

**Smith-Magenis syndrome (SMS) is a rare genetic neurodevelopmental condition caused by a deletion on chromosome 17p11.2 or a mutation of the RAI1 gene. It affects many areas of development and daily functioning. While every person is different, SMS is widely recognised as a condition that results in lifelong disability, with significant needs across cognition, communication, health, behaviour, sleep, and emotional regulation.**

## **Key characteristics of SMS include:**

### **Learning disability**

The learning disability associated with SMS is typically mild to moderate, but it sits on a spectrum that includes individuals with very low learning disability through to a smaller number who have a severe learning disability. This affects processing speed, working memory, comprehension, and the ability to manage new or complex information without support.

### **Communication difficulties**

Many people with SMS have delayed or limited speech and language. This can include expressive and receptive language difficulties, limited understanding of abstract concepts, and challenges communicating needs, pain, or emotions.

### **Sleep disorder**

A reversed or disrupted circadian rhythm is a core feature of SMS. Individuals often wake through the night and become sleepy during daytime hours. This severely affects daytime functioning, attention, behaviour, and overall wellbeing. It also places a high level of ongoing strain on families and carers.

### **Behaviours that challenge**

SMS is associated with impulsivity, reduced safety awareness, anxiety, emotional dysregulation, aggression, self-injury, and sudden behavioural changes. These behaviours are often linked to sensory needs, communication difficulties, unmet needs, or sleep disruption.

### **Health and sensory issues**

People with SMS may have co-occurring medical needs such as scoliosis, ENT problems, dental issues, cardiac or renal abnormalities, gastrointestinal difficulties, and sensory processing differences. Many require lifelong health monitoring and multidisciplinary input.

### **Daily living and independence**

Most individuals with SMS need significant support with daily tasks, routines, personal care, safety, and decision-making. Difficulties generalising skills, managing transitions, and coping with unexpected change are common.

### **Impact on safeguarding and risk**

Due to reduced awareness of danger, high impulsivity, social vulnerability, and difficulties understanding consequences, individuals with SMS are at increased risk of harm without close supervision.