

**OWLA Meeting Saturday 16<sup>th</sup> October 10am**

<p><b>Meeting Times:</b> 10.00m AEST</p>	<p><b>Facilitator</b> Georgina Loughnan PWSA</p>	<p><b>Joined by</b> James O'Brien</p>
<p><b>Invited</b></p>	<p>BC NSW; DW VIC; EA QLD; JB NSW; KG NSW; KT NSW</p>	<p><b>Apologies:</b> <b>Attended:</b></p>
<p><b>New attendee</b></p>	<p>Kyle introduced himself as a new attendee</p>	
<p><b>Set Questions / Discussion points</b></p>	<p>1. Tell us about 1 movie &amp; 1 TV show you like and why you like them</p> <p>2. Are you working? If yes, what is your job and do you like it? If no, what job would you like to do?</p> <p>3. What would you like PWSA to know about you and your life with PWS.</p> <p>What is one thing you like about living with PWS?</p>	<p><b>BC:</b> Horror movies – Nightmare on Elm Street; TV - Scary Cats  <b>JB:</b> Peter Rabbit – is funny, cheeky, exciting; TV - Home and Away – likes the character - Alf Stewart  <b>KG:</b> Harry Potter/Twilight; TV - Wentworth  <b>KT:</b> Horror Movies – The Conjuring; TV - Home and Away – like the character of Leah  <b>KJ:</b> Stranger Things; TV – (? Queer Eye for) The Straight Guy</p> <p><b>BC:</b> Yes, in a nursery, Thurs &amp; Fri – potting plants. Enjoys the staff and her friends there.  <b>JB:</b> Yes, in a factory removing labels from wine bottles for recycling, Mon Wed Thurs. Likes going to work but not the work he is doing  <b>KG:</b> Yes, dog walking/making candles/selling candles at markets. Worked at Riding for the Disabled &amp; Sydney Maritime Museum – giving ship tours  <b>KT:</b> No. Previously &amp; would like to do again – factory work assembling exercise books. Would like to support school students with PWS, by teaching others about PWS &amp; mentoring the students with PWS  <b>KJ:</b> No. Would like to work with kids with disabilities</p> <p><b>BC:</b> “Food makes me stressed”  <b>JB:</b> He needs help doing things and with money. “Food is hard!”  <b>KG:</b> Exercise is good for you  <b>KT:</b> “It’s stressful having PWS, especially for women. Most women with PWS cannot have children. I always wanted to be a mum”.  <b>KJ:</b> He would like PWSA to make available more varieties of food for people with PWS</p> <p><b>BC:</b> “It’s OK”. Is enjoying making new friends.  <b>JB:</b> “Making new friends to talk to”.  <b>KG:</b> Can only think of many things he doesn’t like. Panel suggested PWS has made him world famous (due to his photo and story of fitness being shared in presentations)  <b>KT:</b> Being able to go to university (Catholic University in Strathfield, Sydney) and talk about her life with PWS – pre COVID19.  <b>KJ:</b> There are lots of things he doesn’t like about it but “having PWS has made me learn things and has made me who I am”.</p>

<b>Further Discussion</b> (attendee - initiated)	About food	<b>KT</b> : “I don’t think about food, because where I live it is all locked up”. Kate stated this is a good thing. Other attendees agreed it is good to have the food locked up. <b>KG</b> : Suggested that Kyle looked like another man he knows with PWS. Shared that he is moving soon to a new residence – PWS specific house with 2 other men, on Central Coast of NSW, where a highlight is, he will have his own bathroom attached to his bedroom.
<b>Highlights</b>		Ongoing conversations most of the time and most commented or added to others responses to discussion topics & questions. All attendees liked the idea of making short videos about living with PWS / about their workplace / teaching others about PWS.
<b>Comments from facilitator</b>		Participants appeared more familiar with each other today. 3 people shared their mobile numbers with all attendees. Kate, again ate her am Tea during the end of the group. Will ask all participants, again, not to eat, only drink during the group
<b>Other Business</b>		PWSA to prepare a permission request for recording of the next session and use of their names and comment for the PWSA website – possibly including a “Hear Our Voice” blog.
<b>Next Meeting</b>	Saturday 20 <sup>th</sup> November 10.00am	

Members of the OWLA Group are reminded of the meeting with an invitation and topics/questions listed 2 weeks before the meeting, then again 3 days before the meeting.

Their answer to topics/questions are to be prepared before the meeting.

Some members prefer to send their answers to the topics/questions ahead before the meeting so they can be prompted to speak to their answers during the meeting.