



IPWSO
International
Prader-Willi Syndrome
Organisation

IPWSO Caregivers' ECHO abstract summary

Dec 15th, 2021: The Power of Exercise for people with 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 Lynn Garrick (LG)

Presenter: Georgina Loughnan (GL)

Video link

["The Power of Exercise for people with PWS"](#) Georgina Loughnan, Prader-Willi Syndrome Clinic, Royal Prince Alfred Hospital, Sydney, Australia

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

[Q&A Following Georgina's Presentation](#)

HS: Thank you to Georgina for your presentation, I think it shows us how important exercise and sports is for people with PWS, especially how it can enhance and improve their quality of life.

Comment: I think it's so important to stress about the mood and the behaviour. Because you see, when you walk, and I think it's so important to stress that walking is the easiest way to exercise, don't need to be in a club or anything, you can just walk after each meal. And then, it is so striking every time you walk with a person with PWS, he or she will start talking, and telling, and then after half or one hour, then you have a much more relaxed person.

Therefore, I'm a bit concerned about in some group homes or some homes that they are sitting down for too long time at their work place. So, I think it's so important again to remind about walking and how much the stepping (audio issue) the mood and then helps for the behaviour.

GL: That's so true. We've actually used walking a few times when clients are in the hospital and they're about to have a tantrum, and they're starting to yell at me or maybe somebody else, and I come down and I say, "Let's have a talk and we'll walk." so I keep them walking while we talk it through. And then they don't have a tantrum.

That's lovely, so we keep them totally occupied. That's good. So it's probably the occupation as well as the mood.

Comment: I think another thing is, when you go in a fitness center or anywhere, it is so important, as you stress, that you supervise the person. Because many have such a bad conception of their own body. So you have to stand beside them, because I've seen so many examples where a physical therapist has given instructions to the person with PWS, and then the caregiver in the group home says, "Oh you know how you have to do it." and then the person for himself does not know how to do it. So, it takes some hours of the caregivers to stand beside them, and follow, and I think it's number two important thing.

GL: Absolutely, there's actually a study being conducted in Australia at the moment. It's called PRESTO, and it's getting people with PWS to exercise, in a gym and with a personal trainer twice a week. And the whole aim of the study is certainly to see what changes occur physically, but more importantly, are they capable of exercising in a public gym or gym that's used by other people.

Before the study started. We put together a handbook for the personal trainers to cover all those aspects - you must stay with them, and to explain about PWS. And it'll be interesting. Unfortunately, it's been heavily impacted by Covid but hopefully...

We have 40 people so far, but we need another 20 involved, so should be good.

HS: We should add, it's also a possibility for with PWS to come in social contact, if they are in public. And that's another dimension we shouldn't forget. I agree it's necessary to evaluate if it's really the right ways they are trained, and if someone is really experienced to do it with people with PWS, even if you look on the body composition and other things. How can we combine it, to have social contact, the possibility to make social relationships and also stabilize their muscles and give them the chance to improve their body composition, and so forth. I think that's always tricky, but we shouldn't forget both.

NHS: Do the others have experienced with gyms with fitness studios. Maybe positive, maybe negative, and the aspect of helping them in the social environment, is so important, but are you experienced with this?

Comment: All of our boys go to the gym, we use the gym all the time. I find it easier to set it in as a programme, that's the time of day you go. Even though we've got it at home which, thank goodness we've been able to use it through Covid. Whoever's with them stays right beside them. I've done this now for a couple of years with them so we've used the gyms right through. But they love it because a trainer, or it could be just someone in the mall walks over and then fix it up and says you should stand like that or do that, and I get so much out of the gym, and, like you say they're mixing with other people as well. I just love it because I get so much result from it.

GL: The fact that they feel they doing what other people do important.

Q: Can I ask, we support 90 odd people from their early 20s up until, now mid 50s. What about people in their late 40s and early 50s? Can what you're advocating be applied across all age ranges?

