

Living with MS – a personal perspective

Officially I am a 'service user', unofficially I'm Ros and I was diagnosed with relapsing/remitting MS in 2009. This document lists some of the tools, services and other products I have used, or know about since being diagnosed.

I am not endorsing any particular suppliers, medications, supplements etc; I've just mentioned those I have tried or am using. This isn't an exhaustive list, there are medicines, therapies and other things I haven't tried or even know about.

My main advice is:

- Talk to your MS nurse about treatments/medicines
- Don't use the Internet as a reliable source of information about MS, there is a lot of rubbish and unsubstantiated nonsense out there. Of course, the MS Society, Berkshire MS Therapy Centre (BMSTC) and MS Trust sites can be trusted.
- Surf the Internet before you make any purchases to find the best deal.
- **"Manage your condition, don't let it manage you"** as someone told me!

I appreciate this may be a bit daunting/scary to those recently diagnosed. But I also know folk diagnosed for years who didn't know some of the info in here.

1. You are not alone - sources of support

The **MS Society** holds social gatherings and drop-in sessions for carers and those with MS. They produce a series of leaflets with a wealth of information to inform you, your friends/family and your workplace about MS. We come under the Reading, Wokingham and districts branch – see their web site <http://www.msreading.org.uk/> for details of events, contact information etc.

Getting to Grips – a programme of information and discussion sessions arranged by the MS Society aimed at the newly diagnosed and their friend/family members. Talk to your MS nurse to find out how to register an interest in attending.

MSquared – a social group meeting one lunchtime/afternoon and one evening per month, sometimes just for a drink and sometimes for events like a quiz evening. A monthly newsletter gives all the information sent out by email or in the post. Personally, I found this group a valuable source of information about living with MS and recommend all to join in. Its free to join so just use the contact information to get involved. Email msquare_rwd@yahoo.co.uk to be added to the email distribution, find us @MsquaredRWD on Facebook.

Berkshire MS Therapy Centre (BMSTC) – Based off the Oxford Road in Reading, with a smaller venue in Henley, have access to a number of contacts who offer help, such as IT support and legal advice. They offer a range of therapies – find out more at <http://www.bmstc.org/>.

Social network for newly diagnosed - Shift.ms is the social network for people with multiple sclerosis. Founded by MSers, for MSers, the charity supports many thousands

of recently diagnosed people across the world as they make sense of MS. It's independent and it's free. <https://shift.ms/>.

CommuniCare – www.communicare.org.uk/ is '...an advice and support centre based in the Community of East Reading. Our service is confidential and free. We provide all sorts of practical help ...'. They helped me, and other people with MS I know, complete some of the forms we need to submit like DLA/PIP, Blue Parking Badge, ESA and others. They understand 'the system' so give good information and guidance 0118 9263941.

Stepping Forward can also help you to access services and/or benefits, especially when there is usually a form to complete. Anyone applying for PIP (personal independence payment) will know the daunting form to be completed. And, of course, that assumes you know what is available in the first place. Get it right from the outset to minimise delays by seeking assistance from folk who have experience. Contact [Stepping Forward](#) to support you with the first steps.

2. Things that can help me manage my fatigue

Light box – I've had my LitePod for years – go to this site and look under 'light therapy' <http://www.betterlifehealthcare.com/>. I know someone who swears by her dawn light simulator – wakes you up in the morning more naturally than an alarm – they are also on the above site and in high street shops like Boots.

Oxygen therapy – Available at the Berkshire MS Therapy Centre (BMSTC) <http://www.bmstc.org/> – you'll need to go on a three-week 'induction' programme and then decide how often and when you want to receive the therapy. I go once a week and now do a session on the outside of the tank. 'Dives' inside the chamber are either 33ft, 24ft or 16ft, some go fortnightly while others go twice a week.

Rest. Don't fight it; don't try to work through it. When fatigue hits – and for me that might mean my speech get slurred, my legs feel heavy, I can't concentrate – the best thing is to have a lie down (resting does not mean sitting down with a cuppa in front of the telly) so you can relax your whole body.

Physiotherapy – Strengthening your core will help with balance – talk to your MS nurse and/or the physiotherapists at the BMSTC. You'll need an initial assessment – call the centre to book one. They offer one-on-one sessions and there are classes at the centre during the week (I do a Friday morning group session).

