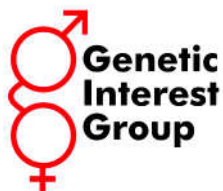


Acknowledgements.

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Genetic Interest Group (GIG)

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Registered Charity No 1114195

Company Registered by Guarantee 05772999

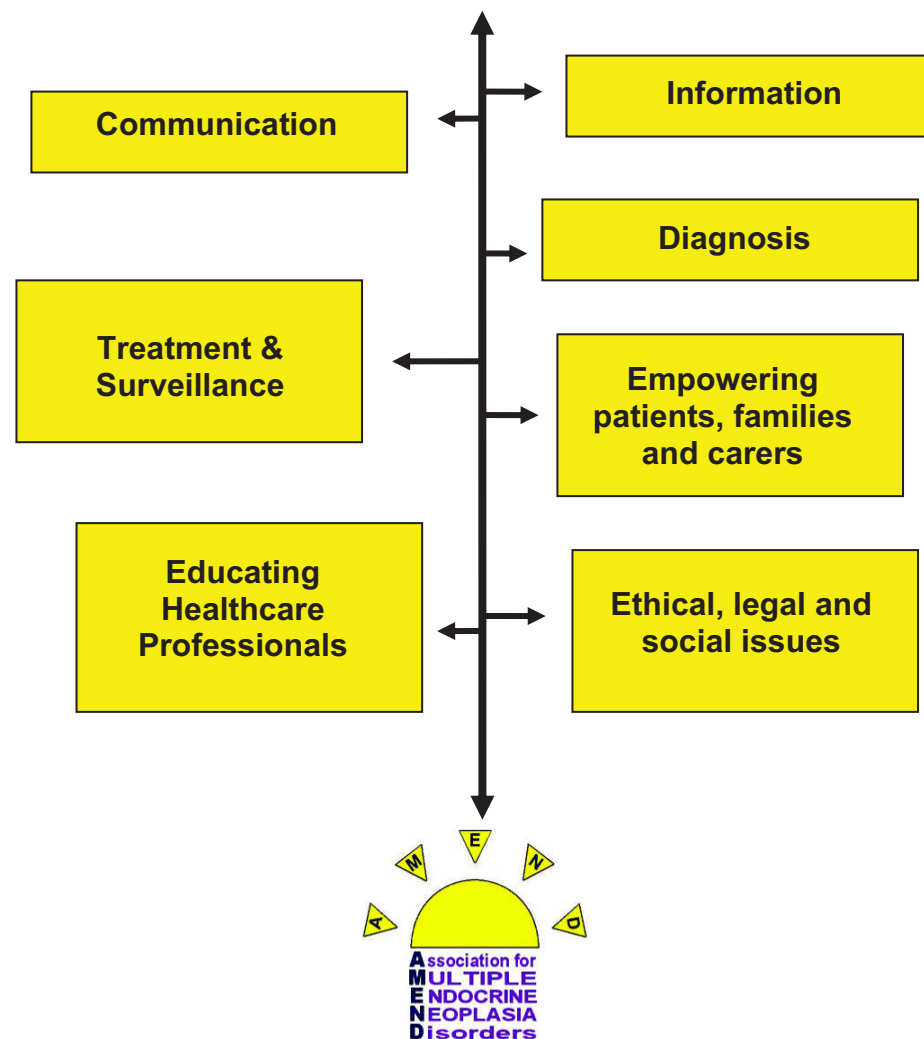
This leaflet has been prepared in good faith to provide patients with a guide to current services and information. Neither GIG nor AMEND can be held responsible for the accuracy of the information it contains. Links to other organisations are included for information purposes only and are not recommendations from GIG or AMEND.

Date published: February 2008

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Multiple Endocrine Neoplasia Disorders Family Route Map

This Family Route Map is a guide to current services and information.



Registered Charity No. 1099796

INTRODUCTION

This leaflet is designed to provide signposts to sources of current information and appropriate services for patients, their families and carers, together with healthcare professionals. The issues and concerns raised during a series of patient focus groups in 2006 organised by the Genetic Interest Group (GIG) identified seven themes (see front cover) which have been used as the basis for developing this resource with the help of patients, families and carers, and clinical staff with experience and expertise of this condition.

INFORMATION

Multiple Endocrine Neoplasia is a group of genetic disorders (MEN type 1, MEN type 2a, MEN type 2b and FMTC). They are inherited disorders, which cause more than one gland of the body's endocrine (gland) system to develop growths. The affected glands then produce abnormally increased amounts of hormones, the body's chemical messengers, which in turn cause a variety of different symptoms. Each type of growth may occur alone and independently of MEN.

