

1

### Introduction

In 2023, the Redbridge Safeguarding Adults Board (RSAB) carried out a Safeguarding Adult Review (SAR) for a man who had Prader-Willi Syndrome, often referred to as PWS. One of the findings of the SAR was that there was a lack of understanding of PWS, and it was recommended that information be made available across the workforce. This brief guide has been produced with support from the [Prader-Willi Syndrome Association UK](#), a charity providing support to all those affected by PWS. The Executive Summary of 'JS' SAR can be downloaded from the [RSAB website](#).



Redbridge Safeguarding Adults

## Learning from Case Reviews: Prader Willi Syndrome

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2

### What is PWS?

PWS is a rare genetic condition that causes a wide range of physical symptoms, learning difficulties and behavioral challenges. It is caused by some missing genetic material in a couple of genes on chromosome number 15. This is thought to impact on the part of the brain which produces hormones and regulates growth and appetite. The presence of PWS can usually be confirmed by carrying out genetic testing.

7

### How can I find out more?

For information on PWS, check out the links below:

- [NHS – Health A-Z: Prader-Willi Syndrome](#)
- [NHS Choices Video Prader-Willi Syndrome \(03:35 minutes\)](#)
- [NHS England National Genomics Education Programme – Prader-Willi Syndrome](#)
- [Prader-Willi Syndrome Association UK](#)

3

### What are the symptoms?

Symptoms of PWS include:

- An excessive appetite and overeating
- Restricted growth in height
- Floppiness caused by weak muscles (hypotonia)
- Learning difficulties
- Lack of sexual development
- Behavioral challenges e.g. emotional outbursts

More details on the symptoms can be viewed [here](#).

6

### Safeguarding and PWS

When supporting someone diagnosed with PWS, it's worth considering the following:

- Are risk assessments up to date?
- Is there a clear plan in place to support nutrition and dietary aspects of care?
- Is there evidence that the person has been attending regular health appointments?
- Sometimes, PWS could be seen as the individual self-neglecting

5

### What are the long-term issues?

PWS itself is not life-threatening but compulsive eating and weight gain can be as it leads to type 2 diabetes, heart failure and breathing difficulties.

If diet is well controlled, and the individual doesn't become obese, then life expectancy is not majorly impacted, unless there are other co-existing conditions. Adults with PWS are not usually able to live fully independent lives but remain with family or in supported living accommodation with a care package.

4

### Managing PWS

There is no cure for PWS, so treatment aims to manage the symptoms and associated issues. This includes helping the individual manage excessive appetite, weight gain and behavioral challenges. It is important that the individual has access to a healthy, balanced diet, avoiding high-calories food. Limiting food intake can be difficult and requires professional support.