

Bedfordshire Community Health Services MS Specialist Nurse:

Miranda Olding Contact us on: Call 0345 6024064

email: elft.msservice@nhs.net

Monday, Tuesday, Wednesday, Friday 9-4pm

- If you are concerned about your symptoms or an aspect of your MS
- About someone you care for who has MS
- If you think that you may be having a relapse
- To rearrange or ask to bring forward one of your appointments
- We can see you in a clinic, speak on the phone, possibly share video-call, visit you in hospital, or if necessary, make a home visit

Hello from Miranda:

Hello, I spend quite a lot of time emailing links to people, so I thought I would try to compile a resource of both local, national, and health information that I hope you will find useful! Of course you can still get in touch to discuss any of this on the contacts above.

Worried you might have MS?

https://mstrust.org.uk/about-ms/what-ms/worried-you-have-ms



Worried you have MS? | MS Trust

There is a wide range of possible symptoms but most people experience only a small number around the time of diagnosis and won't go on to experience them all. Some of the most common first symptoms are: fatigue (a kind of exhaustion which is out of all proportion to the task undertaken); stumbling more than before; unusual feelings in the skin (such as pins

and needles or numbness)

mstrust.org.uk

SUPPORT AND INFORMATION FOR PEOPLE WITH MS Information, mental, emotional and peer support:

Peer support locally: Beds & Northants MS Therapy Centre

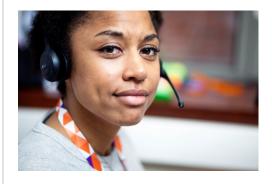
https://mscentrebedsandnorthants.com/

MS Therapy Centre Beds & Northants

The Bedfordshire and Northamptonshire MS Therapy Centre - We provide a wide range of support and therapies to people living with MS.

mscentrebedsandnorthants.com

National helpful websites with helplines: MS Society <u>0808 800 8000</u> https://www.mssociety.org.uk/



MS Helpline | Multiple Sclerosis Society UK

We don't want language to be a barrier to contacting us. If your first language isn't English, we offer Language Line translation services in over 170 languages. Just call us on 0808 800 8000, ask for a translation service and we'll arrange it for you.

www.mssociety.org.uk

MS Trust: <u>0800 032 38 39</u>

https://mstrust.org.uk/



Home | MS Trust

MS doesn't stop for the new normal, and the new normal has left those with MS behind. With delays in diagnosis, specialist services and healthcare, a donation from you to the MS Trust can give people the support they need during these uncertain times.

mstrust.org.uk

MS-UK: 0800 783 0518 https://www.ms-uk.org/

MS-UK | Multiple Sclerosis Information, Helpline, support, MS news and research

This is the home page for MS-UK, About us MS-UK was established in 1993, and is a national charity dedicated to empowering people with multiple sclerosis to make the most of today, and live life to the full. We put people affected by MS at the heart of our work. We provide high quality, professional services to support people living with multiple sclerosis, and we listen to

www.ms-uk.org

MS specific: MS-UK counselling; telephone counselling specific to MS https://www.ms-uk.org/counselling

MS-UK | Counselling

MS-UK Counselling is confidential and is for people who have a diagnosis of multiple sclerosis (MS) and live in the UK. It is the only service of its kind available in the country.

www.ms-uk.org

Local talking therapies:

https://bedfordshirewellbeingservice.nhs.uk/

Bedfordshire Wellbeing Service

Bedfordshire Wellbeing Service provide mental health and talking therapy treatment for those living in Bedfordshire. We are a NHS run service.

bedfordshirewellbeingservice.nhs.uk

For more severe mental health concerns speak to your GP or nurse about getting access to the right support

Peer support locally:

Local MS Society groups: Luton and Dunstable

https://www.mssociety.org.uk/care-and-support/local-support/local-groups/luton-dunstable-district-group

Milton Keynes:

https://www.mssociety.org.uk/care-and-support/local-support/local-groups/milton-keynes-district-group

Northamptonshire groups:

https://www.mssociety.org.uk/care-and-support/local-support/local-groups/northamptonshire-group

Northamptonshire Group | Multiple Sclerosis Society UK

Multiple Sclerosis Society. Registered charity nos 1139257 / SC041990. Registered as a limited company in England and Wales 07451571

www.mssociety.org.uk

Peer support nationally

Social networking community and information for people with MS:

https://shift.ms/



Shift.ms - Learn about multiple sclerosis and connect with other MSers

Your community. Shift.ms is the social network and community for people with multiple sclerosis. Founded by MSers, for MSers, the charity supports recently diagnosed people across the world as they make sense of MS.

