Living well with an illness or dis-ability

Here we are! See us!

Having an illness or disability shouldn’t make us invisible. People with an illness or disability are an integral part of society and contribute alongside other members of society. We’re valuable, whether or not we fit into society’s box.

Tips, hints and ideas to help people in Manchester living with long-term illness or disability
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## About us

We are a group of 9 people living with various long term health conditions. We came together to share our thoughts on how to get the most out of life and explore different ways of looking after ourselves. We hope these tips and ideas may help you to deal with the challenges you might face.
Some things we’re learning along the way

- To accept my condition and to live with it.
- Living life in the now.
- Listening to my body first and pacing myself.
- To slow down and take care of myself.
- A balance of resting and going out.
- My health is more valuable than THINGS.
- Saying no.
- Being more open and more assertive about my needs.
- I don’t have to be perfect.
- Being okay with who I am and not apologising.
- I don’t have to engage with anybody else’s bad mood. I can walk away and let it go.
- I can still do things I enjoy and be with people.
- I get a lot out of volunteering.
- I’ve learned to accept that I can’t do everything – much as I’d like to.
Some things that we’ve found helpful

Living with a long-term condition can add to the many stresses of life. We all find different tools to help us cope better. Here are some of our favourites so you can try and find out what works best for you.

**F** has been on a really useful **Positive Living Course** run by Chorlton Good Neighbours. For more info call 0161 881 2925. **There’s also a regular positive living course at the Kath Lock Centre in Hulme (see resources section).**

**F** also uses **Hydrotherapy** (contact the South Manchester Arthritis Group for more details). “Weekly hydrotherapy is fabulous”, she says. “I really get a lot from both relaxing and exercising in the warm water.”

**J** uses **Qi Gong** to help her relax. **Classes around Manchester including at the Kath Lock Centre in Hulme (see resources section).**

**K** finds **More to Life** courses really useful. “I have learned tools that help me to respond to challenges in a way that really makes a difference.” **Contact: More To Life in the North: northengland@moretolife.org, 0161 312 6013. www.moretolife.org.uk**

**R** says that **mindfulness and meditation** is her greatest self-management tool. “Not only has it really helped me learn to manage my arthritis flare ups but it’s also helped me in all areas of my life.” she says. **Breathworks** runs courses specifically for people living with pain and illness. 16 - 20 Turner Street, Manchester M4 1DZ, 0161 834 1110. [http://breathworks-mindfulness.org.uk](http://breathworks-mindfulness.org.uk)

**S** is really enjoying her **Pilates** class at Henshaws and is finding it really relaxing and useful. 0161 872 1234 [courseenquiries@henshaws.org.uk](mailto:courseenquiries@henshaws.org.uk) [http://henshaws.org.uk](http://henshaws.org.uk)

Many of us find that exercise of some sort helps. You don’t need to belong to a posh gym to find a class to suit you. Manchester City Council has lots of different classes around the city. Find out more: [www.manchester.gov.uk/activelifestyles](http://www.manchester.gov.uk/activelifestyles)
Several of us enjoy **yoga** and find it really helpful for our physical and mental health. There are a number of therapeutic yoga classes around Manchester:

Jane Craggs runs classes for people with chronic fatigue, exhaustion and insomnia. *Contact:* yogaspace@hotmail.com 07764 963 138  www.janecraggs.co.uk

Hil Bichovsky runs gentle **Dru Yoga** classes and **Deep Relaxation** classes for all abilities, in Chorlton, and in Didsbury (accessible venue). All welcome, including those with limited energy or mobility and also with back pain. *Hil Bichovsky, DYT (Dru Yoga Teacher Training), 0161 445 3914, 07982 479636, hil.b@zen.co.uk*

A few of us have also tried **Emotional Freedom Technique** (EFT) – also called ‘tapping’.

### Other useful tips and techniques

- **T**rying to stay and think positively as much as possible
- **M**edication/brace/walker/helper
- **H**ow can I make this work for ME? How can I do it?
- **G**etting out and about/meeting people
- **P**acing
- **G**oing out with friends
- **T**ake things one day at a time
- **L**earning to swim
- **O**nly do half of what you think you should do. Don’t be tempted, when well, to overstretch yourself because you might pay for it later!
- **R**eiki
- **E**xercises for people with low mobility
How to handle your GP and other appointments

- When dealing with the doctor try and pre-book a longer appointment or a double appointment so that you have more time.

- Some of us feel that having someone else in with you during your appointment can be helpful whether that’s a friend, relative or another medical professional.

- Sometimes, the medical terms used can be confusing. Ask them to repeat what they’ve said if you don’t understand – or if you are upset by the way you’ve been spoken to. “Could you just say that again so that I can write it down?” This is also why it can be useful to have someone along with you.

- It can also be helpful to record appointments on a phone or MP3 recorder.

