

Association for Multiple Endocrine Neoplasia Disorders

Registered Charitable
Incorporated Organisation
no. 1153890

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**AMEND Membership, resources
and services are FREE**

**WORKING WITH YOUR
MEDICAL TEAM**

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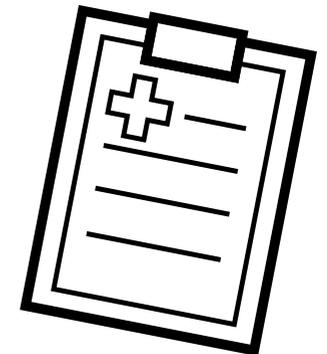
Introduction

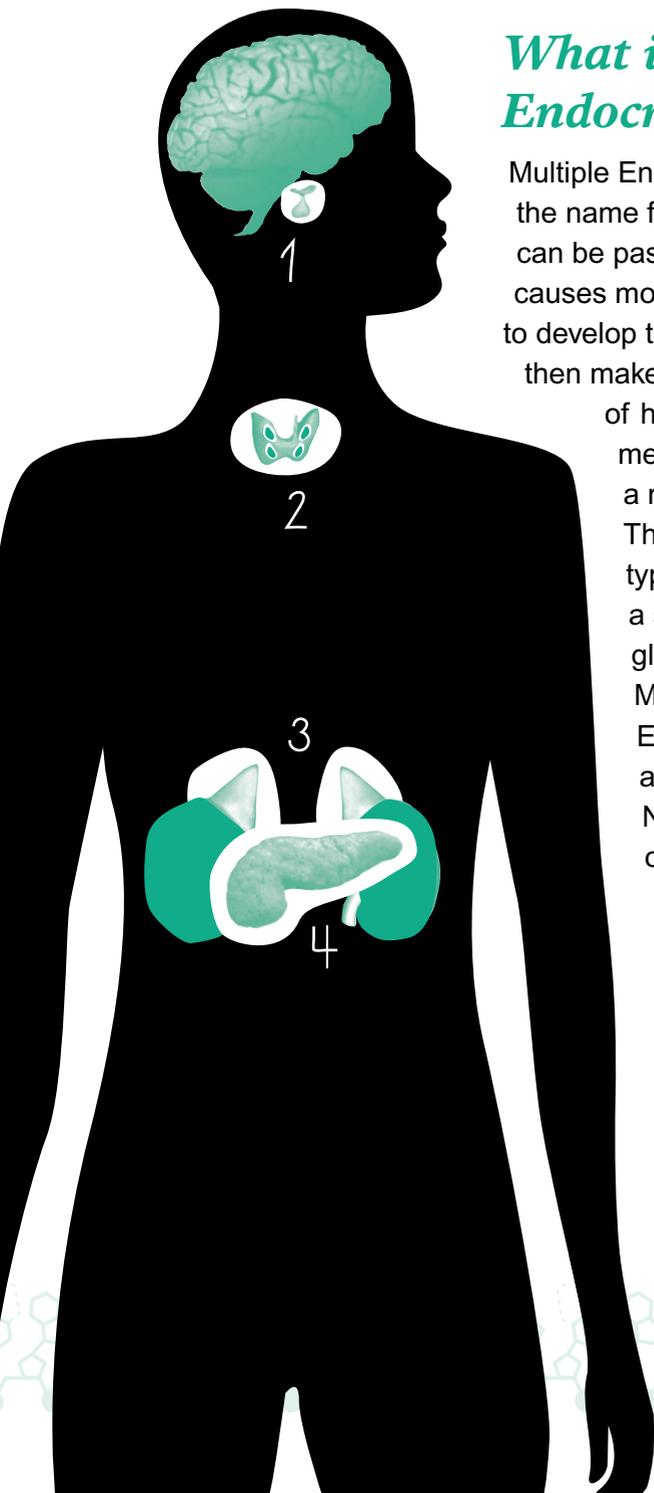
Living with a life-long condition like multiple endocrine neoplasia means that patients and medical staff will have plenty of contact with each other over the course of the patient's life. The aim of all this contact is to help the patient stay as healthy as possible, both in body and in mind. Some people find communicating with medical staff very easy, while others may find this difficult. Research has even shown that effective communication between a patient and their doctors will often result in a patient who is more comforted by the care they receive.

