

Your voice matters!

What every parent with a child with Down syndrome should know about diagnostic overshadowing.



As a parent, you know your child best. When something doesn't feel quite right, your instincts are powerful and valid. That's why it's important to be aware of something called **diagnostic overshadowing**.

What is diagnostic overshadowing?

Put simply, diagnostic overshadowing is when doctors or health professionals assume that a symptom or health issue is just part of having Down syndrome, rather than investigating the cause and potential treatment further. This can mean that real, treatable medical conditions get overlooked, leading to delays in care and/or unnecessary discomfort/lack of treatment for your child.

Why is this important?

Children with Down syndrome are more likely to experience certain health conditions, like thyroid disorders, heart conditions, digestive problems, gastrointestinal issues, and sleep apnoea - but it's vital that you tell your doctor or healthcare provider about your concerns as a parent so that any symptoms are taken seriously and investigated and potentially treated, and not brushed aside. As a parent, advocating for thorough medical checks can make a significant difference in your child's health and well-being.

Common examples

- **Growth concerns:** A child with Down syndrome might be considered "typically small", but underlying issues like coeliac disease or hypothyroidism may be the real cause. Refer to the DSMIG (Down Syndrome Medical Interest Group) Red Book insert for guidance on recommended blood tests and monitoring- [A5-Downs-charts.pdf](#).
- **Fatigue & low energy:** Often attributed to a child having Down syndrome, but could indicate anaemia, sleep apnoea, a thyroid dysfunction or an undiagnosed cardiac condition. It is important to highlight if there is a change in behaviour or pattern, stressing the need for assessment.
- **Digestive problems:** Reflux, constipation or food intolerances might be overlooked as just being common in Down syndrome, rather than properly investigated and treated.
- **Constipation:** May be attributed to slow gut transit, but not be treated properly. It is important to be aware of it. The use of laxatives is helpful and can be considered long-term if needed. It is important to discuss this with your GP or Paediatrician.
- **Behavioural changes:** Anxiety, discomfort, or frustration may be dismissed as "typical behaviour" rather than symptoms of pain, sensory issues, inability to communicate or undiagnosed medical conditions. It is important to highlight any change from your child's normal behaviour.



General advice

It is important to try and make your child or young person familiar with healthcare settings so that they are not anxious when they go there to be seen. Maybe a visit to look around when they are well.

For young people 14 years or above, they should be offered an Annual Health Check by their GP's surgery. This helps to familiarise staff with them, their communication and general demeanour, and any changes which occur are easier to flag. It is also a good opportunity for your young person to become familiar with visits, and if able, to start to advocate for themselves.



Questions to ask professionals

When discussing concerns with doctors, asking the right questions can help ensure your child receives a thorough evaluation. If you feel a concern is being attributed to your child having Down syndrome and not investigated, here are some key questions to consider:

"What would you be suggesting we consider/test for if my child didn't have Down syndrome?"

"Could this symptom be linked to another medical condition? What tests can we do to rule that out?"

"Is there a specialist we should consult to get a second opinion?"

"How do we determine if this is a particular health condition/issue rather than just part of my child having Down syndrome?"

"Can we try a treatment plan or lifestyle change and monitor if symptoms improve?"



Take action

Trust your instincts: If you feel something isn't right, push for further investigation.

Keep records: Document symptoms, behaviours and any changes over time to provide clear evidence to medical professionals.

Seek second opinions: If concerns are dismissed, consider consulting another doctor or specialist.

Join [DSUK online support networks and local groups](#): Connecting with other parents can provide valuable insights and shared experiences.

We know that your child's health and happiness mean everything. By understanding diagnostic overshadowing, we hope we're giving you the confidence and tools to speak up, ask questions and make sure your child gets the care they need. Don't be afraid to trust your instincts - whether it's asking for a test, getting a second opinion or simply saying, "something doesn't feel right". Your voice matters, and your advocacy can make all the difference.

Parent experiences and research findings

A response from a healthcare professional:

“Children with Down syndrome always get constipated.”



Parent:

“After the fourth trip to A&E in a week, he was admitted later that day with a urachal abscess. He required four-hour emergency surgery, and his recovery took three months.”

A response from a healthcare professional:

“Children with Down syndrome have big tummies.”



Parent:

“Harvey was sent home from the GP and A&E on numerous occasions. We later found out Harvey had stage 4 high-risk Neuroblastoma (cancer), which was fatal. If we had had an earlier diagnosis, who knows how different the outcome may have been.”

A statement from a healthcare professional:

“Babies with Down syndrome cannot breastfeed due to low muscle tone.”



In DSUK's survey conducted in March 2024 by 50 professionals who work (or would potentially work) with babies with Down syndrome in the UK, 30% of professionals said they weren't sure or didn't think a baby with Down syndrome would be able to breastfeed. The other 70% thought it was likely.

Our research shows that 77% of women breastfed their babies, and that at 6 months, 66% of babies with Down syndrome were still being breastfed.