GL: Absolutely, yes, the two fellows I showed with the treadmills they were probably in their early 30s when they first came, but I've had people start in their 40s. It doesn't matter what age. We do groups for people who don't have PWS and many of them are in their 60s and 70s and it's just the same for the older people, anybody can exercise, even if they're in a wheelchair, they can still exercise other parts of their body.

Q: We do see a natural slowing down some of the females and whether that's because it hasn't been a lifelong exercise regime in place. Would you recommend any particular exercises for those in their late 40s and 50s?

GL: I would recommend exactly the same exercises, starting at a lower intensity and building it up. The oldest person we see in Sydney is 65. She lived in a psychiatric unit from the age of six, up until when she was 32. Then they finally came to our clinic and we said, she's not psychiatrically ill, and eventually they got her out and in to a group home. She exercised while she was in that institution, and she would do it because they were very adamant so she would do it, six days a week. And although she's in quite poor physical shape now at 65, she has quite severe scoliosis and neck problems, she's still pretty fit for her age, quite amazing.

And the fellow I showed who does a lot of bush walking, the guy I said had really good muscles, he's 55 in two weeks, and he's as fit as a fiddle.

GL: I know research is really important, but if we only listened to the research about exercise, people wouldn't do exercise, because it's never good enough. The research often goes for 12 weeks or a few months. It's not long enough to show the real results. I only work clinically basically but a lot of our guys are involved in research which is lovely. And there's a lot more research coming through, but I guess that would be my dream, to have somebody look at all these things that I believe happens in people with PWS, we know happens in people who don't have PWS, and say yes, here, look, the research is telling you (to exercise), then we might get more people doing it.

Comment: About the question about the social contact. My experiences with some people with PWS, they experienced that they have social contact when they go to the gym and talk with other people there, when they change clothes and so on. So they feel they have a social contact because they meet Mr. X and Mr. Y. And some of them, they have also mentally a kind of ADHD, so they cannot cope so well. If there are too many in the room where the gym is. So they have to be only with a few people. But still they can experience the social contact, when they change clothes. And they tell about who they met and they talk to and asked about the dogs and their cars and everything.

So we have to look at them individually, but of course they should have social contact, as much as much they can.

GL: On that point too it's quite important to support them when they are changing in the change rooms because often there are other people's bags and they're in lockers and one of my guys is very good at finding credit cards from other people. So, he used to exercise really well and love the gym, but yeah, that's another time they need support.

Q: Can I be slightly provocative and ask, do you think that when staff are appointed to work in group homes for people with PWS, one of the questions they should be asked is about their attitude to exercise? Because my experience of it is, if the staff aren't interested in exercise, then the person with PWS or whoever it is they're supporting is not going to be interested in exercise. Do you think that should be part of the employment criteria?

GL: If you could get away with it, yes that would be great to have.

Comment: You think it might be slightly discriminatory in some way?

GL: I think it's a really good point. However I would see it slightly differently, I think. For people who are not particularly motivated themselves, they'll be the ones who will say, "Go and get on your treadmill." rather than encourage them and do other things. I mean, I think home exercise equipment or gym exercise equipment is fabulous as a backup, but I tend to agree that it's so much better if you can get them out into nature, like walking along the beach or through the bush is so much more pleasant. But we need something regular and sometimes that's not always achievable on a regular basis.

Comment: At recruitment stage in our service we emphasize they are coming to support people with PWS and one hugely important component in that support is exercise, encouraging and enthusing people to exercise, and how that transfers down the line, one can only guess, to a certain extent. Some staff are brilliant very, very creative, and some people have their own issues of weight and exercise and therefore it can be difficult to actually strike that balance and encourage people to exercise others who need it maybe perhaps more than them.

