

Risk Factors in PWS - General

Risk factors which result directly from the eating disorder include:

- Total control of own finances means in most cases that money will be spent on food – household bills may remain unpaid.
- Some will also steal food, or money to buy food. This could result in police involvement, which potentially could be very distressing.
- People with PWS may be easily bribed by offers of food, or they may ask strangers for money or food. This, together with naivety in many matters, places them at risk of exploitation and abuse.
- Indiscriminate eating of items such as frozen food, food from rubbish bins and off the ground, berries etc, could result in food poisoning or death.
- Eating non-food items (*pica*) may occur in some individuals. Known examples include soap, toothpaste, and ointments, especially those which are food-scented.
- Over-eating can cause death before the age of 30, as a result of complications arising from morbid obesity.
- Possibility of asphyxia, due to choking on food or regurgitation. This has been known to cause death.
- Binge eating (especially when weight is usually well-controlled) can cause necrosis of the stomach or severe gastric dilation, which can be fatal.
- In some cases, individuals may tell doctors they have medical symptoms in order to get extra medication (especially syrups and large pills) which are seen by them as an additional food source. On the other hand, it is important that all symptoms are investigated fully because of the high pain threshold and otherwise under-reporting of symptoms (see below)

Other risk factors unrelated to food

- Inability to recognise internal injury or disease because of high pain threshold is potentially life-threatening.
- Lack of vomiting reflex – lack of vomiting is NOT a sign that everything is OK.
- Bruising may appear for which the person is unable to account, because of their high pain threshold and/or easy bruising body composition. Carers should be aware that this could be accidental or non-accidental.
- Inability to distinguish between hot and cold temperatures is potentially life-threatening (eg scalding or too cold baths, hypothermia in cold weather).
- Base body temperature may be lower than the normally accepted 37°C or 98.6°F. However, “normal” body temperature actually ranges between 36.1C (97F) to 37.2C (99F), depending on various factors. Check body temperature when healthy to establish what it is. If it is usually on the low side, a rise in temperature to say, 99°F would be more serious than if usual temperature is 98.6°F
- A tendency to “daydream” can make an individual with PWS unaware of their immediate surroundings. Thus they may be slow to take action if, for example, a car is speeding towards them.

- Difficulties in spatial awareness, general clumsiness.
- More likely to trip or fall due to poor balance and coordination.
- A poorly developed sense of danger and/or disgust.
- Risk of severe injury to self and others resulting from temper outbursts.
- Some obsessive activities (eg extremely heavy smoking, skin-picking, drinking liquids to excess, playing with matches) are a serious threat to health or may involve the person in preventable risk.
- Underdeveloped social skills and immature emotional development can lead to misunderstanding and isolation.
- Possibility of developing mental health problems – any marked change in a person's behaviour or general mental well-being needs to be assessed.

Further information

- [Healthcare](#)
- [Medical alert – available in several languages](#)