



# DISCUSSING HUNTER SYNDROME WITH YOUR CHILD'S DOCTOR

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**It can be hard to know what questions to ask, and to keep track of all the information from your appointments with healthcare professionals. This leaflet may help you talk to your doctor about your child's symptoms.**













This leaflet highlights the key signs that should prompt suspicion of Hunter syndrome. You will find space for your notes from appointments in the **Hunter syndrome diary**, which is also available for download from **Huntersyndrome.info**.

The information in this leaflet is not intended to replace any medical advice from healthcare professionals. If you have any concerns about your or your child's health, you should contact your doctor immediately.

## Key signs to prompt discussion with your doctor

There are certain key signs that, when seen in combination, may prompt suspicion of Hunter syndrome. It is also important to note that many of these symptoms are common childhood complaints, but it is the combination of these that may indicate Hunter syndrome.

Remember that not all people with Hunter syndrome have all of these signs, and different people experience these to different degrees.

-  Particular facial features, such as a prominent brow, broad nose, and thick lips
-  Frequent ear infections
-  Hearing loss
-  Long-term runny nose
-  Frequent respiratory infections
-  Respiratory problems, including noisy breathing and snoring
-  Heart murmur
-  Enlarged belly
-  Hernias (umbilical or inguinal)
-  Repeated watery diarrhoea
-  Joint stiffness
-  Delays in development or in speech

Visit **Huntersyndrome.info** to learn more

**Shire**

This resource is intended only to provide knowledge of Hunter syndrome health topics. This resource is not a substitute for medical advice, and should not be used in place of advice from a healthcare professional. Please contact a healthcare professional for advice. This resource is intended for an international audience outside of the USA and has been produced by Shire. This resource has been developed in accordance with industry and legal standards to provide information for the general public about Hunter syndrome health topics. Shire makes every reasonable effort to include accurate and current information. However, the information provided in this resource is not exhaustive.

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## Ongoing healthcare appointments

People with Hunter syndrome need lifelong healthcare, which often comes from a varied team of specialists. It is advised that there is a full assessment at diagnosis, and regular follow-up reviews.

Regular appointments can help the healthcare team to keep track of your child's health, and the management of any symptoms. It can also be helpful to keep a note of any symptoms in between visits.



**The following are some questions that you might want to discuss in your child's healthcare appointments.**

- What is causing the symptoms?
- Are any medical tests needed?
- How might the symptoms affect everyday life?
- What are the options for managing the condition?
- Which options are most appropriate for my child?



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## Useful information for getting the most out of your healthcare appointments:

- Stay well-informed; know what tests and appointments your child should be having and when
- Ask for the test results and don't be afraid to ask questions so you understand what they mean
- Repeating back in your own words what the healthcare professional has said will help make sure you have understood the information
- Report all signs and symptoms, no matter how trivial or unrelated they may seem

**Your local or national MPS society may be able to offer further support and information.**



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