

Leadership ECHO Session 8: Challenge – 8 June 2021

This scenario highlights potential dilemmas and challenges involved for people living with PWS and those who support them.

A 25-year-old with PWS is eager to begin driving lessons with a view to taking a driving test and earning a driving license.

The person is living in a residential setting with frequent visits to family. Both the family of the person with PWS and the professional caregivers believe that it is possible that the person, with practice, could pass the driving test.

The family of the person with PWS is strongly opposed to the person driving and believe it is likely that during times of anxiety or emotional outbursts the person could endanger both themselves and other road users. The professional caregivers share the family's concerns. The person with PWS continues to express the view that if someone passes their driving test then they are qualified to drive and that it is very important to them to learn to drive.

Participants acknowledged this as a real dilemma; whilst wishing to respect the individual's hopes and desires and to empower the person with PWS to live to their full potential, there was concern about possible harm both to the individual and to others.

Two participants reported that they knew of individuals with PWS who were capable of driving and were coping well, albeit that in once instance it was a rural location with little traffic.

With regulation differing across countries, some felt that where theory is tested, this might be prove onerous, as it is for many learner drivers. Other factors may preclude individuals with PWS obtaining a license such as medical conditions; often license permits are subject to satisfactory medical reports. When an external body is the decision-maker, the responsibility is removed from the parents/caregivers and this can be helpful in circumstances where it is clearly not in the person's best interest nor in the interests of others.

It was suggested that the motivation to learn to drive is fully explored as there may be alternative ways to address the issue once a fuller understanding is obtained.

Participants concluded there is no simple answer; every person with PWS is different and each needs to be treated according to individual circumstances.

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