Association for Multiple Endocrine Neoplasia Disorders:

AMEND is a patient support group run by volunteers for the benefit of everyone affected by the multiple endocrine neoplasia disorders and their associated familial and sporadic growths. In addition to providing worldwide email and telephone support, AMEND runs its own website, a UK research database and produces patient information. With strong medical advisory team backup, AMEND has gone from strength to strength since its inception as a registered UK charity in 2002, and in 2007 formed a patient/professional partnership working group to look at ways of improving the care and management of MEN patients throughout the UK.

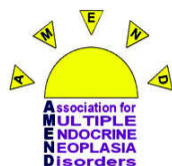
AMEND Contact Details:

Address: PO Box 89, Tunbridge Wells, Kent, TN2 9GL, UK

Telephone: 01892 525308 (9am to 8pm)

Email: info@amend.org.uk

Website: www.amend.org.uk



ETHICAL, LEGAL & SOCIAL ISSUES (Continued)

Genetic testing:

Genetic testing can have implications on many areas of life, particularly when applying for insurance or mortgages, and an experienced genetic counsellor should be able to advise you on these aspects. For life insurance it is advisable to take out a policy (or retain it) before undergoing predictive genetic testing as premiums may rise prohibitively for patients with a known medical condition. However you must always let your insurance company know about your condition to avoid discovering that you are not covered should you try to make claim on it.

Employment:

Issues around careers and work can be addressed locally with a Disability Employment Adviser (DEA) based at JobCentre Plus. Further advice can be found at The Department for Work and Pensions website www.dwp.gov.uk or Connexions www.connexions.gov.uk

EMPOWERING PATIENTS, FAMILIES AND CARERS

With rare genetic diseases, it is important for patients to be as knowledgeable about their condition as possible in order to communicate effectively with medical professionals regarding their care and treatment.

Patient Information:

AMEND produced the following Patient Information books with the help of an expert medical advisory team:

MEN 1, MEN2a, MEN2b, FMTC & Sporadic MTC

Each book contains detailed information on living with the disorder. Contact AMEND for a copy or download them for free from the AMEND website at www.amend.org.uk.

TIP

Say how you feel: if you don't want your picture taken, or if you don't want medical students participating in your appointments, don't be afraid to say so.

ETHICAL, LEGAL & SOCIAL ISSUES

Insurance:

It is common to have difficulties finding adequate and affordable insurance policies once diagnosed with MEN. The following companies offer travel insurance for people with pre-existing conditions. There may be others available and this list should not be taken as a recommendation:

- Freedom Insurance www.freedominsure.co.uk
Tel: 01223 454290, email: information@freedominsure.co.uk
- Free Spirit (AXA Insurance UK plc) www.free-spirit.com
Tel: 0845 2305000, email: sales@pjhayman.com
- AllClearPlus (Groupama Insurance Co Ltd)
www.allcleartravel.co.uk
Tel: 08712 088500, email: info@bishopscurtas.co.uk
- The Insurance Surgery, www.the-insurance-surgery.co.uk
Brokers who promise to find a good deal on all types of insurance for those with pre-existing medical conditions.
Tel: 0800 083 2829. Online quotes available.

Financial help:

- CAB (Citizens Advice Bureau) can help with advice on benefits. Find your local branch in the phone book or online at www.citizensadvice.org.uk (co.uk for Northern Ireland) or www.adviceguide.org.uk.
- Macmillan Cancer Support provide advice to cancer patients. www.macmillan.org.uk or freephone 0808 808 2020 from 9am to 10pm, Monday to Friday.
- AMEND may be able to help with travel costs associated with participation in some clinical drug trials.

Psychological help:

Psychological counselling is not commonly offered on diagnosis or even later on (note: genetic counselling does not usually include psychological help). If you feel that you need extra help in coming to terms with your condition or any other aspect of your life, don't be afraid to ask for this via your GP or specialist.

INFORMATION (Continued)

Prescriptions:

Patients in England and Scotland taking life-long medications such as levothyroxine, corticosteroids (hydrocortisone & fludrocortisone), and insulin are entitled to free prescriptions for all medications. Speak to your GP to obtain the relevant form (P11 form B).

