

Other Resources

AMEND has produced several information resources to help patients with MEN to understand and manage the conditions. These are available for adults, teenagers, and young children. Information on the disorders, and on some of the issues surrounding being a patient with MEN are available to download for free at www.amend.org.uk or by contacting AMEND on 01892 516076 / 841032.

Information Booklets

- Patient Information booklets: MEN1, MEN2, MEN3
- Resources for Children : MEN1 and MEN 2/3 Medikidz comic (from age 8)
- Living with Uncertainty
- Talking to Children & Young People About MEN
- How to Choose your Medical Team

Video and audio resources

- Patient experience films on MEN1 and 2/3
- Children's cartoons (age 5yrs +) : 'What is MEN1?' and What is 'MEN 2/3?'
- Managing stress and anxiety: an Introduction to Mindfulness
- Mindfulness podcasts
- Talks from medical specialists at our Annual Patient Information Days

"This is an awesome group - you'll get a lot of great info and support"
(social media member)

You can view all the above and download them for free from our website: www.amend.org.uk

AMEND has received endorsements for its information resources from the Society for Endocrinology, the British Association of Endocrine & Thyroid Surgeons, the British Society for Paediatric Endocrinology & Diabetes and the UK & Ireland Neuroendocrine Tumour Society.

'an amazing service' (service user)

'literally life-saving' (service user)

Need to talk with someone?

Friends and family can be a good source of support when coming to terms with your diagnosis, but there might be times when you feel it would help to talk through difficult feelings with someone outside of your usual support networks. You could ask to be referred to a counsellor through your GP or specialist. Alternatively, AMEND's free specialist Counselling Service provides a limited number of sessions of confidential online or telephone counselling with a specialist rare disease counsellor. The service is available to all registered AMEND patient members and their families. Membership registration is available via our website.

"I have felt so alone all these years in regards to MEN ... Now I feel I am not alone anymore, thanks to AMEND" (MEN1 patient)

You might also be interested in joining one of AMEND's active private **patient-only social media groups** where you can be in contact with others in similar situations. Please contact AMEND directly for more information on how to join.

"Emailing you has made me feel like I am not alone in this and I am very glad I contacted you." (patient)

About AMEND

AMEND is a charity registered in England and Wales (number 1153890). It provides support and information services to families around the world who are affected by multiple endocrine neoplasia and related endocrine tumours. AMEND encourages research into the conditions by awarding annual medical prizes and research awards. It hosts a patient information event every year and runs social media forums connecting patients from around the world.



Registered charity no. 1153890
Tel: 01892 516076
Email: info@amend.org.uk
www.amend.org.uk
Membership is FREE

Dealing with Diagnosis



written by Kym Winter

If you are reading this leaflet, it's likely that you - or someone you know - have recently been diagnosed with Multiple Endocrine Neoplasia, or MEN for short.

What are MEN Syndromes?

Multiple Endocrine Neoplasia (MEN) syndromes are rare genetic conditions, meaning that they can be passed down in families. MEN syndromes cause more than one gland in the body to form tumours (neuroendocrine neoplasms). Most of the tumours occurring in MEN patients are benign (not cancer), but some can become cancer. Affected glands make too many hormones (the body's chemical messengers). The large amounts of hormones can cause a range of different symptoms. There are three main types of MEN syndrome; MEN1, MEN2 and MEN3 (formerly MEN2b). Each child of a parent with an MEN syndrome has a 1 in 2 or 50% risk of inheriting the condition.

MEN is a life-long condition that shows up in different ways depending on which type you have. If you were not given information on your MEN by your medical team, please visit the AMEND website (www.amend.org.uk) or call AMEND on 01892 516076 / 841032.

To be told you have any type of medical condition can be a challenge. The most important thing at the moment is to remember that:

a) there is no right or wrong way to react, and

b) you are not alone

What now?

Over the next few weeks and days, you might experience conflicting and changing feelings or emotions. You might want to:

- find out as much as possible about MEN as quickly as you can, or
- push it to the back of your mind and forget about it completely, or
- think about nothing else

These reactions can take time to settle, as can coming to terms with your diagnosis. This process takes different lengths of time for different people. In addition, it is likely that over the next few months you will have further tests and hospital appointments in order to help work out how best to manage your condition. This is important because MEN can affect different people in different ways, even in the same family.

It is not unusual to feel or think any of the following when you hear about your diagnosis:

- **Anxiety or fear** – of the future and what effect it may have on your life and relationships
- **Anger** – 'why me', and a sense of injustice, unfairness or resentment
- **Relief** – if you have been suffering with difficult or confusing symptoms for some time it can help to know what has been causing these
- **Disbelief or denial** – 'it can't be true'; 'this isn't happening to me'
- **Injustice** – 'it's not fair', or a sense of unfairness and bitterness

- **Worry** – about possible treatments, your long term health, or for other family members, partners or children
- **Guilt** – about how it might affect those you care about

Remember: coming to terms with a diagnosis takes time and is different for everyone.

It is Early Days...

In the early days it can help to recognise that you are trying to come to terms with a great deal of information, and what that might mean for you and your family. This takes emotional energy.

It can help to reduce the number of other practical or emotional demands on yourself for a few weeks whilst you deal with this. You might find that you are more tired, cross or weepy than usual, or that you eat and drink more or less than normal. Recognise these as signs of being under stress, and seek the support of those around you with whom you feel comfortable enough to share your thoughts and feelings. This might include family, friends, your GP or a specialist counsellor such as the one available through AMEND's free Counselling Service (see below). There are also peer support groups available through AMEND.

It is also not unusual to want to 'forget about it all' for a while, or to try to ignore your diagnosis. This might be helpful in the short-term in order for you to allow yourself to get used to the idea at a deeper level, but in the long-run it is important to notice and acknowledge if you begin missing hospital appointments either because of other commitments, or

because you can't face them. This is because with MEN you are an essential member of your own care team.

Becoming an active member of your own Care Team

Now that you have a diagnosis of MEN, you will be offered specialist life-long care to make sure that you stay well, and to help identify any problems as early on as possible. This might feel reassuring, or a lot to get your head around. It might feel like both of these things. If you are struggling with this aspect of your condition, do talk to someone. AMEND has other patients who would be happy to talk to you, as well as a free confidential telephone Counselling Service (see below). You can also ask to be referred to a counsellor by your GP.

It can help to remember that you are the most important person in your care team, and that you can work with your hospital team by:

- Attending all your appointments
- Working pro-actively with your specialist team (e.g. taking correct medication doses, staying as active as possible and learning about what symptoms to watch out for)
- Letting your GP or specialist know if you notice any new symptoms or changes in your health.

In this way, your condition can often be managed very well throughout your lifetime, and lessen the effect that it has on your everyday life.