A complex endocrine disease like MEN will require a patient to communicate with a variety of different specialists over the course of their lifetime, even if they have one main key worker such as their endocrinologist. From a General Practitioner (GP) to a specialist hospital surgeon, it is essential that

patients feel confident in communicating and working with their medical team. This can be a challenge if, as happens in many cases, the road to diagnosis has been difficult and long, resulting in a possible loss of trust in the medical profession.

This booklet aims to address all these concerns. It will explore what the ideal medical team (MDT) for MEN may look like, how you can tell if you are being cared for by an expert medical centre, and how to become an effective part of the team who are helping to keep you in the best health possible.





What is Multiple Endocrine Neoplasia?

Multiple Endocrine Neoplasia (MEN) is the name for a group of conditions 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. There are several different types of MEN which each affect a slightly different range of glands.

Multiple = more than one
 Endocrine = system of glands and hormones
 Neoplasia = increase in growth of cells to form a tumour

- 1 pituitary
- 2 thyroid and parathyroids
- 3 adrenal glands
- 4 pancreas

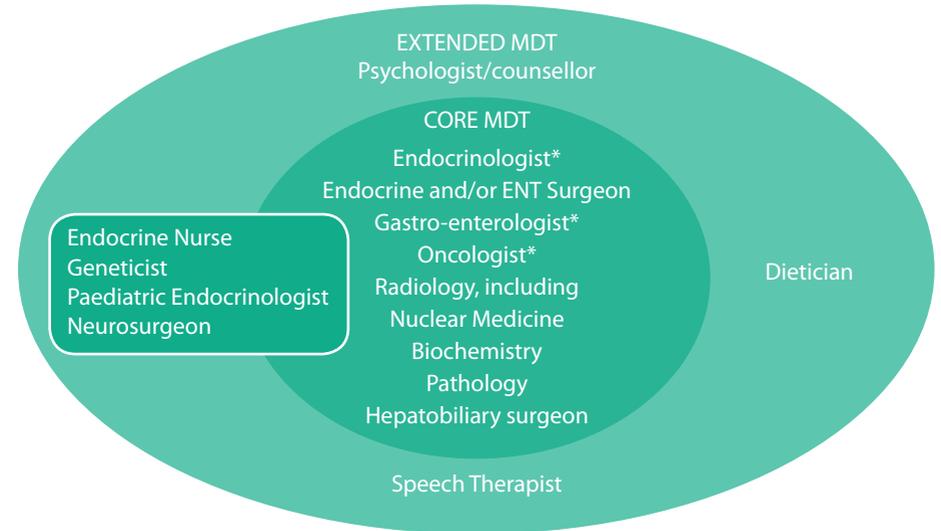
What is a Multi-Disciplinary Team?

A Multi-Disciplinary Team (MDT) is formed of different types of doctors and other health workers who are needed to care for and treat people with rare and complex diseases over their lifetime. The MDT will work all together to make sure that the best treatment possible is given to the patient. Much of this work is done 'behind the scenes' and you will rarely if ever see an entire MDT in the same room! MDTs which are truly specialised in endocrine and neuroendocrine conditions such

as MEN are usually found in larger university training hospitals that may be Centres of Experience. It can feel confusing at first to know 'who does what', so this booklet aims to help you understand how everyone fits together to look after you.

What should my MDT look like?

