National Hospital for Neurology and Neurosurgery

Charles Dent Metabolic Unit

Resources for people with Inherited Metabolic Disorders
If you need a large print, audio, braille, easy read or translated copy of this document, please contact us on 020 3448 4778. We will try our best to meet your needs.

**Contents**

1. Introduction 3
2. Help for psychological difficulties 3
3. Help for parents and carers 6
4. Help with difficulties at work 8
5. Improving general wellbeing 9
6. Patient support groups and organizations 11
7. Where can I get more information? 13
8. Contact details 13
9. How to find us 14
1 Introduction

This leaflet is written for people living with Inherited Metabolic Disorders (IMDs) and their families and carers. It contains a list of resources such as NHS services, charities, books, apps and websites that may be useful in coping with some of the problems commonly associated with IMDs.

If your problems are severe and are affecting your ability to do and enjoy things in day-to-day life, talk to your GP.

You can also discuss any difficulties with your Metabolic Centre.

UCLH cannot accept responsibility for information provided by other organisations.

2 Help for psychological difficulties

Depression and low mood

We know that people with IMDs can be at increased risk of depression or low mood.

There are a number of self-help resources that have been designed to help people who are feeling low.

The book *Overcoming Depression* by Paul Gilbert (ISBN: 1849010668) provides a self-help programme that you can work through on your own or with a therapist. You might also be interested to read *The Happiness Trap* by Russ Harris (ISBN: 184529825X).

Online, the Moodgym and Living Life to the Full websites can be found at [www.moodgym.anu.edu.au](http://www.moodgym.anu.edu.au) and [www.llttf.com](http://www.llttf.com)
Anxiety and stress


Fear Fighter is an online course for anxiety, panic and phobias which is available as an app on the Apple or Android store.

Mindfulness

Mindfulness skills are psychological and behavioural versions of meditations practices from Eastern spiritual training. Research suggests that they help some people to cope with chronic physical health problems.

If you would find out more, there is information and a selection of free guided meditations at www.franticworld.com

General information about mindfulness is available at www.mind.org.uk if you search for “mindfulness”.

If you would like to learn about mindfulness in more detail, *Mindfulness: A practical guide to finding peace in a frantic world* by Mark Williams and Danny Penman, provides a useful introduction (ISBN: 074995308X).

There are a number of eight week mindfulness courses across the country. You can search for courses by postcode at www.bemindful.co.uk
Counselling and therapy

NHS

Every borough in the UK has a team of psychological therapists. You can find your local service online at [www.nhs.uk/Service-Search/Psychological-therapies-(IAPT)/LocationSearch/10008](http://www.nhs.uk/Service-Search/Psychological-therapies-(IAPT)/LocationSearch/10008)

Most of these services will allow you to make a self-referral by telephoning or filling in a form online. If not, you can request a referral from your GP.

Charities

A number of charities also offer therapy or counselling.

- **Mind** is the mental health charity [www.mind.org.uk](http://www.mind.org.uk) 0300 123 3393
- **Cruse** offers support to people who have experienced bereavement [www.cruse.org.uk](http://www.cruse.org.uk) 0808 808 1677
- **Relate** provides couples counselling, with fees on a sliding scale depending on your income [www.relate.org.uk](http://www.relate.org.uk) 0300 100 1234

Private therapists

If you decide that you would like to try private therapy, it is important that you choose an appropriately qualified therapist. You can find a therapist through one of these professional bodies:

• for counselling and psychotherapy: British Association of Counselling and Psychotherapy  
  www.itsgoodtotalk.org.uk/therapists  
  UK Council for Psychotherapy  
  www.psychotherapy.org.uk/find-a-therapist  
  British Psychoanalytic Council www.bps.org.uk/find-a-therapist

• for neuropsychology: British Psychological Society  
  Specialist Register in Neuropsychology  
  https://www.bps.org.uk/lists/SRCN

Medication

Medication is also an option to treat psychological problems such as anxiety or depression. You can discuss this option further with your General Practitioner (GP).

3 Help for parents and carers

Parenting

If you are the parent, you might find the following books helpful:


How to talk so kids will listen and listen so kids will talk by Adele Faber and Elaine Mazlish (ISBN: 1848123094).

How to talk so teens will listen and listen so teens will talk by Adele Faber and Elaine Mazlish (ISBN: 1853408573).
www.understandingchildhood.net has a range of helpful leaflets covering common issues for children of all ages such as tantrums, overactivity, starting school, bereavement, divorce and separation, and teenage years.

**Family Lives** is a charity for parenting and family support www.familylives.org.uk 0808 800 2222.

The charity **Young Minds** runs a helpline for anyone concerned about the mental health of a child or young person and for parents who need help **0808 802 5544**.

**Carer support**

Some charities provide help and advice specifically for people who are carers:

**Carers Trust**
0300 772 9600
www.carers.org

**Carers UK**
0207 378 4999
www.carersuk.org

If you provide care and support to a person with IMD you may be eligible for help from your local council. You can find more information at www.nhs.uk/Conditions/social-care-and-support-guide/Pages/carers-assessment.aspx

If you are a carer for a person who does not have capacity to make some or all of their decisions, you can find information about making decisions for someone and power of attorney at www.gov.uk/make-decisions-for-someone
4 Help with work

Difficulties at work

Living with any long-term, complex health problem may affect you at school and at work.