TIP

MedicAlert Foundation. MedicAlert ID emblems enable emergency medical staff to call a 24-hour helpline number to obtain detailed information on your medical condition, a summary of which is engraved on the emblem.
www.medicalert.org.uk

Links to Other Useful Organisations and Information:

Addison's Disease Self Help Group (ADSHG): www.adshg.org.uk
Tel: 01483 830673

British Thyroid Foundation (BTF): www.btf-thyroid.org.uk
Tel: 0870 7707933

Diabetes UK: www.diabetes.org.uk Tel: 020 7424 1000

Pituitary Foundation: www.pituitary.org.uk Tel: 0870 774 3355

NET Patient Foundation (incorporating Living with Carcinoid):
www.netpatientfoundation.com

Contact-A-Family: www.cafamily.org.uk Tel: 020 7608 8700

The UK Genetic Testing Network patient leaflet
www.ukgtn.nhs.uk/gtn/UKGTN-information/Patient-leaflet.html

GIG (Genetic Interest Group) patient leaflets www.gig.org.uk
Tel: 020 7704 3141

UK Network and IPSEN DVD and booklets 'Living with a Neuroendocrine Tumour' www.ipsen.co.uk/ipsen_net_form.php,
Tel: 01753 627777

Further links are available via the AMEND website at
www.amend.org.uk

DIAGNOSIS, TREATMENT AND SURVEILLANCE

Doctors, hospitals, multidisciplinary medical teams:

MEN is best managed and treated in a large university hospital setting where a full range of the experienced medical professionals necessary to treat the MEN conditions may be found. Contact AMEND for further information on centres of expertise.

Second Opinions:

In the UK, patients have the right to ask to be referred for a second opinion, particularly to a centre of expertise, via their first specialist or through their GP. They are not, however, entitled to receive that second opinion if the clinicians do not think it necessary. A patient may appeal against any decision via their Primary Care Trust (PCT). For more information on the Referral Process please see www.gig.org.uk/docs/referrals.pdf

Surveillance:

Investigations, including blood tests, scans and imaging, and their frequency are outlined in the AMEND *Patient Information Books* for MEN 1, MEN2a, MEN2b, Familial Medullary Thyroid Cancer(MTC) & Sporadic MTC. See www.amend.org.uk or contact AMEND.

TIP

MEN Passport: a portable personal record file produced by AMEND is available to help patients keep track of tests and treatment.

Genetic Testing:

There are a number of issues surrounding genetic testing particularly in relation to children and as such, all patients should be seen and counselled by a consultant clinical geneticist as early on as possible (please note that genetic counselling is not the same as psychological counselling). As MEN is an inheritable condition, other family members will be offered predictive gene testing. If the gene fault cannot be found or if a blood sample from an affected person cannot be obtained then predictive genetic testing on other family members cannot be done. Genetic testing and counselling is available at 23 regional NHS genetic centres in the UK; see www.bshg.org.uk Referrals to genetic centres are usually made through your GP or specialist.

EDUCATING HEALTH PROFESSIONALS

Information for healthcare professionals:

- AMEND Patient Support Group www.amend.org.uk
- Hammersmith Hospital www.carcinoid.co.uk and also Dr Meeran's homepage www.meeran.info
- NIH (USA) www.endocrine.niddk.nih.gov
- 2001 Consensus Guidelines for Diagnosis and Therapy of MEN Type 1 and Type 2: The Journal of Clinical Endocrinology & Metabolism 86(12):5658-5671
- NHS National Genetics Education and Development Centre www.geneticseducation.nhs.uk

Patient-aimed information:

Detailed Patient Information Books on MEN1, MEN2a, MEN2b, FMTC and sporadic MTC have been produced by AMEND and are available free to patients via their website www.amend.org.uk or contact AMEND for a printed copy.

Patient-led education:

AMEND volunteers visit clinics and departments to talk to both patients and staff about MEN from the patient's perspective.

MEN Consortium:

Set up in 2007, this AMEND patient/professional partnership working group looks at ways to improve the care and management of all patients with MEN in the UK. Please contact AMEND for further information.

Other information:

Visual aids: website video clips of both patients and expert medical professionals are currently in production by AMEND and can be found on their website.

Clinical Societies:

The following professional clinical societies have members involved in the care and management of MEN patients

- The Society for Endocrinology www.endocrinology.org
- British Association of Endocrine and Thyroid Surgeons (BAETS; currently BAES) www.baes.info
- British Society for Paediatric Endocrinology and Diabetes (BSPED) www.bsped.org.uk