Eye health - Regular checks by an optician are key for eye health. However, getting to an optician and into their chair can be an issue for some. You could try Visioncall Home Visiting Opticians on 0845 050 1831, delivering free NHS eye tests at home. Also available from The Outside Clinic on 0800 60 50 40 or 01793 64 22 00.

Other therapies that help some people with MS:

- Reflexology – available at BMSTC
- Acupuncture – available at BMSTC
- Foot health care – available at BMSTC, especially important if you have peripheral neuropathy (numb feet)

- Hydrotherapy – MS Society service held at the Royal Berks hospital, talk to Diane Goodlock 0118 9267174
- Pilates – available at BMSTC
- Advice from a specialist if experiencing choking when drinking/eating – talk to your MS nurse.

Diet – I find dairy affects my legs and I am following (albeit with the occasional slip-up!) the principals of the ‘Overcoming MS Diet’ – essentially vegan plus fish but I have been a vegetarian for years so miss out the fish.

<http://www.overcomingmultiplesclerosis.org/>

There are periodic Fatigue Management programmes run by the MS nurse with input from physiotherapists and dieticians – talk to your MS nurse if you are interested. One-to-one fatigue management is also provided by the community MS Specialist Occupational Therapist, contact Wokingham 0118 9746800 or Reading on 0118 9373737.

Hot chocolate has been shown to help reduce fatigue in some folk. But, it is the dark, flavonoid, anti-oxidant kind to reach for - <https://www.mssociety.org.uk/research/latest-research/latest-research-news-and-blogs/research-shows-hot-chocolate-could-help-reduce-fatigue>

3. Things that help me with the impact of hot and cold

Chill Mate active cooling wrist wrap or neck wrap for natural cooling relief, very useful in humid weather <http://www.livingiseasy.co.uk/>. Someone I know recommends the **Chillow** - <http://www.chillow.co.uk/2010/template/>

I have a memory foam mattress and pillows and have ‘**Coolmax**’ bottom sheets and pillow cases. The sales pitch says Coolmax ‘is a modern hi-tech fabric that helps to keep you cool and dry, similar to material used in sportswear... it eliminates hot spots in your bed and helps prevent your body overheating, even in warmer weather.’ I bought mine from Marks and Spencer online.

Kool Ties – gel crystals fill with water and good to wear around your neck. <http://www.soo-cool.co.uk>

Cooling scarves – wet and then drape around your neck, over your knees etc. they work a treat. Designed for sports use, just as good for overheated MSers.

I find my **circulation** is more sluggish and I get very cold feet – someone recommended ski socks/thermal socks that are 2.3 tog, I got my one Bay.

4. Things I use when my mobility isn’ t so good

Stick seat – you can use it as a walking stick and then take a rest when needed, I’ve used mine to queue at a concert <http://www.activemobility.co.uk/shop/stickseat-p-1523.html>

Folding walking sticks – They are lightweight so easy to carry around in your bag ‘just in case’. Get advice on the right height and how to use them from a physio- or occupational therapist. Widely available in John Lewis, show shops and there loads of funky colours on good old eBay.

Mobility scooter. I use a Pride GOGO sport – the one recommended for me to meet my needs. My advice is to be clear what you plan to use it for; else it can be an expensive mistake. Shop around as prices vary,

If you want to find out more about other disability aids which may be suitable for you, such as ‘perching’ stools, grab sticks, walking frames, shower seats grab rails inside and outside plus checking the correct height of a walking stick, contact the community physiotherapist via your own GP or Occupational Therapy (if you have already been seen by the OT as they do not provide this one-off service). My advice: contact them now, don’t wait until you really need some help – be proactive (did I mention to manage your condition?!).

5. Medication and supplements

Firstly, talk to your MS nurse. They will discuss the possible use of any disease modifying drugs (DMDs) that may suit your condition. There are several new drugs going through trials which sometimes hit the headlines – talk to your consultant to get the facts, please don’t rely on the Internet. I started injecting Rebif in July 2009; the support available is very good. Yes, I wasn’t sure I could cope with injections but I did, it wasn’t the highlight of my day but became just part of my routine. I swapped to Fingolimod (Gilenya) in February 2013, a once-a-day tablet.

