



It can be distressing to receive a diagnosis of Hunter syndrome, and to know what to do next. Support is available and can help you and your family.

Talking about the diagnosis

It can be hard to explain the disease to others. You could say that your child has a long-term condition that, depending on the individual's needs, may require regular healthcare management. You may wish to tell only a few people who need to know, such as family, close friends, and key people at school.

When talking to your children about Hunter syndrome, you will need to judge how much information to give them without making them anxious. It may be best to give children age-appropriate information in small amounts. Your local MPS society can offer help and support, and your specialist nurse, paediatrician, or family doctor may also be able to advise.

Hunter syndrome is managed by a diverse team

Hunter syndrome is managed by a large and varied team of healthcare professionals who specialise in the medical side of the condition (e.g. cardiac, neurological, eye, ear, nose, and breathing symptoms) and specialists who provide supportive care (e.g. physiotherapy, speech therapy, hearing support, dentistry, and behavioural therapy). A family practice physician or paediatrician can facilitate the support from the various members of this 'multidisciplinary team', and provide a consistent medical base for you and your family to talk to.

It can be overwhelming to deal with this number of specialists, and to keep track of appointments and the information from each one. The **'Discussing Hunter syndrome with your child's doctor'** leaflet provides information you may find useful in helping you make the most of your appointments.

Visit [Huntersyndrome.in](https://huntersyndrome.in) to learn more



Reference: Takeda Pharmaceutical Company Limited. Welcome to Huntersyndrome.info [Internet]. [updated April 2020; cited 2022 March 20]. Available from: <https://huntersyndrome.info>.

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Emotional support

Caring for someone with Hunter syndrome is very challenging and has a significant impact on family life and emotional wellbeing. Your family doctor may refer you or your child for counselling. Being open with your family and friends, and sharing your experiences with them, will help them to understand your situation and feel involved.

Contact your local or national MPS society for information or support

There are a number of support groups and networks that can give advice, as well as providing the opportunity to get in touch with others in the same situation.



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