

AI Guide for Parents to prepare for Healthcare Appointments



DSUK
Down Syndrome UK

AI-Supported Medical Appointment Guide for Parents of Children with Down Syndrome

This guide can help you use AI tools (such as ChatGPT, Copilot, or Gemini) to prepare for medical appointments, ask questions, understand information, and communicate effectively with healthcare professionals.

**AI is not a substitute for medical advice.
Always follow the guidance of your healthcare team.**

Before You Use AI

- Avoid entering identifying information such as names, addresses, dates of birth, or NHS numbers.
- AI can sometimes be inaccurate or "hallucinate" information. Use it to organise your thoughts and generate questions, not to diagnose or make treatment decisions.



Why Use AI?

AI can help you:

- Organise information before appointments
- Prepare questions and concerns
- Understand medical terminology
- Summarise appointment notes
- Feel more confident during discussions with healthcare professionals

Useful AI Prompts

Preparing for an Appointment

"We are seeing a [doctor type] about [concern]. Help me prepare by listing the important information to bring, including symptoms, timeline, impact on daily life, treatments tried, and current medications."

Explaining Your Concerns

"Help me write a short summary explaining why we are attending this appointment, what concerns us, what we have already tried, and what we hope to understand."

Questions to Ask

"What questions might be helpful to ask a [doctor type] about [condition or symptom]? Please keep them parent-friendly."

"What would you be considering if my child didn't have Down Syndrome?"

Understanding What to Expect

"What topics are usually discussed during an appointment about [condition or symptom]? I am looking for general information, not medical advice."

Understanding the Appointment Afterwards

"Please explain these appointment notes in plain language and summarise the next steps: [paste notes]."

Reducing the Risk of Diagnostic Overshadowing

People with Down syndrome can sometimes have symptoms incorrectly attributed to their Down syndrome or their Down syndrome diagnosis rather than being fully investigated.

Consider asking:

- *"Could there be another explanation for these symptoms?"*
- *"What possibilities have been considered and ruled out?"*
- *"Are there any tests or assessments that might help clarify this?"*
- *"Would you expect these symptoms to occur because of Down syndrome alone?"*
- *"What changes should prompt us to seek further review?"*

These questions support discussion and shared decision-making without being confrontational.

Some condition-specific examples

These examples show how to use the prompts in common scenarios for children and adults with Down syndrome. They are not medical advice.

A. Constipation

Before the appointment

Prompt:

"We're seeing a GP about constipation in my child with Down syndrome. Help me prepare by listing key points — stool pattern (frequency and consistency), duration, diet and hydration, behaviours (straining, withholding, pain), medications/therapies, and what we've already tried."

Questions to ask

Prompt:

"What parent-friendly questions should I ask the doctor about constipation? Include monitoring, assessment options, typical approaches, and when to seek further help."

What to expect

Prompt:

"What topics do doctors usually discuss at an appointment about constipation? Keep it simple so I know what may come up."

B. AVSD (Atrioventricular Septal Defect)

Before the appointment

Prompt:

"We're seeing a GP about constipation in my child with Down syndrome. Help me prepare by listing key points — stool pattern (frequency and consistency), duration, diet and hydration, behaviours (straining, withholding, pain), medications/therapies, and what we've already tried."

Questions to ask

Prompt:

“What helpful questions can I ask the cardiologist about AVSD — including scan results, assessment and monitoring, expected progression, timing of interventions, follow-up, and red-flag symptoms?”

What to expect

Prompt:

“Give me a parent-friendly overview of common topics a cardiologist covers when discussing AVSD.”

C. Chest infection (including prophylactic antibiotics)

Chest infections are common in people with Down syndrome due to airway anatomy, immune differences, and reflux-related aspiration risks.

Before the appointment

Prompt:

“My child with Down syndrome may have a chest infection. Help me prepare by listing what to tell the doctor — cough type, breathing pattern, temperature, chest sounds (if noted), energy levels, feeding/drinking changes, nighttime symptoms, duration, recent exposures, and what we’ve tried so far. Also include whether prophylactic antibiotics were ever used, are currently used, or have been discussed by healthcare staff previously.”

Questions to ask (including antibiotic prophylaxis)

Prompt:

“What parent-friendly questions should I ask the doctor about a chest infection? Include monitoring at home, tests they might consider, typical management options, follow-up, and whether prophylactic antibiotics are appropriate in cases of recurrent infections — if this has been mentioned before.”

What to expect

Prompt:

“What topics do doctors usually cover when examining a child for a chest infection? Provide a general overview, including that prevention strategies may be discussed, which can include prophylactic antibiotics in some cases at the doctor’s discretion.”

D. Sleep apnoea

Sleep apnoea is common in people with Down syndrome across all ages.

Before the appointment

Prompt:

“We’re seeing a sleep specialist about possible sleep apnoea. Help me list the important observations — snoring, pauses in breathing, noisy breathing, restlessness, unusual sleeping positions, daytime sleepiness, morning headaches, mood/behaviour changes, school/work impact, and any patterns I’ve noticed.”

Questions to ask

Prompt:

“What helpful questions can I ask the specialist about suspected sleep apnoea? Include questions about types of sleep studies, what results mean, typical management pathways, equipment support, and follow-up.”

What to expect

Prompt:

“What topics do doctors typically discuss when evaluating a child for sleep apnoea? Keep it simple and parent-friendly.”



Appointment Preparation Sheet

Reason for appointment: _____

Main symptoms/concerns: _____

How long has this been happening? _____

Impact on daily life (sleep, eating, behaviour, school, activities):

What we have already tried:

Current medications/therapies:

Questions I want to ask:

1. _____

2. _____

3. _____

What I hope to understand or achieve from this appointment:



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please email info@downsyndromeuk.co.uk



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