Low Dose Naltrexone (LDN) – your MS nurse won’t talk to you about this as it is not a recognised medication for MS. Some consultants will talk about it but don’t (as far as I am aware) prescribe it (although I do know of one GP who does but they are an exception). Visit the LDS Research Trust site (<http://www.ldnresearchtrust.org/>) talk to others with MS and you then can make an informed choice on whether to give it a go. I started on LDN in Sept 2011 but then swapped to CBD oil.

Gamma-Amino Butyric Acid (GABA) – Some people who experience the nerve pain associated with MS take GABA. I tried Swanson from www.healthmonthly.co.uk A review of it can be found here: <http://www.denvernaturopathic.com/news/GABA.html>.

Vitamin D – lots of research and items in the press about links between Vitamin D and MS. Views vary on the use and magnitude of supplements – talk to your GP, a blood test may show up any deficiencies and they can offer dietary/supplement advice.

Methylprednisolone is a steroid that the MS nurse can arrange for you if you are having a relapse. I have only had the pill version but others I know have attended hospital to have the treatment intravenously. I have had them twice and both times encountered side-effects. A leaflet is available to explain the side-effects, but sometimes this doesn’t reach the patient so ask for it to be emailed to you. My advice: be prepared! I know they do the job but I do suffer many of the side effects for a week or so. The first time I was prescribed them I struggled to find a chemist that could get this high dose for me – Sainsburys by M4 J12 have since proved reliable.

CBD oil is cannabis oil without the elements that cause a 'high'. Approved by NICE but not yet available to those with MS as clinical trials are needed to prove it is both effective and value for money etc. I have tried it but not currently using it. I purchased it privately and use CBD Brothers Blue oil. Do your research as it pricey, and tastes revolting!

Things to make it all just a bit easier

PIP (Personal Independence Payment) (replacing Disability Living Allowance (DLA) and for new claims starting May 2013) – Conditions apply regarding age, residency and 'You must have a long-term health condition or disability and have difficulties with activities related to 'daily living' and or mobility. You must have had these difficulties for 3 months and expect them to last for at least 9 months.' I strongly recommend completing the form with someone with experience, such as CommuniCare. <https://www.gov.uk/pip>. *I recall filling in the DLA forms and was advised to complete it 'as you are on a your worst day'...I'll admit (as have others) that it didn't feel comfortable as I do have good days but was reminded the benefit is for me when I need it most i.e. the bad times.*

Blue Badge scheme – I don't always use mine but when I need to park as close as possible to somewhere I want to go then it makes all the difference. You can even park on double yellow lines with a blue badge! This is also a way to manage your condition! http://www.direct.gov.uk/en/DisabledPeople/MotoringAndTransport/Bluebadgescheme/DG_181208

ESA – Employment Support Allowance – a means tested benefit. If on ESA you can claim free prescriptions & may qualify for free/reduced rates on adult education classes.

Congestion Charging – If you hold a valid Blue Badge you are eligible to register for a 100 per cent discount, even if you don't own a vehicle or drive. Visit the Transport for London site here <http://www.tfl.gov.uk/roadusers/congestioncharging/6736.aspx>

M6 Toll Mobility Exemption Pass (MEP) – If you are disabled you may be entitled to a toll exemption for your vehicle when using the M6 toll. The MEP allows free passage of the *nominated vehicle on the M6 toll only. If you think you may be eligible for an MEP, you must apply to Midland Expressway Limited before you travel *the nominated vehicle is the one exempt from Road Tax). <http://www.m6toll.co.uk/pricing/exemptions/>

Motability – if you receive the higher level of DLA/PIP mobility allowance then you could get a vehicle through the Motability scheme. This could be a car for you – or someone who cares for you – to drive or even a motorised wheelchair or scooter. The Forum of Mobility centres <http://www.mobility-centres.org.uk/> is also a good resource; the local one to us is in Oxford, they do home visit's however they do charge for this. Their contact number is 0845 3371540. Ricability (<http://www.ricability.org.uk/index.aspx>) is also a good resource. <http://www.motability.co.uk/main.cfm>. Cars – I restricted the options to those with a relatively shallow lip on the door – they vary a lot and I know on 'bad days' I simply would not get my leg to lift over the lip. Think about if an automatic would suit you best too. Other adaptations are available, see Motability site for details, see note from Ruth at the end of this document.