An Endocrine / Neuroendocrine Tumour Syndrome MDT experienced in care of patients with MEN and associated tumours should include the following:



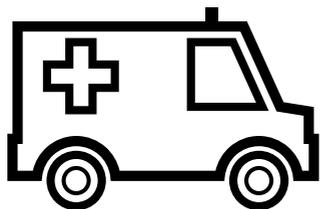
* Your MDT Lead Physician may be any one of these specialists depending upon your route to diagnosis, and/or your main treatment needs. For descriptions, please see the Glossary at the end of this booklet

Sometimes, not all of these specialists are available at the same hospital, but will be based at other nearby hospitals which form a network. This means, for example, that surgery or other forms of therapy might be done at a different hospital from the one you usually go to for your outpatient appointments.

What does an MDT do?

When an MDT meets, they look over all scan and test results that you have had since your diagnosis. This helps them to plan the treatment that is best for you, taking into account your age, general health, and how far your disease has progressed. Some MDTs discuss patients from different hospitals, and specialists may be on different teams for a number of other types of disease and specific cancers.

How often a MDT meets may vary. This could mean that you have to wait a bit longer to get all the results of your scans and a treatment plan from your doctor. This can be frustrating and worrying – but the pooling of different types of expertise should mean the best possible decisions are made about your treatment and care. Not knowing how long you will have to wait for results can feel very difficult. You may find the wait more bearable if you ask when your results should be back, or when you may receive your appointment date. In some cases there may be a designated nurse who will contact you soon after the MDT meeting.



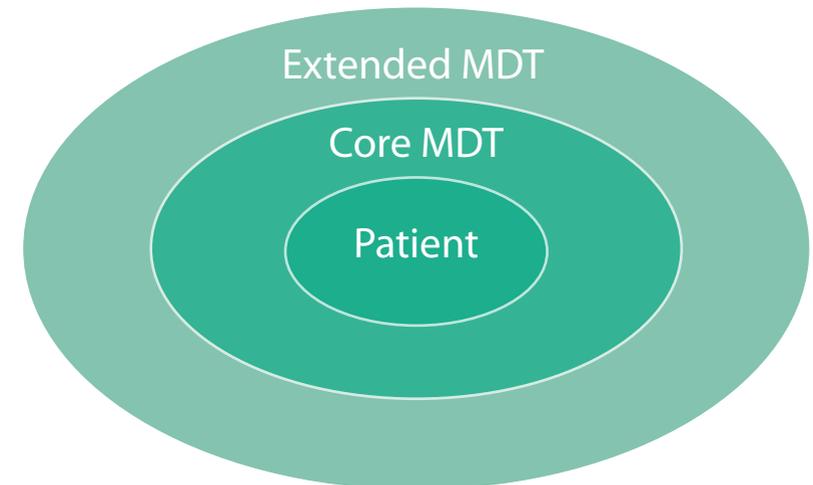
What are the benefits of an MDT?

Research that looked at how effective MDTs are in the UK found that as a result of being cared for by an MDT you're more likely to:

- Receive an accurate diagnosis and staging of your disease
- Be offered a choice of treatments identified by a group of experts
- Receive better coordination and continuity of care throughout your treatment and monitoring plans
- Be treated in line with national guidelines
- Be offered appropriate and consistent information
- Have your psychological and social needs considered.

How do I fit in?

Although not shown in the previous diagram, the patient is the most important part of the MDT and at the centre of discussions, as shown in the diagram below. Without you there is nothing to discuss and no decisions to be made. It is very important that you become an effective part of the team since you need to understand fully what impact any decisions may have on you and your health. Being part of the team does not usually mean that you will be included in the MDT meetings, since other cases are also discussed there. Instead, you will need to develop a relationship with a member of the team (key worker) who will help



explain everything to you. The responsibility of being a part of the team can take some getting used to and is not always easy at first. We hope that this booklet will help you to develop an effective relationship with your key worker and other members of the MDT. It is also important to note that the MDT does not 'make a decision', but provides expert advice to be discussed between you and your key worker/consultant.

What is a Centre of Expertise?