- Write down what you want to ask the doctor before your appointment so you can make sure you remember what you need to say – and what you need to know.

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Energy

Most of us don’t have as much energy as we’d like. We found a really useful analogy on the internet called the ‘Spoon Theory’. This theory uses spoons to represent the available energy we have. It says that whereas most people have unlimited spoons each day, people living with illness or disability only have a limited number of spoons (energy) available each day – meaning that careful choices need to be made. Most of us are still learning how to make wise spoon choices! It’s not easy to do, but thinking of our energy in terms of something more tangible – like spoons – helps us think more about the choices we make.

www.butyoudontlooksick.com/wpress/articles/written-by-christine/the-spoon-theory
Saying NO! Our tips

Lots of us find saying no really difficult but saying yes all the time can be really bad for our health. We can take on too much, burn out, overdo it or just end up doing things that aren’t great for us or that we don’t even want to do! We think that some of these ways of thinking or attitudes might make saying no easier.

Thinking:

- I’m important too
- I’m not a bad person if I say no
- If we don’t look after ourselves, we can’t help others
- My health comes first
- Thinking: If I say yes, what happens? If I say no, what happens? Think about the consequences
- You can’t please everyone, so what would please me?!
- When we say no, we’re still saying yes to something, so work out what are we saying yes to. For example, thinking: I’m saying YES to something else (for example – no to late night = YES to rest. No to social event = YES to solitary time or balance)

Though learning to say no is important, sometimes it still might be better to say yes. Don’t put limits on yourself and jump straight to no!

Take risks sometimes.

Helpful ways to say no!

- Take a couple of breaths before replying.
- Say “I need time to think about that” – taking time to really think about it.
- Say firmly, “No, I’ve made my decision”.
- If someone says, “It’ll do you good” reply with “No, not this time. Maybe another time”.

No!!!
Resources in Manchester

Here are a few of the resources in Manchester that we think could be useful for people with long-term health conditions. We couldn’t fit everything in, so we chose the ones that we think would be the easiest to access financially, services that we’ve tried and liked ourselves, or ones that we thought looked particularly useful.

The Acupuncture Works
Manchester’s community acupuncture clinic offers affordable acupuncture for people who have chronic health issues. London Scottish House, 24 Mount Street, Central Manchester, M2 3NN, Wednesdays: 10am - 5pm. Also at: ‘The Clinic’, Elizabeth Gaskell Campus, Hathersage Road, Manchester. M13 0JA, Thursdays: 11am – 4pm. This site has disabled access. www.manchesteracupuncture.org.uk  To book appointments ring or text: 07590 903 714

Arthritis support group
South Manchester Arthritis Support Group. Pauline: 07751736195

Bodywise Natural Health Centre
Bodywise has a range of different courses and services including homeopathy and a range of natural health therapies, yoga and Qi Gong classes and Feldenkrais “Awareness through Movement” sessions. 16 - 20 Turner Street, Manchester, health@bodywisenaturalhealth.co.uk_ 0161 833 2528. www.bodywisenaturalhealth.co.uk

Expert Patient Programme
A free course which hopes to equip you with a number of self-help techniques to help you live better with your condition: www.uhsm.nhs.uk/community/Pages/EPP.aspx 0161 219 9424 man-pct.epp@nhs.net

Homeopathy: North West College of Homeopathy
The College runs low cost clinics in Manchester at the Kath Locke Centre in Hulme, and in Sale. Contact : 0800 978 8626 info@nwch.co.uk www.nwch.co.uk/patients/consultations-available-html
Kath Locke Centre
Lots of different low cost alternative health services for people including:

**The Manchester herbalist** (Free consultation, £7.50 for herbal medicines)

**Yoga sessions**, A low-cost **homeopath** (£10 per session or drop in clinic £5 per person), **Qi Gong classes**, **Reflexology sessions** (£10 per session)

123 Moss Lane East, Hulme, Manchester M15 5DD
www.kathlockecentre.co.uk 0161 445 0211

Manchester Community Health Trainers
Free service for people within Manchester.
0161 861 2902

Manchester Mind
Provides advice, information and support to people experiencing mental distress. 339 Stretford Road, Hulme, Manchester, M15 4ZY 0161 226 9907
info@manchestermind.org  www.manchestermind.org

Manchester People First
is run by learning disabled adults and is independent of services. Gives training, support and advice to learning disabled adults and professionals and campaign for disabled people’s rights. 3 Broughton Street, Cheetham Hill, Manchester, M8 8RF 0161 839 3700  mcrpeoplefirst@googlemail.com
www.manpf.org

Self-Help Services
A user-led self-help charity providing a number of services around Manchester including a free computerised cognitive behavioural package for anyone experiencing low-self-esteem, anxiety, low mood, sleep problems, poor concentration and depression. Also runs self-help groups and courses including the Boost: Emotional Resilience course, self-esteem and assertiveness courses, anxiety management etc. 0161 226 3871
http://www.selfhelpservices.org.uk/