Driving and MS – Multiple sclerosis is a notifiable condition so legally you must tell the Driver and Vehicle Licensing Agency (DVLA) that you have been diagnosed. They will ask you to fill in a form, send them your license and, usually, they will provide you with a three-year licence (and will prompt you to renew it in due course).

http://www.direct.gov.uk/en/Motoring/DriverLicensing/MedicalRulesForDrivers/MedicalA-Z/DG_185685

VAT refunds – if you are buying equipment directly as a result of your medical condition you can sometimes sign a waiver so that you don't pay VAT at the point of sale or can claim the VAT back afterwards. I am planning to claim the VAT back on some of the purchases for adapting my home, e.g. the wider than normal doors that are more wheelchair-friendly. During planning application, my Occupational Therapist sent Reading Borough Council a letter confirming I had MS and I then didn't have to pay for the building regs visits, save me money.

Grants for adaptations – the council does offer some grants should you need adaptations to your home – they are means tests, see the Reading Borough Reading Borough, Wokingham District, or West Berkshire councils web site for information.

Also, the MS Society can give grants towards items you may need as a result of your MS, if there is no health or social services funding available. They can help with things like home & car adaptations, mobility aids, wheelchairs and other specialised equipment, driving lessons for a person with MS or their carer, short breaks and respite care, activities for adult carers, including hobbies or courses and grants for young carers to help with things like music lessons, school trips and sports equipment. To find out more about financial assistance from the MS Society, [contact your local branch](#) or the grants team at the MS Society's national office in London on 020 8438 0700.

Tax Credits – you may qualify if you or your child receives disability benefits – claims can be back-dated but only for a few weeks so check them out now!

http://www.direct.gov.uk/en/MoneyTaxAndBenefits/TaxCredits/Paymentsandentitlement/otherbenefits/affectofbenefitsontaxcredits/DG_172873

National Key Scheme/RADAR key – this is a special key that gives the holder access to a toilet which is not otherwise open to the public. You can buy them online from places like Amazon.

Sample bottles – the MS nurses will always suggest you have a urine test if your symptoms flare up as a UTI can cause them. Ask your GP surgery for a few sample pots to keep at home.

Free tickets for carers – If you are a wheelchair user/need a carer to support you at time then some events allow you to get a free ticket for your carer – always worth checking 'accessibility' and talking to the venue at the time of booking.

Free carer ticket at the cinema – go to the CAECARD site <http://www.ceacard.co.uk/> to download a form to get an annual card so you can get a carer ticket when you buy yours at the cinema.

Accessible Britain - <http://accessiblebritain.co.uk/> 'Accessible Britain has one main aim: To provide a forum for disabled people to share positive experiences of all accessible places throughout the UK.' You can add your reviews to help others find out if an event or venue might suit them.

Contact Occupational Therapy to discuss your individual needs and any adaptations that may be appropriate at home. Ask your MS Specialist Nurse/GP to be referred and contact them now; *don't wait until you really need them.*

Keep it together – set up a folder for all the forms, letters, paperwork etc. Keep notes of conversations, it is all too easy to forget stuff so I write it all down and make sure I note who I spoke to and date(s) etc.

Warm Home Discount scheme run by energy suppliers. Look on your energy supplier's web site or call for details of their scheme as they do vary. This link takes you to the scheme for British Gas customers <http://www.britishgas.co.uk/products-and-services/gas-and-electricity/the-warm-home-discount.html>.

MS Society minibus – call the MS Society to discuss your transport needs.

The government offers a scheme called **Council Tax Disability Reduction** designed to prevent those with disabilities from paying more tax as a result of the extra space they require. Enough space in the property for the disabled person to use a wheelchair indoors. <https://www.counciltaxadvisors.co.uk/council-tax/disabled-reduction/> - never seen it advertised, found out about it by chance!

Message in a bottle scheme is a simple idea designed to encourage people living on their own to keep their basic personal and medical details in a common location where they can be found in an emergency. As the name suggests, the personal information is kept in a small plastic bottle. The bottle has a push-fit lid and is big enough to hold the necessary information. The bottle is then kept in the fridge, where the emergency services will expect to look for it in the event of being called to your home.



