Patient information

Multiple Endocrine Neoplasia (MEN Type 1)

Diabetes and Endocrinology

What is MEN?

M.E.N stands for Multiple Endocrine Neoplasia. M.E.N is a condition, which causes over activity and enlargement in more than one endocrine gland.

MEN type 1 (MEN-1) is one of a group of conditions which is usually (but not always) an inherited genetic condition and therefore tends to run in families.

What is an inherited genetic condition?

An inherited condition is one caused by a faulty gene. The gene is passed down in families from one generation to the next. Genes determine how your body functions and are present in every cell of your body. You inherit half of your genes from your mother and half from your father. You can inherit MEN-1 even if only one of your parents had the condition.

What are endocrine glands?

Endocrine glands produce hormones that are released directly into the bloodstream. Hormones are chemical messengers that regulate the way in which your body works.

The endocrine glands most commonly affected by MEN-1 are:

- **Pituitary gland** (around 30%)
- **Parathyroid** (around 90%)
- **Pancreatic gland** (around 75%)

Less common sites include:

- Stomach and duodenum.
- Adrenal glands – outer layer.
- Thyroid glands.
- Lipomas (benign tumour in fat cells).

What medical conditions are caused by MEN-1?

The overactive glands produce increased amounts of specific hormones. This can lead to different medical conditions, for example kidney stones, osteoporosis (brittle bones), high calcium levels, fertility problems, visual disturbances, stomach ulcers and diarrhoea.

Does having MEN-1 mean that I have got cancer?

Not necessarily. The majority of the endocrine gland tumours are slow-growing and benign. This means they do not spread to invade other parts of the body. However, they can upset the normal function of the endocrine gland by producing extra hormones or by compressing nearby tissue.

Malignancy (cancer which spreads to other parts of the body) can occur in 50% of MEN-1 patients who have pancreatic endocrine tumours. Fortunately, regular screening can help to detect many of the problems caused by MEN-1 tumours years before serious complications develop.

Remember, most people with MEN-1 do not develop a malignancy due to this condition.

How will I know if I have MEN-1?

You may suspect you have MEN-1 because other members of your family have the condition. However, the symptoms of MEN-1 are variable and a person with MEN-1 may not always know they have the condition.

We will arrange for you to have routine investigations including blood, urine and radiology tests to check for endocrine gland over activity. We will also get a genetic confirmation through a blood test if we suspect that you have MEN- 1

Why do I need to have these tests if I feel well?

People with a family history of MEN-1 as well as those individuals in whom illness may be related to MEN-1 will be offered gene testing to find out if they have inherited the MEN- 1 gene.

For example; a child whose parent is a carrier for MEN-1, will be offered screening for the faulty gene. Once identified, carriers will normally have yearly testing (screening) to identify endocrine gland overactivity.

By the age of 30, most people who inherit MEN-1 will have some type of endocrine gland over activity. Even then symptoms may not develop until they are in the 40 –50 year age group. For this reason it is important for all people at risk of MEN-1 to be tested even though they may feel quite well.

With early detection and treatment the potential problems caused by MEN-1 can be greatly reduced.

What tests are needed to screen for MEN-1?

The first step to finding out if you have endocrine gland over activity is to have blood and urine tests as an out-patient. The tests measure the levels of various hormones and minerals in your blood and urine.

You will need to be fasted from midnight for some of the tests. You may also be referred for CT and/or MRI scans. The doctors and nurses in the clinic will be happy to explain the tests to you.

What are CT and MRI scans?

MRI stands for Magnetic Resonance Imaging. The scan uses powerful magnetic fields to take detailed pictures of your body.

The pictures help the doctor to see if there are any tumours in the endocrine glands. An MRI scanner is like a short tunnel that the X-ray bed moves in and out of.

An MRI scan is painless and lasts from 20-60 minutes. You will have to lie very still during the scan. Some scanning machines can be very narrow so it is important to inform the radiographer (the person who operates the MRI scanner) if you are claustrophobic.

If for any reason you are unable to have an MRI scan, your specialist may refer you for a CT scan, sometimes called a CAT scan.

A CT scanner uses X-rays to take a series of pictures of your body and is painless. The pictures taken by the CT scanner may not be as detailed as those obtained from an MRI scan.

All of your test results will be discussed with you in clinic. You may then be referred for genetic testing to check if you have the faulty MEN-1 gene.

Should I have the genetic test for MEN?

You must decide this for yourself. Having the test will help to confirm that you have MEN-1. This will help the doctors plan your care and follow up. It may also help in screening for MEN-1 in other members of your family.

Several centres in the UK carry out the genetic tests and the results are confidential to you and your doctor. To have the tests you will be referred to a doctor who specialises in genetic problems. They will also provide counselling before the tests and when the results are known so that you can discuss any concerns or fears you may have.

Some people may prefer not to have genetic tests, and are happy to live with some uncertainty. There is a counselling service available for further discussion of the pros and cons of genetic testing. Whether you decide to have the genetic test or not, you will still need routine investigations including blood, urine and radiology tests to check for endocrine gland over activity.

If I have MEN-1 could any of my children or other relatives be affected?

Yes. There is a 50% chance one of your children could inherit MEN-1 from you and a 50% chance they could pass it on to their own children. If you are worried that your child may have MEN-1 then we can arrange for genetic testing for them.

We cannot yet detect MEN-1 before birth although this situation may change over the next few years.

If you have been diagnosed with MEN-1, it is important to let other members of your family know.

What is the treatment for MEN-1?

The treatment for MEN-1 depends upon which of your glands are involved. The treatment usually involves a combination of surgery and medication.

Your specialist will discuss treatment options with you during your clinic appointment.

What happens after treatment?

This depends on what treatment was given. You will need to be seen in clinic regularly. This is because some treatments given for MEN-1 can cause endocrine gland under activity.

You will also need to be monitored to make sure if other MEN-1 tumours develop they can be treated quickly. This lifelong care is provided through a dedicated MEN-1 clinic.

You will need to attend clinic at least every six months so that the consultant can check on your progress and review the treatments you are taking. You will need to have regular blood tests (about twice a year) and occasional ultrasound and MRI scans.

Does having MEN-1 affect my life expectancy*?*

With regular tests and appropriate treatment, most people with MEN-1 can expect to live long and productive lives. However, regular medical follow up is essential to make sure any new tumours or recurrences are detected early and treated.

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further Information

Please feel free to contact the Endocrine Specialist Nurses with any questions you may have. There is an answer machine where you can leave your name and contact details. We will return all calls.

The Endocrinology Specialist Nurses
Tel: 0151 706 2417
Text phone number: 18001 0151 706 2417

Related Patient information leaflets:

Prolactinoma (PIF 1014)
Pheochromocytoma (PIF 1051)
The Pituitary Gland (PIF 1024)
MRI Scan – appointment details (PIF 250/V2)

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