

Association for Multiple Endocrine Neoplasia Disorders

Registered Charitable Incorporated  
Organisation no. 1153890

**MEN SUPPORT**


Tel: 01892 516076 / 841032

[info@amend.org.uk](mailto:info@amend.org.uk)

[www.amend.co.uk](http://www.amend.co.uk)

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The image features two black silhouettes of people's heads in profile, facing each other as if in conversation. A light blue speech bubble is positioned between them, containing white text. The background is a solid blue color.

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



written by  
Alison Metcalfe & Gill Plumridge

## ***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 what they should tell their children and when. Parents are often dealing with worries 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 tumours 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 tumour 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 them. Therefore you may have to prompt your child (this includes older children too), and let them know you are willing to talk with them 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 little by little 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.

### *What is MEN?*

Multiple Endocrine Neoplasia (MEN) is a condition which can be passed down in families. MEN causes more than one gland in the body to develop tumours. These glands may then make greater than normal amounts of hormones, the body's chemical messengers, which in turn cause a range of different symptoms.

Multiple = more than one

Endocrine = gland system

Neoplasia = increase in growth of cells to form a tumour

## *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 difficult 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 may often need 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. They 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.

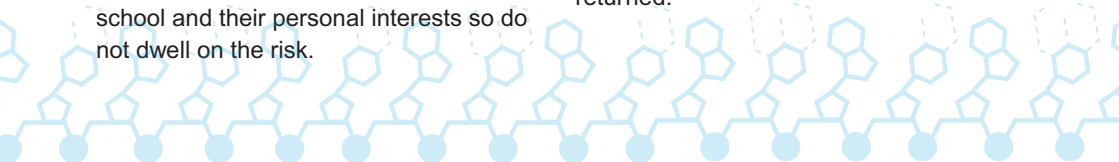
**15 – 17 years:** by this age young people recognise the risks to their parent, themselves and often their future children and if they have not been tested they can begin to consider it. Young people will also be learning about hereditary diseases in school.

Most children are quite sensible and realistic 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.

## *What helped parents talk to their children?*

It has been observed that the following points helped parents talk to their children:

- Younger children do not have the experience to recognise and anticipate the fuller implications therefore there is a gradual realisation.
- Not feeling pressurised to talk by an impending event e.g. a school science lesson.
- Talking was a relief for parents and ultimately easier than secrets. Many parents regretted not talking to their children sooner.
- Parents can be the role model for young people – giving them insight into how to cope with the risk.
- Recognising siblings may all have different needs, try to find out what each understands at different times in their development
- Ensure children and young people understand a positive genetic test is not a cancer diagnosis – some get quite confused about this
- Belief in a child's right to know.
- Support of other family members, friends and health professionals.
- Attendance at support group events gave focus to regular discussion with children and young people with parents discussing where they were going and what they had learned when they returned.



## Preparing to talk to your children

It might be worth considering the following benefits and drawbacks in preparing to talk to your child but try to take naturally occurring opportunities where possible

### Benefits

- Makes family closer
- Support for children and parents
- Gives insight and helps children realise that parents being upset about MEN is not down to them or their behaviour i.e. 'no fault' of theirs
- Confidence to talk to close friends
- Children and young people feel valued by parent(s)
- Allows discussion of MEN and tumour development risk without centralising it to life
- A shared reality and understanding in the family of what is happening helps children and young people cope, they feel less alone
- Agree appropriate times to discuss MEN

### Drawbacks

- It can be emotionally taxing dealing with questions
- Children and young people can remind you about MEN, when you do not want to be reminded
- Questions can arise at difficult moments – explain when it is appropriate to discuss it
- Wanting to talk to people their own age but networks are limited
- Can affect school work for a short time (but so can worrying about what's happening in their family if there is secrecy)

## What resources are already available?

Thanks to an award from the UK Big Lottery Fund, AMEND produced information resources for children from age 5 upwards in 2014 to help parents to explain MEN to younger family members.

AMEND commissioned a Medikidz™ comic each on MEN1 and MEN2. Aimed at 8-12 year olds, the comics explain MEN as simply as possible in an engaging way. The comic is free and available directly from AMEND.

*"[My son] begged to read this comic and was mesmerized when reading it. He asked loads of questions and it has kept it an open topic between us."*

*"It has made me understand my condition and be more confident explaining it to my child."*

*"The book has helped me to understand and I talked with my mum about tumours and operations as this was the part I found scary!"*

Two entertaining and accessible web cartoons on MEN1 and MEN2 aimed at ages 5 years and up are available to view in the children's area of the AMEND website or on our YouTube Channel (AMEND3). The cartoons received a

'Highly Commended' certification from the British Medical Association in 2015.

The above resources have received endorsements from the following professional medical organisations who are involved in treating and managing MEN patients; the Society for Endocrinology, the British Association of Endocrine & Thyroid Surgeons, the British Society for Paediatric Endocrinology & Diabetes, the UK & Ireland Neuroendocrine Tumour Society and the British Medical Association.

### *Emotional Well-Being*

Living with a rare genetic disorder is not always easy. Some people cope better than others, but most people will have periods of low mood at some point along the way. It is now better recognised that overall health depends upon both physical and emotional health. For this reason, AMEND offers a free telephone counselling service to registered members. In addition, AMEND's Counsellor is sometimes available for face-to-face sessions at our free events. See our website for more details.

In 2015, AMEND began a project to look at the psychological impact of living with MEN. The project includes the development of some specific resources that we are sure patients will find useful. The range of leaflets includes 'Dealing with Diagnosis' and 'Living with Uncertainty'. They are available to

download for free from the Resources section of our website or in hard copy on request. A series of podcasts and an introductory video on the relaxation method, Mindfulness, have also been developed as part of this project and are free to access via our website and YouTube Channel (AMEND3).

### *AMEND UK Medical Advisory Team*

- Professor Rajesh Thakker, University of Oxford, Oxford Centre for Diabetes, Endocrinology & Metabolism;
- Dr Caroline Brain, Consultant Paediatric Endocrinologist, UCLH/GOSH, London;
- Professor Ashley Grossman, University of Oxford, Oxford Centre for Diabetes, Endocrinology & Metabolism
- Mr Barney Harrison, Endocrine Surgery, Royal Hallamshire Hospital, Sheffield
- Dr Fiona Laloo, Consultant Clinical Geneticist, St Mary's Hospital, Manchester;
- Mr David Scott-Coombes, Department of Surgery, University Hospital of Wales, Cardiff;



## *Afterword*

This book has been written for families affected by MEN. The aim of this book is to provide ideas and tools to enable adults to explain MEN to children. It is possible that not all of the information in this leaflet will be relevant to you. This book is not intended to replace clinical care decisions and you should always discuss any concerns you may have carefully with your specialist. Every care has been taken to ensure that the information contained in this book is accurate, nevertheless, AMEND cannot accept responsibility for any clinical decisions.

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Written by Alison Metcalfe & Gill Plumridge (2010, University of Birmingham), and adapted from the original by Jo Grey (AMEND CEO) with the help of the AMEND Medical Advisory Team

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## *About AMEND*

AMEND is a Charitable Incorporated Organisation registered in England and Wales (number 1153890). It provides support services and information resources to families affected by multiple endocrine neoplasia and related endocrine tumours, including a free counselling helpline. AMEND encourages research into the conditions by awarding annual medical prizes and research awards. It hosts regular free family-friendly patient information events every year and runs social media forums connecting patients from around the world.

Please visit our website for more information on AMEND or to make a donation: [www.amend.org.uk](http://www.amend.org.uk)

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