The Equality Act 2010 means that employers must make reasonable adjustments to support you if you have a disability.

The Disability Law Service provides free legal advice to people with disabilities and their carers
0207 791 9800
www.dls.org.uk

The Mind legal line offers legal advice on mental health-related law 0300 466 6463.

The Access to Work Scheme offers some help for people who have a paid job or are about to start or return to one. This might include grants for special equipment, adaptations or support work services and help getting to and from work. See www.gov.uk/access-to-work for more information.

Finding a job

Find your local Jobcentre Plus at find-your-nearest-jobcentre.dwp.gov.uk/

The National Careers Service provides information, advice and guidance to help with training and work. They can help with job hunting, interview techniques, CV writing, or finding a course. For more information see nationalcareers.service.gov.uk/

www.do-it.org is a national database of volunteering opportunities. You can search by postcode or by the type of voluntary work that you are interested in.
5 Improving general wellbeing

Looking after your general wellbeing is an important part of managing any long-term health condition.

Sleep

Difficulty sleeping affects 95% of people at some point, but getting enough good quality sleep is important for maintaining mood and wellbeing.

There is information about a range of sleep problems, and tips and resources that can help, on the Royal College of Psychiatry website www.rcp.ac.uk (search for “sleeping well”).

Relaxation exercises can also be helpful if you have trouble sleeping. A range of exercises are available to read about and download at www.getselfhelp.co.uk/relax.htm

Exercise

Exercise has a role in maintaining mood as well as being important for general health and fitness. Many people have found the following programmes helpful for getting healthy exercise:

The Ramblers Association run hundreds of walks each week, from short strolls to long hikes www.ramblers.org.uk

Walking for Health organises walks for people who have a mental or physical health problem www.walkingforhealth.org.uk

The NHS Couch to 5k programme (C25K) is for beginner runners who want to learn to run five kilometres www.nhs.uk/LiveWell/c25k
Park Run organise free, weekly, timed 5k runs around the country. See www.parkrun.org.uk

Green Gym provides exercise options for people who don’t like the idea of using the gym or going to exercise classes www.tcv.org.uk/greengym

Man v Fat Football leagues organise weekly 30-minute matches with support for losing weight www.manvfatfootball.org

NHS Fitness Studio has a number of free workout videos online www.nhs.uk/Conditions/nhs-fitness-studio/Pages/welcome-to-nhs-fitness-studio.aspx

A variety of other options to try are listed on the NHS Get Fit for Free page at www.nhs.uk/Livewell/fitness/Pages/free-fitness.aspx

**Alcohol**

Your GP can advise you about NHS services that are available if you would like help to reduce your alcohol intake.

Addaction is a national service offering support to change drug or alcohol use or mental health. Many of their services offer walk-in appointments www.addaction.org.uk

**Smoking**

Your GP can also tell you about support available near to you for stopping smoking, or you could call the Smokefree National Helpline on 0300 123 1044. You can find a list of NHS stop smoking services at www.nhs.uk/smokefree and there is a list of self-help tips to stop smoking on the NHS Livewell website.
6 Patient support groups and organization

**Metabolic Support UK** – for all IMDs
0845 241 2173
www.metabolicsupportuk.org

**Genetic Alliance UK**
0207 831 0883
www.geneticalliance.org.uk

**The National Society for Phenylketonuria**
0303 040 1090
www.nspku.org

**Galactosaemia Support Group**
0121 378 5143
www.galactosaemia.org

**Alex TLC**
0207 701 2628
www.aldlife.org

**The Alkaptonuria Society**
0122 322 2897
www.akusociety.org

**Fabry Support & Information Group**
www.fabry.org

**Gauchers Association**
0145 354 9231
www.gaucher.org.uk

**Association for Glycogen Storage Disease**
0300 123 2790
www.agsd.org.uk

**Society for Mucopolysaccharide Diseases** – also offer a Fabry Support service
0345 389 9901
www.mpssociety.org.uk

**Niemann-Pick UK**
0191 415 0693
www.npuk.org

**TMAU support website**
www.tmau.org.uk

**The Lysosomal Storage Disorders (LSD) Patient Collaborative Group** is made up of representatives from various charities in the UK who provide services to families affected by LSDs. They offer advocacy and support for difficulties associated with LSDs, including mental health and wellbeing.
www.lsdcollaborative.org.uk
7 Where can I get more information?

If you have questions about any of the information or resources in this leaflet, you can contact your Consultant or other healthcare professional at the Metabolic Unit.

8 Contact details

Direct line: 0203 448 4778

Switchboard: 020 3456 7890 (or 0845 155 5000 - premium call rates apply)

Extension: 84778
Fax: 0207 209 2146
Website: www.uclh.nhs.uk
9 How to find us

The Charles Dent Metabolic Unit is located at the National Hospital for Neurology and Neurosurgery in Queen Square (see the map below).
Notes