then we had a conversation about home visits.

Can the person with PWS learn to manage not only the diet but their emotions and their reactions behaviorally, ways to manage that. We spoke about ways to manage weight gain during home visits. And that's where we ended.

Upcoming Caregivers' ECHO sessions

Weds 15 Dec

The Power of Exercise for People with PWS

Georgina Loughnan, Prader-Willi Syndrome Clinic, Royal Prince Alfred Hospital, Sydney, Australia

Weds 19 Jan

Meaningful Employment for People with PWS

Larry Genstil, Psychologist, Genstil Institute of Human Behaviour, Israel

Thank you very much to everyone who attended the session and participated. We look forward to seeing you on Session 7 in December.