



SMS FOUNDATION UK
Supporting SMS families for a positive future

CAMHS: Where to Start, Who to Ask, What to Expect

Support for Your Child, Clarity for You

I want my child referred to CAMHS: Here's how to start, who's involved, the process, and what to do if your referral is declined.

Helpline: 0300 101 0034

This is an answer phone service – we aim to respond to messages within 24 hours

smith-magenis.org | support@smith-magenis.co.uk | [@SmithMagenisUK](https://www.instagram.com/SmithMagenisUK)

Introduction

What is CAMHS?

Children and young people with Smith-Magenis Syndrome (SMS) often have complex needs that may include challenges with regulating their emotions, behaviour outbursts, sleep issues, and mental health struggles.

This guide is aimed at helping you through this journey, helping you:

- Understand how to access CAMHS support**
- Know who to ask for help**
- Understand what happens once you're referred**
- Learn the roles of different professionals you might meet**

CAMHS (or sometimes referred to as CYPMHS) stands for Child and Adolescent Mental Health Services. It's a part of the NHS that supports young people with:

- Emotional and behavioural difficulties**
- Mental health concerns (e.g. anxiety, depression, self-harm)**
- Complex neurodevelopmental needs**

CAMHS services vary across regions, but their core goal remains consistent: to support young people in thriving emotionally and mentally.

How to get a CAMHS referral

To get help from your local CAMHS, your child or young person will usually need to be referred by a professional. Self-referrals, made by you or your young person, are also accepted in some areas (google search CAMHS self referral and your region to see if this is the case for you).

The following professionals can make a referral for you:

- Your GP
- School SENCO or teacher
- Health visitor or community paediatrician
- Social worker
- Learning disability nurse or community nurse

Simply ask them:

Could you help us get a CAMHS referral?

To help support the referral, it can help to give the professional referring some info. Advised to-do list for you:

- Create a record of their history of behaviours or concerns
- Provide any school reports or letters
- Provide any letters of assessments or diagnoses (e.g. Smith-Magenis syndrome, ADHD, autism etc.)
- Create notes on sleep disturbances, aggression, or mental health symptoms (i.e. self-harm)

Your Reasons for a Referral

Typical Challenges with SMS:

- **Anxiety:** Often triggered by changes in routine or sensory overload
- **Low mood or depression:** Particularly in older children and teens
- **Emotional dysregulation:** Quick mood changes, impulsivity, or aggression
- **Self-injury or self-harming behaviours:** Common and complex in SMS
- **Aggression or tantrums:** Often severe and difficult to manage at home or school
- **Sleep disorders:** Profound sleep disturbance, impacting family wellbeing
- **Impulsivity and attention difficulties:** Sometimes overlapping with ADHD diagnoses
- **Oppositional behaviour or rigidity:** Struggles with transitions or demands
- **Autistic traits or dual diagnoses:** Difficulties with communication, social understanding
- **Sensory processing difficulties:** Over- or under-reactivity to noise, touch, light, etc

Use the rest of this page to write down your own concerns

What happens next?

Screening, assessing, planning

Once CAMHS receives a referral, they will:

1. Complete Triage / Screening

- CAMHS receive the referral and review it
- They decide if:
 - The concerns are something they can help with
 - Additional information is needed
 - Another service may be more appropriate (like a Learning Disability Team)
- You may be contacted for more background or supporting evidence

2. Initial Assessment (if accepted)

- If CAMHS accepts the referral, they will ask you and your child to attend an initial assessment
- This might be a face-to-face or phone/video appointment
- You may meet with a psychologist, learning disability nurse, mental health nurse, or psychiatrist
- The assessment will explore:
 - Your child's behaviour, mood, and relationships
 - Developmental history (e.g. speech, learning, milestones)
 - Impact on daily life (school, sleep, family wellbeing) and any safety concerns (e.g. self-harm)

What can I do at this point?

- Try not to worry if there is a little bit of a delay between you sending in the referral and CAMHS contacting you. If ever you do get worried, you can ask your GP for their number just to ask where they are in the referral process.
- Keep making notes of things you want to bring up in the assessment - this will help you feel less on edge when you do get in there.

What if CAMHS say no?

Next steps after a refusal

Sometimes CAMHS doesn't accept a referral. This can feel frustrating, especially when needs are complex, but it doesn't mean help isn't available.

Why might a referral be declined?

- The child's needs don't meet CAMHS' threshold for mental health support
- The behaviours are considered to stem from learning disability only (and not a mental health difficulty)
- CAMHS recommends another service instead (e.g. Early Help, school-based team)
- Not enough supporting information was included in the referral

What Next?

Ask the referring professional (you can also request this in writing):

Why was it declined? What can we do differently next time?

1. Challenge the Decision

- If you feel CAMHS misunderstood your child's needs:
 - Ask for a review or re-referral
 - Provide new or additional evidence (e.g. diary of behaviours, school letters)

2. Explore Alternative Support

- Ask your GP or school about:
 - Community Learning Disability Teams
 - Behaviour Support Services
 - Educational Psychology
 - Charity-led or local SEND services

What support do CAMHS offer?

A CAMHS psychologist or psychiatrist may offer:

- Therapy e.g. parent support, play-based approaches, Cognitive Behaviour Therapy (CBT)
- Medication (e.g. for anxiety, sleep, mood, aggression, if appropriate)
- Behaviour support (e.g. coping strategies for emotional outbursts or routine challenges)
- Multi-agency support (e.g. liaising with schools, GPs, social care)

Regular reviews will monitor progress and adjust the plan as needed.

Discharge from CAMHS

CAMHS may discharge your child if they believe:

- Goals have been met or support is no longer needed
- Another service is better suited for ongoing help

What to Do If You Disagree

- Request a discharge meeting with the team, before or after discharge, to discuss concerns.
- Ask for the decision in writing, including reasons, support offered, and recommended next steps (helpful for further assistance or appeal). Ask:

"Can you explain why the decision was made?"
"Is there anything we can do to stay open to support?"

- Consider re-referring through the GP or other professionals, providing new evidence (e.g., school reports or incident logs) to highlight ongoing issues or worsening conditions. Be sure to explain the impact on your child, family, and education.

Who's who?

Professionals who may support you and your child in their journey

Clinical Psychologist

Assesses emotional/behavioural difficulties, provides therapy (CBT, parenting work)

Psychiatrist

A medical doctor who can diagnose and prescribe medication

CAMHS Nurse

Offers support, education and sometimes behavioural work or assessments

Learning Disability Nurse

Supports families and children with learning disabilities, offers behaviour and care strategies and sometimes assessments

Speech and Language Therapist (SLT)

Assesses communication needs and can help with social understanding and behaviour

Occupational Therapist (OT)

Helps with sensory processing, daily routines and coping skills

Social Worker

Supports families under strain, may coordinate services and safeguarding

Educational Psychologist

Works with schools to support learning and emotional wellbeing

Further Support

You don't have to go through this alone. Support services can help you and your child.

SMS Foundation UK: smith-magenis.org

SENDIASS: kids.org.uk/sendiaass-home

Contact: contact.org.uk

POhWER: pohwer.net