Comment: I can add that I think it's so important that the staff knows about the poor body concept that those with PWS can have. I have seen situations where a person with PWS was at the physiotherapist, and the caregiver went down to the street and was standing smoking a cigarette. This caregiver did not know how important it was that he was with and saw the instructions that the person got. In our country it is often so that you go, perhaps one or two times per month to a physical therapist, who gives you instruction in daily exercises to conduct at home. But you need to be guided when you

are at home with the caregiver, so the caregiver has to go together with the person. And I just think it has something to do with information to the caregivers, about the importance of guiding those with PWS.

GL: That is so true and the physiotherapist or exercise therapist needs to teach the caregivers how to do the exercises, not just the person with PWS, and say that you have to do them on the other days that you're not here.

NHS: You're right, it should be a criteria, but if we do this 100% then we have only 50% of staff. So, the other part is we have to inform them, we have to train them, we have to teach them, so that they understand why it is important and then they do it by themselves. If people with PWS really know why it is important for themselves then they do more and more by themselves. And so, for example, we create a backpack with different things inside and these backpacks are in the group home, and everyone can take this. If they make a walk in the park, they can use these things, or sometimes it is the situation that the people with PWS take these backpack by themselves, go out or two or three of them, and then they use the things which are inside. And it's so easy so they can do it by themselves. So we have to inform and to give them the idea why it is necessary to do this.

GL: And so they will think outside the square because gyms are expensive and not everyone can afford to go to a gym, but there are plenty of things that you can do at home. In some you have equipment but there are other things that guys do in group homes, even what the boy is doing running back and forth to the different spots on the floor you could do that in a driveway at home it doesn't have to be a gym.

HS: I think it always has to do with fun. If someone is rewarded by fun he will do it for himself and then he is motivated, I can only give him a hint, but the motivation must come from himself, and how to arise this motivation, that's really the biggest task we have.

GL: Yes it is, but I really think once the exercising is in place, very regularly that becomes the motivator. And I have a couple of guys who will ring me up and say, "We have a party, coming up. I would like to go to the party." and we tweak the food and he says, "So I'm going to use the treadmill morning and night before the party." so he starts to say, "I'm going to do more exercise so that I can go to the pub." which is good, which is what anyone, or at least fit people would do.

I think it's also about families. If families have young children are very active it's so much easier for the person with PWS.

NHS: Can I ask a totally different thing? You said five or six times per week. How can we measure how intensive they are doing these things? Can we use these pulse watches, smart watches, do you use this and if so what are the pulse rates on which we can orient ourselves? If it is enough or not enough?

GL: The pulse rates are different. I guess this is why, when we're talking about levels of intensity, that's why I use that simple thing of hot, puffed and sweaty. One of the studies that I've listed there, they found the pulse rate was not as accurate in people with PWS for fitness levels, so I just think if it looks like they are breathing more quickly, they're obviously burning up energy if they're hot and puff, even may not feel the heat. And I always say to them, "Walk like you're in a hurry, like the bus is coming and you're running late, keep it at that pace so that you're moving more quickly than you would be if you're just strolling along, and so that there is effort involved." And anything that they do needs to have effort and I always warn them that their bodies are very clever, and after awhile, the activity they're doing is going to be too easy for them so that's not going to be very good, that's not going to build up your muscles very much if it's too easy so we always need to make it a little bit harder along the way, might be longer or it might be faster, but be prepared because when your body finds that this is all too easy, we go a little bit faster or a little bit harder. I sort of warn them at the very beginning that there's going to be increments along the way. Otherwise they will just want to do the same thing all the time. Sometimes I'll say, "Okay you've put on a few extra kilos but you've been walking six laps of the oval now for a whole three months, I reckon you could do seven laps. What do you think? And that might help get those kilos off." And then I just leave it with them and often they'll say before they leave. "Yes, I'll do seven." that sort of thing.

NHS: So another question for measuring is they lose weight, and we do not know if they lose the fat part or the muscle part and so do you measure the muscles?