A Centre of Expertise is a major hospital (usually a university hospital) that has expertise in certain medical conditions. They may also be referred to as Centres of Experience. Centres of Expertise will not usually have expertise in all areas of medicine, but rather may have extensive specialised expertise in treating a small number of conditions. These specialised Centres are more likely to have a larger number of patients with rare conditions like MEN. Research has shown that patients do better when they are cared for in a Centre of Expertise and that Centres of Expertise are more likely to have MDTs and Clinical Nurse Specialists.

Some MEN Centres of Expertise in the UK may be registered as such by professional medical societies such as the European Neuroendocrine Tumour Society (ENETS), although not all are.

What Questions should I ask to find out if I am in a Centre of Expertise?

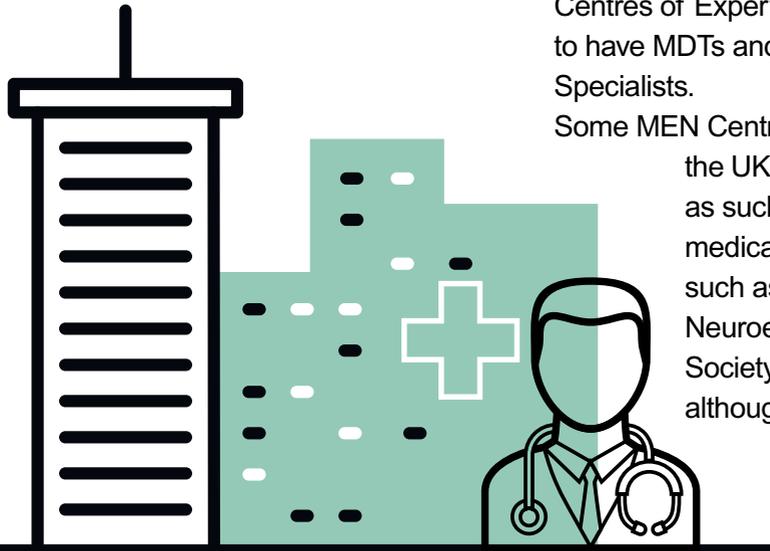
You should never be made to feel that you cannot ask questions. It is your health that is important here, so don't be shy in asking the following:

1. How many other MEN (or other tumour) patients do you care for?
If you are the only one, this is not the place for you
2. Do you have an MDT with whom you will discuss my case?
If the answer is 'no', this is not the place for you
3. If surgery is being offered, ask the surgeon how many of that particular operation he or she does in a year.
If it's just a small number, this is not the place for you

As you go through your testing and treatment, you will have many other questions too. Do feel you can ask those questions if you want to! Together with detailed patient information books, AMEND has produced MEN Passports to help you record these (and the answers) as well as keep track of your tests, scans and treatment. Contact AMEND for your free information books and Passport.

What can I do if I think I am not in a Centre of Expertise?

- **Talk to your Consultant.** Good communication is essential so do not be afraid to talk about how you are feeling and what your concerns are.
- **Ask for a second opinion.** In the UK, if you are unsure of anything that has been suggested to you, you may ask to be referred to another Consultant for a second opinion. Many Consultants actually welcome this and in fact some often seek second opinions and discuss cases with colleagues themselves. It should be noted, however, that whilst you may ask for a second opinion, you do not automatically have a right to receive a referral if your current Consultant does not think it is necessary.
- **Change hospitals.** If you are really unhappy with where you are, you can ask your GP to refer you to another hospital.



How to be an effective member of the MDT

Communication

Good communication between a patient and their medical team is essential in complex disorders like MEN, especially where time in a busy hospital clinic may be limited. You may have a period of time when there is a lot going on with your health, and then a long period of time when things are more quiet. The need to be in contact with your Key Worker and medical team will change during these different periods.

Good communication is easier if you make an effort to learn about your condition, but be careful what information you rely on. Doctors have not always been keen for patients to read information from the internet, but if you use reliable sources of information such as AMEND's website and information booklets, this will help. In fact, research has shown that patients who are knowledgeable about their disorder cope better with it.