They will be alerted to your membership of the scheme by two 'green cross' labels. One is fixed to the back of the front door (or the door most used to access the premises), the second is attached to the door of the fridge. Call 0845 8337 431 to find out more. The medical form to put in the bottle is available from their site.

The Berks MS Therapy Centre has a number of the bottles in their shop too. The Lions Club of Reading covers the cost of the scheme.

Personal alarm - my pendant is through <https://www.bracknell-forest.gov.uk/health-and-social-care/forestcare> "Forestcare lifeline is a personal alarm system that provides 24/7 support". I test my pendant roughly once a month and although not the height of fashion, it gives me, family and friends comfort knowing help is available 24/7. There is a variety of providers out there so shop around.

And, in support of the above I have a **key safe** in my porch, installed through Reading Council. I have had cause to use it when I had a fall and the paramedic needed to get it, and it was installed BEFORE I felt I needed it – BE PREPARED! When I questioned its safety, I was told the police once tried to break in to one during an emergency but couldn't get it open!

Limitless travel - Escape to somewhere beautiful with a specialist with UK & European holidays. [Visit their website](#) or call 0800 711 7232.

AND finally, if work is getting too much and/or if your employer isn't being very supportive (assuming you have disclosed your condition of course!) then please whatever you do don't just resign and walk away. Both you and your employer have rights and responsibilities under the Equality Act 2010 <https://www.gov.uk/rights-disabled-person>.

Ultimately, and depending on many factors, you may qualify for ill health retirement which could mean getting your occupational pension paid early. I urge you to seek advice if you have any concerns regarding employment but DON'T JUST RESIGN. **Remember you automatically meet the disability definition under the [Equality Act 2010](#) from the day you're diagnosed with multiple sclerosis.**

If you have any comments on this document, would like to suggest changes, corrections or additions please get in touch.

Please bear in mind that [this is my personal view of living with MS](#). I have had some feedback on this document from friends and have included their insight at the end.

Ros Hatt
mybox@mybox.plus.com

USEFUL CONTACTS

MS Society Reading, Wokingham & districts branch

MS Support line 07932 508899

Support Volunteers: Andy Welch and Hilary Danelian

Contact readingsupport@mssociety.org.uk.

Branch internet site www.msreading.org.uk

MSquared

Ros Hatt 07557 379548 - msquared_rwd@yahoo.co.uk

Occupational Therapy – contact via through Adult Social Services

Berkshire MS Therapy Centre

Tracy Watkins, 0118 9016000, <http://www.bmstc.org/>

MS specialist nurses

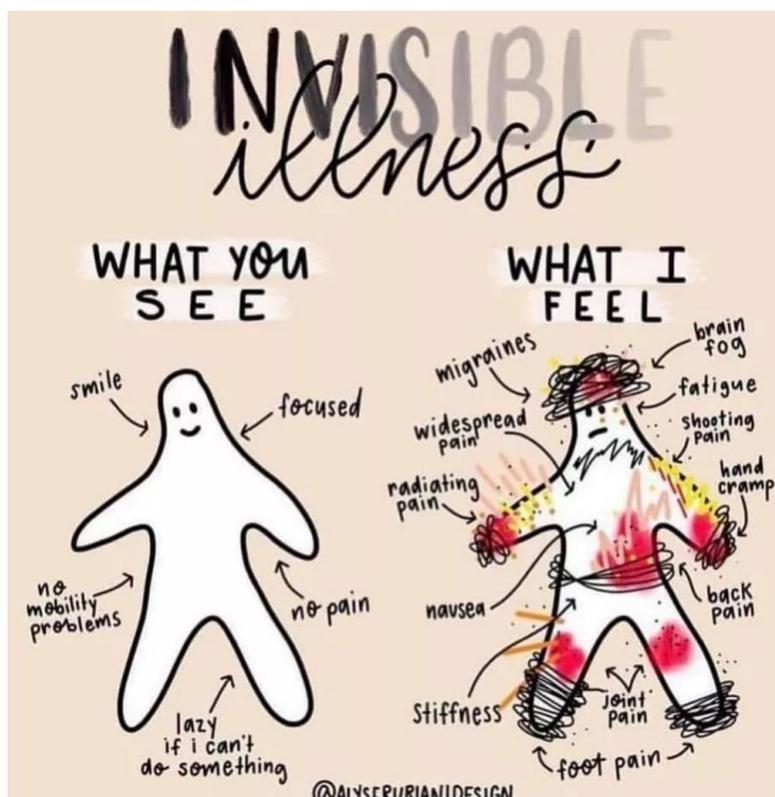
- West Berks - Sarah Wyatt sarah.wyatt@royalberkshire.nhs.uk
- Diane Frampton – Reading diane.frampton@royalberkshire.nhs.uk
- Alison Chini – Wokingham/Bracknell alison.chini@royalberkshire.nhs.uk
- Shared number - 0118 3225369