GL: We don't do body composition tests anymore we used to but not now. We do waist measurements and going by their clothes, and some of them will show me their muscles in their arms are getting bigger, so that that works really well as well. Again it depends where they live, sometimes if they have caregivers who are very much into fitness, I will get them to measure their arms and their thighs and the calf muscles and their waist, and just say that when the arm muscles start to get bigger and the thighs, but the waist goes down then they're losing fat and they're keeping muscle which is good.

Comment: In our PWS centres in Denmark, they make a DEXA scan usually every second year, where you can see the muscle mass and the fat mass and the bones. Especially for adults, they do it also to measure the bones, and see if there are signs of osteoporosis, that should be treated. So the recommendation is that all adults have these types of scans, at least every second year, especially also because of the risk of osteoporosis, and there's a risk of osteoporosis, even at a young age in PWS, also if you're treated with sex steroids, but of course sex steroids prevent it.

GL: We do it every 2 years as well like that for BMD, but I think this is something we have to be very aware of with the younger generation who are on growth hormones. So often they are not exercising because they look like they don't need it, which is really a shame. Certainly, their muscles are heavier than people who are not on growth hormone, but the bones get don't get enough impact through them. Especially in the teenage years it's so important.

HS: Recently, I read a study, which was published in July this year, about the dysfunction of cerebellum activation in movement of people with PWS. They compared it with a control group and there was findings that there is dysfunction of cerebellar activation in PWS. We see often when people with PWS move, their motor functions are really not like other people. And when we see the people you showed us in your videos, can it be that they have learned it from beginning on and maybe their cerebellar activation is much better than in people which are not trained? And should we have special exercises for people with PWS which help cerebellum activation?

GL: The cerebellum certainly coming to the fore with PWS at the moment on research, but yes and this is why I say walking over uneven surfaces and climbing stairs and going over rocks and things, it just helps improve their balance which must be stimulating the cerebellum is so important. Keeping them on the flat and really even surfaces is crazy and normally we let them climb rocks and do the rest. I think people with PWS really need lots of work on uneven surfaces, not just simple easy exercises. I'm hoping that stimulating your cerebellum.

Comment: Also about the balance, you should be sure that their vision is okay because vision can deteriorate, also at a younger age, so check with an eye doctor every third or fourth year also for young adults because sometimes you find out that the vision has become very poor at a rather young age. So don't forget the vision because vision is necessary to keep the balance

NHS: Georgina presented hypoventilation as one of the special things, and the last information about Covid indicated people with PWS were not so affected and we thought that it could be a high risk for them. Do you know something about the latest information about this?

Comment: When we started the IPWSO Covid study that was our concern, that people with PWS they would they would have the same risk of getting COVID as anyone else, but if they got it, they would be very severely affected and possibly at increased risk for dying, but in fact, that doesn't seem to be the case. Maithé Tauber in France, they published a study that seemed to suggest that people with PWS, when they were infected by Covid, the outcome was good. And that is also the impression from the IPWSO Covid study. The paper is submitted at the moment and we've just having to revise it.

It's of course difficult to do such studies, and there's always the possibility of selection bias in the people that have been included. But I think our impression is that maybe there is some better protection against the virus in people with PWS which in itself is a very interesting observation. But I think it's a very positive outcome, given that we all expected to see to see a very poor outcome from Covid.

GL: Maybe the hypoventilation actually helps them because they're not breathing in as deeply.

Comment: Well, virus load is important. And maybe they're not getting quite such an intense viral load. This needs to be looked at. I mean, people are also saying that they don't get other virus infections as much, and also those who had the immunization against Covid, their reaction to the immunization was less harsh. I don't know if that's everyone's experience but people have been reporting this to us.

Comment: Yes, and Tony, when you talk to parents who have more children they say, he's the one who has never ill. I remember my son when he went to the kindergarten he was the only one who was never ill. So I think they have a really good immune system towards viruses, but we do not know. Also I have not seen someone with PWS with autoimmune diseases like, I don't know if you have.