Do not hide feelings or symptoms. If you are feeling unhappy,

stressed, or you have noticed any physical symptoms, you must tell your Key Worker. A symptom may or may not be related to your MEN but, by knowing about it, your doctor will be able to order tests to rule things out if necessary. Sometimes it may mean that you will be put in touch with another member of the MDT who can better help you. It could well be that a small change in dose of a medication is all that is needed to correct an issue.

Never be afraid to say that you don't understand something. Doctors are trained to deal with patients who are experiencing all sorts of difficult feelings such as anger, sadness, worry, and irritability, and in playing their part in establishing good communication between you both. Nevertheless, sometimes they may need to be reminded to talk more simply than usual, and not to use complex medical jargon. Explaining medical terms simply helps patients to understand properly and make decisions that are right for them. So, if you are not sure what is being said, ask for it to be explained again until you do.

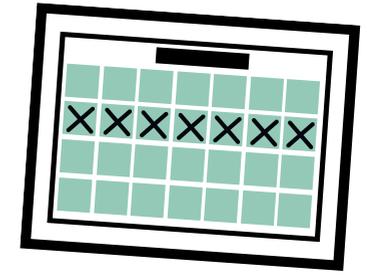
Making the Most of Your Appointments

Tips for keeping track of multiple appointments

1. In 2009, AMEND produced the 'MEN Passport' which is still given out free to patients now. The MEN Passport is a personal organiser for keeping track of your MEN journey and includes pages for recording your appointments, questions, answers, contact details of key workers and key contacts, as well as pages for recording and updating your medication and surgeries. Contact AMEND for your free MEN Passport.
2. If you have a smartphone, there are health apps that you can download and use in combination with the calendar feature.

Tips for Attending a Busy Clinic

1. Keep a dedicated notebook and pen handy, and in between appointments note down any questions or concerns you have, listing them in order of importance. This will help you



remember to raise them either a) in person at the clinic, or b) by phone or email before or after your appointment to your Key 'out-of-clinic' Contact (sometimes this is a Clinical Nurse Specialist). Make sure you have all the right contact details in your MEN Passport and phone/address book so you don't have to waste time digging around for them.

2. Taking a friend or family member with you to your appointments can be very helpful. They can encourage you to ask your questions, and help write down answers for you to read through again later. They may also be able to help in understanding difficult information, or remembering things afterwards, especially if there has been a lot of

information to absorb. Many doctors are not keen on recording discussions between you as it can prevent you both from speaking freely. For this reason, using your phone to record discussions usually won't be encouraged.

3. Make sure you bring a list of all your medication with you (use the MEN Passport if you have one) and any other information from any other hospitals who have been involved in your care up to this point. Contact information for specialists you have seen locally is also useful.



Who should I contact if I have a question or concern between appointments?

You should ask for the contact details of someone within the team who you can contact if you have questions or concerns about your health (this is your 'Key Contact'). Often this is a Clinical Nurse Specialist, who, if they can't answer your question themselves, will seek the answer from your specialist.

The importance of the Clinical Nurse Specialist

Very often, it is the Clinical Nurse Specialist (CNS) who will be your Key Contact within the MDT. The CNS may deal with questions from patients, as well as arrange testing and outpatient clinic appointments. Research has shown that attendance at clinic appointments has increased hugely in clinics that are organised by a CNS.

What do I do if I cannot attend my appointment or tests?

In order to stay as healthy as possible, it is very important to have regular screening tests (and sometimes scans) and to attend all of your out-patient clinic appointments. If you really cannot attend on a date you are given, follow the instructions on your appointment letter for changing the date to one you can make. If you have a problem rebooking within the same timeframe, speak to your Key Contact who may be able to help sort it out.

It's always important to let your Key Contact know about any appointment changes you make, as they may be responsible for scheduling appointments in other special clinics, or tests.