Simply Cycling – Wythenshawe Wheelers
Simply Cycling runs all-ability cycling sessions in Wythenshawe and Trafford. Just turn up and they’ll find a bicycle suitable for you. Small charge only.
Sue: 07753 428937 www.wythenshawe-wheelers.org/

Zion Community Resource
Lots of different low-cost or free health services for people including **Herbalist**, **Qi Gong sessions**, **Art group**, **Yoga**, **Reiki healing**, **Depression group**, **Computerised CBT**, **Massage**, **Crystal healing**. 339 Stretford Road, Hulme, Manchester M15 4ZY 0161 226 5412 www.zioncentre.co.uk
Access

**Manchester Disabled People’s Access Group** has some good information about access issues and access rights.

Contact: [admin@mdpag.org.uk](mailto:admin@mdpag.org.uk)

[http://www.mdpag.org.uk/manchester.htm](http://www.mdpag.org.uk/manchester.htm)  0161 455 0219

**How to get disabled toilets access**

If you are a resident of Manchester who qualifies, you can get a free key to give you access to disabled toilets in Manchester, and around the country in shopping centres, pubs, cafes, department stores and train stations. More information on the City Council website: [www.manchester.gov.uk/info/579/public_toilets/2360/public_toilets_in_manchester/2](http://www.manchester.gov.uk/info/579/public_toilets/2360/public_toilets_in_manchester/2)  0161 234 5000

You can also buy a key for £2.25 plus £1.75 postage from Radar’s online shop: There is a booklet with all the toilets listed, or an app for your phone. You can buy online from the Radar shop. The online shop also sells The Disability Rights Handbook, and a practical guide to help, services and equipment for disabled people.  

**DisabledGo**

DisabledGo provides online access guides to a huge range of venues. We cover any venue you would access as a member of the public – cinemas, hotels, hospitals, colleges, sports grounds, restaurants, council offices, parks, historic land marks, tourist attractions – the list goes on and on. DisabledGo sends a surveyor to every venue and surveyors use the same standards to assess each venue meaning users can rely on the information.  
[www.disabledgo.com](http://www.disabledgo.com)

**Transport for Manchester**

[www.tfgm.com/accessible_transport/Pages/default.aspx](http://www.tfgm.com/accessible_transport/Pages/default.aspx)

**Disability Rights UK** Disabled people leading change, working to create a society where everyone with lived experience of disability or health conditions can participate equally as full citizens. Provides factsheets and helplines.  
[www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)  020 7250 3222
The Social Model

Adapted from the Greater Manchester Coalition of Disabled People website

Traditionally disabled people have been seen as a “problem”, and the answers have been to try and cure or care for us. Over the last 30 years disabled people have increasingly challenged this approach. We have developed our own theory on why we are excluded from society and its activities. The following is aimed as a simple introduction to the Social Model of Disability and to explain what it means:

Impairment: Some disabled people’s bodies are different – part of our bodies work differently, might even be missing. We call this “impairment” and we live with this every day and know all about it, more than any doctor, nurse, welfare professional or charity worker. The fact of our difference does not make us “less” than non-disabled people; however, society has always seen that there is something “wrong” with us, even to the extent of experimenting on us at times.

Disability: When a disabled person is prevented from carrying out a particular activity, such as getting on a bus, because their needs have not been addressed, we call that disability.

Barriers such as inaccessible information, housing and transport, segregated and/or poor quality schooling, hostile environments and attitudes and ways of working which exclude disabled people – these are what underpin our continued exclusion. However, if society were to arrange things differently (e.g. replace steps with ramps, make all telephones with a text facility, provide more information in Braille etc) then the barriers that stop us being independent could be removed.

Greater Manchester Coalition of Disabled People
We campaign for inclusion of all disabled people and are run and controlled by disabled people.
BEVC, Aked Close, Ardwick, Manchester, M12 4AN Tel: 0161 273 5154 Typetalk 18001 273 5154 info@gmcdp.com www.gmcdp.com

Am I disabled?
Under the 2010 Equality Act you’re ‘disabled’ “if you have a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on your ability to do normal daily activities.” This can include a long-term health condition, including those which fluctuate and ones which may not be visibly obvious. www.gov.uk/definition-of-disability-under-equality-act-2010
Credits:

Photos: Gill Moore: www.gillmoorephotography.co.uk gill@gillmoorephotography.co.uk
Clipart images from Microsoft website.
Layout: Ruth Rosselson
Group facilitation: Joyce Kay and Ruth Rosselson for Community Pride.
Contact: Joyce@communitypride.org.uk or Ruth.Rosselson@gmail.com for more information