Comment: I think the problem of course always is that PWS is rare. So, none of us probably know many people with PWS. And in a way, this is the type of thing that if you could do a survey across many countries, you might be able to answer these questions more definitively, I think.

Comment: One of our services, supporting 14 adults with PWS, everyone in that one service had Covid and either had no symptoms or very mild symptoms. Some staff who were working with those people had some severe symptoms and one was hospitalized and close to death and thankfully came through there. So I thought that was weird because certainly some of them even had poorer BMIs, 30, 40, 45 plus, which we thought made them more vulnerable, but thankfully that turned out not to be the case.

GL: I don't know of any of our people living with PWS who've had Covid in Australia, not one of them. They've been in homes where staff have contracted Covid so they've been exposed but none of them contracted it. Then we have one lady who has MS. And she's had MS now for the last, probably eight years, but she's doing well, she's on treatment for it.

NHS: May I pick up on another theme which you mentioned, Georgina, this combination of physical exercise and challenging behaviour or problematic behaviour. Do you check enough that they have enough chances to lose energy during the day, or during the week? Are our programs good enough for thinking about this power program reflected enough about things that they have chance to lose energy enough?

Or do we provoke conflict because they have no chance to walk or to do physical exercise?

Comment: That is how I spend my whole day. They go to the gym in the morning, my troublesome child goes to the gym in the morning, and then he swims in the afternoon. We then bush walk or beach walk all weekend. I basically wear them out. And the more energy they use during the day, the better their behaviour. They're more settled, they come home, they're tired, they get the rewards, afternoon tea time, beauty. I don't reward them with the food, but I work it around the food. Come on, we'll go for a walk, then there will be afternoon tea time, and all that, it's continuous exercise. I went shopping one day and I kept making it I couldn't find what I wanted and I ended up doing nearly 10,000 steps with him in the shopping center, because I kept saying, "No, it's in that in that shop over there." And his reward at the end of it was he got what he wanted. Just took me a while.

HS: I think it's also, it's also a reward if you have no problems, no conflict over the day. If you think in the evening, how was my day, it's a good feeling when there have been no conflicts everything was smooth and that's a big reward, I think.

Comment: Yeah, he's very proud of himself as well, you know he feels it in itself so it's, it does it just works, it works, exercise works.

Comment: We've got not the perfect condition that we changed our sport program completely. Before we had an old concept, so we had 45 minutes sports, two times in the week. And now we changed to they don't do work as much as before, so they are in our group home for doing exercise and this starts in July, and we see that they have less energy, they lose more weight, and with the special condition that the physiotherapist helped us to do the program. So it's not just go for a walk or something like this it is more complete program between coordination, training with weights, walking and other stuff. And I think the behaviour is, much better now. We see that they have not that much energy for getting in conflicts now. So, we've seen it's changed a lot in our group home.

LG: I know we all can do a bit better challenging and keeping our folks active while in the group home. Many of our folks go to work during the day and, as Susanne said, they just sit all day, they don't really work, they sit. And so they come home and they're tired just because they've been sitting, and they're crabby. But we, in our homes, we keep them active by going to the gym with them, and also running errands with them, you know, let's go to the store let's pick up, whatever. Just daily things that we would do naturally for ourselves, we're just bringing them along with. But yes, the more they exercise, the more tired they get the more happy they are and the less conflict they definitely get into with their housemates, and staff.

But I know that we can do a better job, especially here in Minnesota now that it's difficult to go outside because it's cold. And that's not an excuse but it's harder to find outdoor activities that they like to engage in because it's just hard and it's cold.

Comment: The program we had with the physiotherapist was changing. Before we had running on the treadmill, so we change to do more exercise with their own body. So, we had not this problem that they say oh it's cold outside, we can't go outside for a walk or whatever. So we do inside as well, with games on TV or with DVDs on TV. And so we changed it up so that they have not the excuse for not going outside. That's completely changed our program.

