



Hunter syndrome impacts many aspects of life, and if you are growing up living with Hunter syndrome, there will be lots of issues to consider if you wish to become more independent. This guide may help you start thinking about some of these issues.

Many adults who have Hunter syndrome can live full and enjoyable lives. Some adults who are more mildly affected by Hunter syndrome have skilled jobs, are married, and have had children.

Transitioning from paediatric to adult healthcare

As you get older, you are likely to move from being cared for by a team of healthcare professionals who specialise in caring for children (paediatricians), to those who specialise in caring for adults.

The healthcare team might help coordinate this transition to help it go smoothly, and it might be the case that your current healthcare professional or support worker becomes the main coordinator of the transition, overseeing the process and putting you in contact with your new team, and showing you how to access other support services.

You may meet your new adult healthcare professionals before your transition, perhaps in a joint appointment, and there may be peer support groups that you might find helpful as you develop your independence.

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



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 Takeda. This resource has been developed in accordance with industry and legal standards to provide information for the general public about Hunter syndrome health topics. Takeda makes every reasonable effort to include accurate and current information. However, the information provided in this resource is not exhaustive.

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Being more independent

If you start caring for yourself more independently, there are lots of things to consider. Your local MPS society and your healthcare team can advise you, and direct you to other sources of support.

You may find it helpful to keep track of your healthcare appointments by keeping notes, if you are managing these yourself. You could keep a diary between appointments, to help you when talking to your healthcare team. It is important to have regular check-ups.

You could talk to your healthcare team about how best to take care of things like personal care, what you eat, and what exercise you do.

There are lots of home adaptations that you could consider, which might make home life easier for you. You may be entitled to support with installing adaptations or getting equipment.

If you have questions about education, or if you are thinking about getting a job, your local MPS society will be able to give you advice and let you know what other support you might be able to access.

Emotional wellbeing

Growing up with Hunter syndrome can affect your emotional wellbeing, but support is available. Counselling can help you to keep positive by focusing your thoughts on your abilities. Being in touch with other teenagers and adults who have Hunter syndrome might be helpful, and your local MPS society can put you in contact.

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