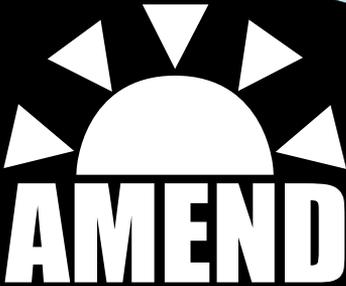


The background of the top half of the page features two black silhouettes of people's heads in profile, facing each other as if in conversation. A light blue speech bubble originates from the person on the right and contains the title text. The overall background is a solid light blue.

Talking to  
Children and Young  
People about  
Multiple  
Endocrine  
Neoplasia  
(MEN)



Association for Multiple Endocrine Neoplasia Disorders

written by  
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## *Talking to Children and Young People about Multiple Endocrine Neoplasia (MEN)*

Many parents find the prospect of talking to their children about the presence of a Multiple Endocrine Neoplasia (MEN) gene within the family difficult and distressing. Studies show that parents feel that their first instinct is to protect their children and they find it difficult to know when and what they should tell their children. Parents are often dealing with concerns about their own health and future wellbeing, and can feel a sense of guilt that their children may also be at risk.

### *What helps children and young people?*

In many cases children cope better when the family are more willing to discuss what is happening to different members. Talking to children helps them feel valued and respected and helps them cope better than when they are left feeling confused and unsure how or what to ask. Children get information from many places including school and television and friends. They are likely to already have some knowledge about cancer and possibly about hereditary cancer. By talking to them you can help them sort out what is accurate and what is inaccurate and clarify things they are not sure about. Children will probably be most worried about their parent developing cancer so they will need reassurance and reminders that having the MEN gene does not always result in all the MEN growths or cancer developing. You can also remind children that knowing you carry the gene means that you can have regular tests to ensure that if a growth arises it can be detected very early on and treated.

### *When is a good time to tell your children?*

There is no 'right' age but try not to keep secrets. Children and young people place great emphasis on trust and honesty from parents. Children often observe changes in their parent's behaviour and may try asking questions or be waiting for you to discuss what's happening. Watch for any changes in your child's behaviour, it may indicate that they are worried or concerned about what they have observed or overheard.

By the age of 8 years, children learn not to ask difficult questions unless their parent(s) gives them permission because they fear upsetting their parents. Therefore you may have to prompt your child (this includes older children too), and let them know you are willing to talk about MEN, genetics and inheritance. Sometimes it may take several days or even weeks for children to act on your prompts.

### *What information do you tell children?*

Try to respond to children's questions, using language appropriate to their age. Providing small amounts of information gradually is likely to help children understand and cope best. Check on the question being asked so that you find out what your child actually wants to know. Explain and provide the name: multiple endocrine neoplasia or MEN - children cope better because knowing the name allows them to discuss it with you, and this knowledge also gives them a sense of control. Parents can place a positive emphasis on the importance of knowing about the MEN gene because it means

there are improved screening and perhaps treatment options. When children become adults, there may be even better treatments available, which you can explain to your child.

### *Communication Tips*

- Children and young people prefer informal discussion often whilst doing other things together e.g. driving, cooking or gardening.
- Check their understanding because children worry about upsetting their parents and so may not always ask.
- Talking about MEN is an ongoing discussion rather than a one off conversation. Like many adults, children probably need information given to them more than once. They may need time to digest the information and then want to come back and discuss it with you.
- Discuss information young people find on the Internet or in newspapers
- Discuss emotions – provide reassurance they are not alone.
- Explain parents' behaviour if they are anxious or upset.
- Being with peers e.g. cousins in similar circumstances might be helpful
- Support and guide decision-making, especially with young people who usually like to make their own decisions but with advice from parents.
- If you do not know the answer, explain some questions do not have answers or that you will try to find out for your child.
- Agree appropriate times to discuss MEN if your child asks questions at inopportune moments.

### *What are children likely to know about genes and inheritance?*

**8-11 years:** they have a very basic understanding of inheritance and that they share characteristics with parents. They may talk about genes but not fully understand what they are. Often children of this age cope with simple explanations in response to their questions and are not easily upset, although you may have to reassure them that having a MEN gene is not the same as having cancer. Children and young people can easily confuse this and so it often needs repeating throughout development into adulthood.

**12 – 14 years:** young people are beginning to develop more insight about inheritance, and will begin to recognise that you having the gene may have implications for them but will usually cope well if you explain there is only a 50% chance of them having the MEN gene, unless they have already been tested.

**15 – 17 years:** by this age young people recognise the risks to their parent, themselves and often their future children and if they have not been tested they can begin to consider it. Young people will also be learning about hereditary diseases in the school curricula.

Most children are quite pragmatic in response to genetic risk in families affected by inherited genetic conditions. Children and young people are often focused on developing friendships, school and their personal interests so do not dwell on the risk.