HS: It should be a principle of daily activation, to keep them always in movement, and it should be daily practice in everything they are doing, not to sit down and always to keep them from sitting down for a long time, or lying down. And therefore, they get tired, they lose energy and, and I think that is really helpful, especially for their mood.

GL: Even with employment, we've had people work for the local council where they picked up papers, along the road and so they were busy all day. And then others do pamphlet drops so they walk around for four hours, dropping off pamphlets. It's not particularly aerobic exercise because they're stopping and starting but at least they're moving.

NHS: I think is important when we hire people, I think it is necessary to talk with them about how this is part of the care you will have to do, and someone is there and says no sports, nothing for me, maybe then it could be a criteria to discuss it deeply if it is good or not to hire him. But on the other end, I think, to inform them so that they have knowledge about and are curious why it is necessary.

Comment: And I also think that you should inform staff that is part of PWS. Many of them spontaneously, they will sit down and in Norway some years ago they made a study to see who moved less. They compared PWS, Down syndrome, Fragile X and Williams syndrome, and even those with PWS who had more weekly planned exercises, those who moved less were those with PWS. So, there is a tendency for many of them just to sit down, if there's a chair, just sit. So, I think it's important to inform staff that of course it's not all people with PWS and the younger ones who are accustomed to moving, perhaps they do not do it. But I think it was a very interesting study done about the differences in the way of seeking the chair.

HS: I think, Georgina, that you showed us what a big difference it makes if you are exercising, and if you don't exercise, you show it in your pictures, in the information you give us. And I remember a study from Karolinska Institute in Sweden, and they compared (not in PWS) the epigenetics of people on the right leg and on the left leg in exercise. And there was a change of 5000 genes, also in the network of 5000 genes. I think that's impressive. Therefore, simple things like sport can change a lot of our life.

Lynn Garrick Summary

LG: When we think of the balance of calories in, calories out, what was important to me was to learn that the scales are tipped to the exercise, because our folks start with a deficit of decreased muscle tone and strength, they have increased body fat, they don't burn as many calories, as fast. So, because of that they're always at risk of osteoporosis and muscle wasting, and getting the comorbidities that go along with obesity. So exercise, from the very beginning, in childhood, is very important to develop in order to meet those milestones. Making it fun is also important, but to develop those daily exercise habits at a young age. Even if it's something, 10 to 20 minutes.

Both aerobic exercise, 30 to 60 minutes, five days a week. They should be hot, sweaty and breathing a little bit faster, but not fatigued and exhausted. The strength trainings that target specific muscle groups, that has been shown that they can build muscles through exercise. It's also important to warm up and cool down, so you don't get those changes in blood pressure, and soft tissue damage.

And I especially like the red carps analogy. **Respect, Challenge, Acquired Agreement, Responsibility, Rewards, Praise and Security**, all of these things go into supporting our individuals through exercise and a healthy lifestyle, which benefits not only physical health but mental health too.

Upcoming Caregivers' ECHO sessions

Weds 19 Jan	Meaningful Employment for People with PWS Larry Genstil, Psychologist, Genstil Institute of Human Behaviour, Israel
Weds 16 Feb	How to attract and retain PWS Caregivers Lynn Garrick, IPWSO PPCB Chair, Programme Director for AME Community Services, Minnesota, USA
Weds 23 Mar	Managing routine medical checks and other regular requirements Susanne Blichfeldt M.D, Denmark
Weds 20 Apr	Education of PWS, behaviour appreciation, and positive support strategies Patrice Carroll, Director of PWS Services, Latham Centres, USA
Weds 18 May	Looking at different diagnostics Norbert Hödebeck-Stuntebeck, Psychologist, Diakonische Stiftung Wittekindshof, Germany

Thank you very much to everyone who attended the session and participated. We look forward to seeing you on Session 8 in January.