shift.ms

One to one 'Buddy' support: https://shift.ms/the-buddy-network



The Buddy Network - shift.ms

Request a Buddy What is the Buddy Network? The Buddy Network connects MSers on a one-to-one basis. We have a number of MSers who have lived experience and are ready to support you.

shift.ms

DIET:

No one diet has enough evidence in MS to be recommended by NICE. The MS dietary approach most evidence, and most in line with the guidance from the World Health Organisation for diet (LINK

https://www.who.int/campaigns/connecting-the-world-to-combatcoronavirus/healthyathome/healthyathome---healthy-diet) Is:

https://overcomingms.org/



UK, USA & Australia | Overcoming MS - Overcoming MS | OMS | Multiple Sclerosis Charity | UK | USA | Australia

Overcoming Multiple Sclerosis are a MS charity committed to improving the lives of people with MS through a scientific diet and lifestyle recovery program.

overcomingms.org

They also have a very positive Facebook group at https://m.facebook.com/groups/489380497836671/

Overcoming MS Lifestyle Support Public Group | Facebook

Overcoming MS Lifestyle Support has 4,680 members. ***PLEASE READ BEFORE JOINING*** This group is based on Dr George Jelinek's Overcoming Multiple...

m.facebook.com

However, remember that people are all individual, and you may have individual dietary problems or needs. For this reason, I wrote this blogpost on diet READ MORE LINK?

My take on Diet & Supplements in MS.

(This advice is to go alongside your medical and disease modifying treatment, not instead of it. It's not medical advice, but a personal viewpoint, and I am not a dietician. Ensure that any dietary change or supplement is safe for you with your conditions and medications.)

- Diet plays a huge role in health and disease. MS is a condition that involves inflammation, and everything we eat can either provoke more inflammation or help to calm it down and encourage regeneration. A low fat, plant-based whole food diet consisting of wholegrains, vegetables, pulses, nuts seeds and fruit is what is recommended by the World Health Organisation, see https://www.who.int/news-room/fact-sheets/detail/healthy-diet and is also the ideal to help stabilise MS and improve health. See
 www.overcomingmultiplesclerosis.org
- In some people, a protein in dairy (cow,goat,sheep) milk and dairy products can trigger an immune over-reaction, leading to increased auto-immune behaviour. It also contains saturated fat. Completely avoiding milk and dairy products is a good idea. Ensure you get calcium from dark green leafy vegetables. If you become vegan, it's a good idea to take a B vitamin complex. Ensure you get enough protein by eating beans, nuts, tofu, pulses etc.

• Some, but not all people with MS have food intolerances. If you have a food intolerance, it can cause an immune reaction in the body and thus aggravate MS. Look up 'Leaky Gut' theory online. Food intolerance blood tests (eg York labs food intolerance test) are available privately and can identify immune reactions to certain foods. Although it's possible for them to be unreliable, and an 'exclusion diet' is recommended to identify intolerances, due to the fluctuations of MS, it can be hard to identify food intolerances using the exclusion method, so you may choose to use the blood testing.

The book 'The MS Recovery diet' by Sawyer & Bachrach discusses the role of food intolerances in MS. There is also a huge array of recipe blogs and resources online to support diets which exclude common intolerances. Eg 'Deliciously Ella'

Supplements that many people consider to address MS:

- Vitamin D3. minimum 5000 IU daily, unless sunbathing. To check for very low Vitamin D, you can get your vitamin D levels tested for around £30 at www.vitamindtest.org.uk/ if your GP can't run the test. Ideally keep your blood levels at 150nmol/litre. Under the tongue spray is the best-absorbed.
- We still don't know whether vitamin D deficiency is a cause or a result of inflammation, or which is the best way of getting vitamin D. Strong sunshine on bare skin is ideal, & it may be that in the winter months, a 10 minute sunbed (one that puts out UVB rays) once a month, if your skin is ok, is a better way to absorb the vitamin D & use it in the body. Ensure you have dark green leafy veg to supply calcium in your diet, and to find out more:, including how much vitamin D3 to give your children if you have MS, visit:



