

7 Minute Briefing



Safeguarding Adults Review 'Joseph'

Safeguarding Adults Review (SAR)

Joseph was a 20 year-old man with a learning disability, Prader-Willi syndrome (PWS), obesity hyperventilation syndrome and type II diabetes. Joseph died during a hospital admission where he was being treated for genital cellulitis.

Following Joseph's death [Sunderland Safeguarding Adults Board](#) (SSAB) undertook a scoping exercise, which determined that the circumstances prior to his death met the [statutory requirement](#) to undertake a safeguarding adults review (SAR) under the Care Act (2014).

Background

As a child, Joseph lived with his parents in Stockton-on-Tees. Upon reaching adulthood Joseph was keen to move out of the family home and live independently. Joseph was eligible for Continuing Healthcare and initially moved into a residential home in Stockton-on-Tees, however the placement was not suitable and an emergency placement was found at a care home in Sunderland. The placement was intended to be temporary, enabling him to develop skills before moving to more independent living. Joseph was subject to Deprivation of Liberty (DoLS) authorisations throughout this placement.

Joseph was diagnosed with genital cellulitis, and was admitted to hospital for this issue three times. During his final hospital admission, Joseph refused medical interventions resulting in a deterioration in his condition which led to his death.

The Review

The review covers the period 21st September 2020, the date Joseph moved into the care home in Sunderland, to his death in May 2022 and involved a number of partner agencies who operate in Sunderland as well as involvement from agencies operating in Stockton-on-Tees and [Teeswide Safeguarding Adults Board](#).

The purpose of the review was to identify multi-agency learning, exploring information under the broad themes of mental capacity (including deprivation of liberty safeguards), advocacy, multi-agency working, communication and information sharing, risk assessment and care planning, organisational factors, the impact of the Covid-19 pandemic and cross-boundary working. As part of the review, frontline staff who worked with Joseph participated in a practitioner event which provided valuable insight & supported the SAR process.

The review was published in July 2024.

Prader-Willi Syndrome (PWS)

PWS is caused by missing genetic material in a group of genes on chromosome 15. This is thought to affect the hypothalamus, which produces hormones and regulates growth and appetite; a person with PWS can eat much more than other people and still feel hungry. There is no cure for PWS, so treatment aims to manage the symptoms and associated difficulties, including managing the person's excessive appetite and behavioural changes.

If allowed to eat as much as they want, a person with PWS will quickly become dangerously overweight. However, limiting food intake can be very challenging.

PWS is not life-threatening, however compulsive eating and weight gain can cause the development of serious obesity-related conditions. If diet is well-controlled and a healthy weight is maintained, adults can have a good quality of life and a normal life expectancy.

SSAB has produced a 7 minute briefing regarding PWS, which can be accessed from the [website](#), or by clicking this [link](#).

Key Learning

Understanding of PWS

- Understanding of PWS and a lack of specialist support and training impacted all areas of Joseph's life, how he was supported and professionals' assessments of him. It meant that his mental capacity was not formally assessed, and he was presumed to have capacity which consequently led to significant weight gain as his dietary intake was unrestricted. This weight gain led to a deterioration in health which was ultimately fatal.
- Professionals working with people with PWS need specialist support and training. Ideally people with PWS should receive support from specialist PWS services and in specialist PWS placements, although it is acknowledged that these services may be limited, particularly in the area in which Joseph lived.

Mental Capacity Assessments

- Mental capacity assessments should be undertaken in person wherever possible and this should be the default option. This allows the practitioner to gain a greater consideration of the person's understanding of the relevant information, ability to weigh and use the information, retain the information and communicate the decision.
- With regards to PWS, professionals should have a good understanding of the interface between PWS and mental capacity, and have regard to executive capacity (also known as executive function) to assist in assessing mental capacity.

Deprivation of Liberty Safeguards

- The use of equivalent assessments should not be relied upon in the interests of efficiency, particularly where there has been a change in circumstances. When detailing the nature of the deprivation, all aspects of a person's care should be included (such as nutritional intake and diet) and the Guzzardi framework (a principle which details the nature of the deprivations including: type, duration, effect, manner, degree and intensity) applied to reflect the nature of the deprivations clearly.

Hospital Passports

- Hospital passports should be completed as soon as a provider commences their support of a person. Hospital passports should contain information about decision making as it is undoubtable that decisions about care and treatment will need to be made when someone is admitted to hospital. Hospital passports should be shared at the point of admission and when the person moves from one area of the hospital to another to ensure this important information is shared with the relevant professionals.

Support for and involvement of parents/guardians/informal carers

- Parents/guardians/informal carers can often hold invaluable information and knowledge about the person and as such should be consulted with, particularly when issues and challenges arise. Parents/guardians/informal carers of people with PWS should also be provided with specialist PWS support and signposted to support agencies.

Action plan and referral tracking

- Agencies should have in place mechanisms for recording and tracking agreed actions and referrals to ensure they are completed in a timely manner, and enable follow up and review. This will prevent delays, and failure to complete agreed actions, and will assist in holding others to account.

Commissioning of placements for people with PWS

- When commissioning placements for PWS consideration should be given to placements which are PWS specialists and placements with experience of working with people with PWS. Where a person with PWS is placed in a non-specialist placement, commissioners should ensure that the service is adequately prepared and supported and that support is maintained for the duration of the placement. Preparation and support would include specialist PWS training, development of clear care plans and guidelines for managing PWS, regular review of those plans and guidelines, and clear directions for escalation.

Awareness of self-neglect

- Professionals across all areas and agencies of the care sector should have a good understanding of self-neglect and how to recognise it. Agencies should recognise the multi-agency approach to self-neglect and be familiar with the local multi-agency self-neglect guidance.

Case management

- Where case management responsibilities are devolved to other organisations, the responsible authority should be assured that those functions are delivered as per the relevant guidance and policy.

Further Resources

- The [Prader-Willi Syndrome Association UK](#) website contains detailed supportive and practical information for people with PWS, their parents and families, and also professionals who are working with those individuals and their families.
- The NHS website has an [information section about PWS](#), covering symptoms, causes, diagnosis and management.

- The Gov.UK website has a page on ['Mental Capacity Act: Making Decisions'](#) and also a page on ['Making Decisions on behalf of Someone: Assessing Mental Capacity'](#)
- The NHS website has a page on ['Consent to Treatment: Assessing Capacity'](#)
- It is recommended SSAB's [7 minute briefing regarding PWS](#) is read alongside this briefing.