

Supplement 2

Illness plot addressed to underaged people with PWS

Hi! Can you tell us about yourself? [...] May you introduce yourself and tell us about your life [...]. How do you feel with your friends [...], your schoolmates [...], and teachers? [...] You know that eating too much is not good for you: what do you do for not eating too much? [...] How do you feel with your family? [...] Can you tell us about your visits to the doctors? [...] What is your favorite game? [...] What will you do when you grow up? [...]

Thank you for the time and energy you dedicated. One last question:

How did you feel in narrating your experience? [...]

Illness plot addressed to adult people with PWS

I introduce myself [...]. I feel [...]; at home [...]; at work [...]. The people next to me [...]. The food [...]. The treatments [...]. What I like to do [...]. For me, I think of a future [...].

Thank you for the time and energy you dedicated. One last question:

How did you feel in narrating your experience? [...]

Illness plot addressed to caregivers of people with PWS

When I felt the first signs that something was going wrong [...] I feel [...]. They told us that it was [...]. The hospitals I visited, the professionals I met [...]. That period at home [...], at work [...]. The people next to me [...]. People around the person with PWS [...]. Food [...], and treatments [...]. Today the person with PWS [...], and treatments [...]; I feel [...]. At home, people with PWS [...]. Outside domestic context, the person with PWS [...]. What I like to do [...]; what the person with PWS likes, beyond food [...]. My life at home is [...]; the food [...]. I look at the person with PWS and I think for her/him a future [...], and for me I imagine a future [...].

Thank you for the time and energy you dedicated. One last question:

How did you feel in narrating your experience? [...]