Sunlight & Vitamin D | Overcoming MS

OMS recommends that people with multiple sclerosis keep their vitamin D level at 150 - 225nmol/L or 60-90ng/ml. Those with a vitamin D level below the lower limit should consider a suitable mega-dose (this is a perfectly safe way of boosting a vitamin D level quickly).

overcomingms.org

or https://mstrust.org.uk/life-ms/diet/vitamin-d



Vitamin D | MS Trust

Vitamin D is essential for bone health and immune system regulation and may have a role in multiple sclerosis too. Regular time in the sunshine could provide enough Vitamin D for good health, but you can also get it from your food or take supplements, particularly in the winter months. Low levels of ...

mstrust.org.uk

- As much high dose omega 3 essential fatty acids as possible; best supplied by drizzling at least 2 dessert spoons a day of cold pressed flax/linseed oil on your food, cold. Don't cook with it, as this destroys the benefits, and keep the bottle in the fridge. www.flaxfarm.co.uk. is one supplier. Omega 3 is also present in pumpkin& chia seeds, oily fish, and dark green leafy veg (tiny amounts)
- B vitamins are only present in animal food, live fermented foods, yeast products (like marmite, yeast flakes) or fortified foods. If you aren't eating meat or dairy products, consider either regular fermented products like water kefir, live sauerkraut, live kim chi, or a B complex supplement.
- Pro-biotics There is a strong link between the health of the gut and auto-immune disorders, and lots you can do to help restore the health of your gut. Read up online or get a book on repairing and building up your 'Gut Health'. Probiotics (good bacteria) are an important part of this, along with avoiding intolerances, and supporting good bacteria by eating a diet rich in 'prebiotic' foods, and other possible supplements such as I-glutamine. Capsules or powder are preferable to milky drinks, available in health stores on online.
- Anti-oxidants help to protect brain cells; eat all the different colours of fruit & veg, especially the dark black, purple, red. Recent research showed 66% less brain shrinkage with a supplement of 1,200mg of the anti-oxidant lipoic acid daily.
- Co-enzyme Q10 has shown benefit in trials for MS fatigue.

Yeast overgrowth/candida

• If you have had a lot of yeast infections (thrush, athlete's foot, ringworm,) or feel that your health problems started after having a lot of antibiotics, learn about candida. The book 'Healing Multiple Sclerosis' by Ann Boroch is about this. Getting rid of candida can take time, and involves: taking something to kill it off (there any many candida killing products online), eating right so as not to feed its growth (most importantly, reducing sugar) and restoring the good bacteria in your intestinal tract. See http://www.candidasupport.org/

SPORT AND EXERCISE

Exercise is an absolute cornerstone to staying well with MS; it has antinflammatory effects just as the disease modifying drugs do, offesets any deconditioning caused by the MS, has mood boosting properties, and in the long term, when done regularly, helps to reduce fatigue.

Any exercise is good, but if you can't do what you have been used to doing, consider something different. Exercise equipment can be used which has power assist, bikes can have electric battery packs added

We have some great local and national opportunities to take part in sport for people with MS or disability:

National:

http://oceansofhope.co.uk/



Oceans of Hope Challenge - Sailing Sclerosis

A chance for you to experience sailing Welcome to Oceans of Hope UKWe are a charity based in the UK which organises sailing events for people with Multiple Sclerosis (MS). We are the home of the award-winning Oceans of Hope Challenges, offering people from all over the world the opportunity to sa...

oceansofhope.co.uk

https://www.sportability.org.uk/

Sportability

SPORTABILITY IS REOPENING-With the country slowly reopening we carried out a small straw poll of our members to gauge how they are feeling about Sportability recommencing activities. As you might imagine, there has been a mixed response which equates to a roughly 50/50 split between: Those who can't wait and are raring to go; and those who are understandably cautious and not yet ready to return.

www.sportability.org.uk

Local:

sailing:

https://www.grafhamwatersailability.org.uk/

Local exercise schemes via councils:

https://www.bedford.gov.uk/leisure-and-culture/sports-and-physical-activity/

Sports and physical activity · Bedford Borough Council

Leisure and Culture - Sports and physical activity. Sport provides a fun way to meet

people as well as improving your energy levels, flexibility, strength and balance. www.bedford.gov.uk

Exercise programs

The MS Society and MS Trust both have online exercise videos for people with MS. There is a commercial MS specific program called MS Warriors (I have not personally checked this out so can't vouch for it).

Exercising in gyms is good, as you can move form station to station and not worry so much about your balance once at a station.