CommuniCare

0118 9263941

www.communicare.org.uk/

Ever stuck trying to explain how MS affects you, and others? Try using this visual to share with friends, family & work colleagues to explain some of the common symptoms which can't be seen.



CONTRIBUTIONS FROM FRIENDS WHO ALSO HAVE MS

Ana, relapsing/remitting MS:

On the steroids, I found the IV version brilliant - I know it's not your experience but it might give people hope! You might want to say that you are typically in hospital for 3 days, for 3 doses via IV. Each dose takes about 2 hours, from memory, when you are actually hooked up to the IV machine. It is a faster, harder hit than the pills and, for me, had almost instant effect. The last lot took a while longer for the full effect (3 weeks) but that is apparently quite common. But miraculous in resolving all my symptoms, particularly walking and optic neuritis. You can only have 3 lots in a year though. I had two in one year, for two different relapses. Often useful to be in hospital as the physios tend to try and see you while you are in too (or they did with me).

Also, might want to mention that you shouldn't go into oxygen if you have a cold as it kills your ears - agony. I didn't know that until I tried, with regret, and had to come to the surface again after about 4 minutes!

Also, that having a cold / flu / anything that is fairly run of the mill for normal people can exacerbates symptoms but doesn't mean it's a relapse necessarily. Again, I hadn't appreciated that and learnt from experience the hard way....I should have taken more days off work rather than "working on through", as I used always to do. Recovery was longer...

The whole 'extremes of temperature' is also worth hammering home. The cold can cut your legs from under you in a heartbeat and humidity is a killer. Pacing yourself is key. I was kindly given a foot massager with heat which, when I remember to use it, is brilliant. Resting each day, if possible, also hugely worthwhile. Luckily I have an enduring love affair with my bed.

One thing to bear in mind too is that, sadly, MS doesn't make you immune to other health issues. You might think something is MS related when, in fact, it could be something else entirely. So, don't self-diagnose and assume its just MS! Go to your GP.

The website I have found really useful recently is ShiftMS (<http://shift.ms/>). It's more accessible, I found, once you've read all the serious stuff on the MS Society etc. website, which I found a bit depressing. Real people with MS, open forums plus useful, easy to understand explanations of what MS is.

PS Get a flu jab. We are near the top of the list anyway but definitely get one each year.

☺-☺

Suzanne, relapsing/remitting MS:

You can get your council tax down graded by one band – speak to your local council office and then fill out the form. (<http://www.reading.gov.uk/residents/CouncilTax/HowtoReduceYourBill/how-to-reduce-your-bill/>).

☺-☺

Sally, relapsing/remitting MS:

I woke up one morning with double vision which was caused by MS which meant I couldn't drive. I have learnt the best thing to do is go straight to Eye Casualty (you don't need an appointment) at the Royal Berks. They will assess you and refer you on to the Orthoptic Department which happens very quickly. They put a stick on prism on my glasses which meant I saw one vision rather than the two and could drive again. After speaking to my MS nurse my neurologist gave me 5 days of high dosage anti-inflammatory steroids which after a period of a couple of weeks my vision went back to normal.

☺-☺

Ruth, MS

Regarding Motability – get assessed first and get the letter/assessment form from Motability about any adjustments needed before ordering a car – the adjustments are then funded before you take ownership otherwise you pay for them if adaptations are required once you have taken ownership. Make sure you are happy with any adaptations

installed before you accept the car. I suggest you go to the Oxford, not the Basingstoke, centre as they have machines to help you determine any adaptation you may need.