Being in hospital as an in-patient

Patients with rare conditions like MEN often talk about 'becoming their own expert'. At times this may feel frustrating. For example, at a time when you want to be looked after and for someone else to 'know what to do', you may find yourself having to explain your condition to someone who doesn't know much about it. You will probably come across lots of different staff on a busy ward whilst you are in hospital, many of whom will not know much about your particular condition. Therefore, before you are admitted, it can be helpful to write up a short summary of your condition, what medications you are on and how often you take them, any particular ways of managing your condition that work for you, and anything else you may want to make ward staff aware of in advance.

If there is anything you are particularly worried about with respect to going into hospital (for example, pain, dietary or toileting needs) do let someone on the ward or your Key Contact know so that they can work with you to help address your worries in advance, and whilst you are there.

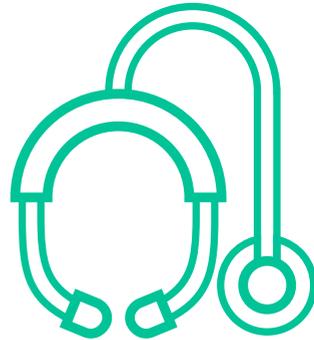
When things go wrong

What can I do if I do not get on with my doctor?

Personality clashes happen in all walks of life, including in healthcare. We all find it easier to get along with some people more than others. Sometimes it can help to say to your consultant how you were left feeling when you last saw them, and see if that can help improve things between you. If you really feel you are just not able to get on, do speak to either your Key Contact or another member of the team, and ask to see a different person in the future.

What should I do if I have a complaint about my care?

First of all, try to speak honestly to your doctor about any problems you have with your care. If you really cannot do this – or if you would like help to do this - all hospitals have a Patient Advice & Liaison Service (PALS) who can act as an intermediary to help resolve any difficulties. You can find their contact details on your hospital website.



Glossary

1. **Clinical nurse specialist (CNS)** - although not all hospitals are lucky enough to have a specialist endocrine nurse, the best teams usually will. These nurses will often be the main point of contact between the MDT and patients with life-long conditions like MEN
2. **Dietician** – an expert on diet and nutrition, sometimes needed after surgery to the pancreas in MEN1
3. **Endocrinologist** - a doctor specialised in endocrine glands of the body and the hormones they produce
4. **Endocrine surgeon** - a surgeon who specialises in surgery for the endocrine glands, though some may be general surgeons with an interest in endocrine glands
5. **ENT surgeon** – surgeon specialised in operations of the ear, nose and throat (ENT)
6. **Gastroenterologist** – a doctor specialised in the treatment of conditions of the digestive system (gut), liver and pancreas
7. **Geneticist** - a doctor specialised in diagnosing and discussing inherited conditions and genetic testing with affected families. They work closely with Genetic Counsellors
8. **Hepatobiliary surgeon** – a surgeon specialised in operations of the liver and other organs such as the pancreas
9. **Histopathologist** - a doctor who makes diagnoses from tissue samples
10. **Neurosurgeon** - a surgeon who specialises in surgery in and around the head and brain, such as pituitary gland tumours
11. **Oncologist** – a specialist cancer doctor
12. **Paediatric endocrinologist** - a children's doctor specialised in endocrine glands and the hormones they produce
13. **Psychologist /Counsellor** - a specialist in dealing with the emotional impact of ill-health and other issues
14. **Radiologist** - a specialist in x-rays and scans including nuclear medicine imaging
15. **Speech therapist** - sometimes needed after surgery to the neck area

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Afterword

The aim of this book is to answer those questions, sometimes in great detail, that someone with MEN may come across when working with their medical team. It is possible that not all of this information will be relevant to you and should not be used in self-diagnosis. This book is not intended to replace any clinical advice. 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 or disputes.

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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. AMEND hosts regular free patient information events each year and has a free counselling service for members. We rely entirely upon donations in order to provide all our resources and services for free.

If you have found this resource useful, please visit our website for more information on AMEND or to make a donation: www.amend.org.uk

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