Home exercise equipment can also include equipment that has power assist.

Local:

Locally, the MS Society in Luton has an exercise class called 'MS Stars' run by a physio, and the MS Therapy Centre in Bedford has a specific MS gym, with physio, and classes in yoga and Pilates.

The Lifestyle Hub (GP Exercise Referral Scheme)

The Exercise Referral Scheme (GPER) is administered by **Bedford Borough** Council's Sports Development team in partnership with the Lifestyle Hub. If you are looking to lead a healthier lifestyle by making some positive changes and wish to increase your physical activity levels, then speak to your GP and request a referral to the Lifestyle Hub. Providing you meet the criteria you will be invited to join the scheme which offers a range of different options at locations around Bedford, delivered by Fusion-Lifestyle and others.

There is a gym based exercise programme, currently available at Robinson Pools and Fitness; Kempston Pool; John Bunyan Sports and Fitness Centre; The University of Bedfordshire; and The Paula Radcliffe Sharnbrook Community Centre. Alternatively we offer some non gym based physical activity sessions including a Sunday morning gentle exercise class at John Bunyan Sports and Fitness; daytime gentle swim sessions at Kempston Pool; and an evening relaxation swimming session at Robinson Pools and Fitness. We also hope to add an Aquatone class at Kempston Pool.

The scheme lasts for 10 weeks and upon completion you will receive details of ongoing physical activity opportunities at a discounted price.

For more information email sport@bedford.gov.uk

For **Central Beds**, follow:

https://www.centralbedfordshire.gov.uk/info/87/active_lifestyles/626/how_to_get_refe_rred

How to get referred | Central Bedfordshire Council

Are you worried about your health? Struggling to get active and don't know where to start? If you live in Central Bedfordshire, speak to your GP or health professional about an active lifestyles referral.

www.centralbedfordshire.gov.uk

Driving

https://www.mssociety.org.uk/sites/default/files/2020-10/Motoring-with-MS-April-2016.pdf

Motoring with multiple sclerosis

3 Driving with MS Multiple sclerosis is unpredictable and can affect people in many ways. Some symptoms are common but people will experience different symptoms.

www.mssociety.org.uk

Our nearest main driver mobility centre is at Wellyn Garden City: https://www.drivingmobility.org.uk/information-centres/view/welwyn-garden-city/

Welwyn Garden City - Driving Mobility

Contact Services; Herts Ability Unit 2 WelTech Business Centre, Ridgeway, Welwyn Garden City, Hertfordshire, AL7 2AA 01707 384 263 01707 371297 driving@hertsability.org.uk

www.drivingmobility.org.uk

It costs £110 if you refer yourself for a driver assessment with adaptations, or £90 if a healthcare professional refers you. If you are struggling to get to work due to driving problems, then you can ask the Job Centre to refer you, and this can be fully funded.

Money, legal and work

See MS Society and MS Trust for excellent info on work, but these sites can also be useful:

MS legal advice:

https://www.mssociety.org.uk/care-and-support/financial-help/legal-advice

Money advice (government)

https://moneyandpensionsservice.org.uk/

Turn2Us for grants

https://www.turn2us.org.uk/



Fighting UK Poverty - Turn2us

Turn2us is a national charity that helps people in financial hardship to gain access to welfare benefits, charitable grants and support services – online, by phone and face to face, through partner organisations and our volunteers.

www.turn2us.org.uk

For retraining or looking for work, the charity Remploy may be helpful:

https://www.remploy.co.uk/

Holistic treatment of MS Symptoms

Fatigue: https://mirandasmsblog.com/2016/11/17/fatigue-in-ms-and-what-to-do-about-

it/#:~:text=Posted%20on%20November%2017%2C%202016.%20by%20mirandasmsblog.%20Fatigue,troubleshoot%20in%20a%20holistic%20way%2C%20Fatigue%20was%20top.



<u>Fatigue in MS – and what to do about it |</u> <u>mirandasmsblog</u>

Fatigue - that horrible overwhelming inability to do another thing, sometimes even to think straight, is one of the most disabling invisible problems of MS. When I took a poll of the top symptoms that people wanted to troubleshoot in a holistic way, Fatigue was top. So here goes: Why do people with MS experience...

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Urine Infections: https://mirandasmsblog.com/category/urine-infections-2/

Pain: https://mirandasmsblog.com/category/pain

Sexual function problems: https://mirandasmsblog.com/category/sex-and-ms/