



Multiple Sclerosis
Resource Centre

MSRC Moderated Chat Session with Special Guest Judy Graham – Thursday 29th April – MS Awareness Week

- Judy_Graham** Hello Anne
- squiffy_admin** welcome Anne :)
- Anne** Obviously haven't brought brain with me or I'd have noticed the full instruction!
- squiffy_admin** That's ok first time we have used this is this week :)
- squiffy_admin** Judy, I have one question left from Tuesday
- squiffy_admin** Debra - Once I've done the basic household chores, I have the MS 'bear-hug' pain around my ribs - the banding. It is usually only about mid-morning at this time and I feel a bit guilty resting so carry on doing various things e.g. on the computer - again in a sitting position which isn't good for the banding pain. After lunch, I do have a solid sleep as by then, I'm exhausted. What I would like to know is:- Should I take a break mid-morning and then carry on with things after lunch? Also, and perhaps more importantly, I don't understand how PWMS in wheel-chairs are always in the sitting position. I would find it easier to lay prone, as this is the only way the pain is relieved.
- squiffy_admin** How are you doing Anne?
- Judy_Graham** You gotta rest! It's crazy to carry on doing anything to the point where you bring on MS symptoms! How can household chores be more important than your health? Rest. Let the house go dusty
- squiffy_admin** Reminds me of the saying "Boring women have clean houses" lol
- Judy_Graham** That makes me more interesting than I really am!

Anne I had a friend who had a beautiful cross stitched plaque on her wall the said ' a perfectly clean house is a sign of a sadly wasted life!'

squiffy_admin lol

squiffy_admin NO wasting round here then lol

Judy_Graham Debbie should NOT feel guilty about taking a break.

Anne it's something I really struggle with. I am finding it increasingly hard to keep on top of the household stuff because I am working ludicrous hours. MS Nurse encourages me to get a cleaner but I feel 2 able adults should be able to keep the house clean

Judy_Graham Hi Anne

Judy_Graham Are you one of the two able adults? But don't you have MS? If so, conserve your energy for other things. Maybe you might qualify for some domestic help from Social Services. Have you tried?

squiffy_admin Hi Jac

jac_mod hi squiffy/helen x

squiffy_admin Hi Rox, and welcome

Anne Yes I have MS but I am still an able adult. I qualify for absolutely nothing. I find fatigue increasingly impinges on my life and I do now succumb to sleeping after lengthy exercise

Rox hello

jac_mod hiya rox

Judy_Graham Anne - no shame in sleeping after exercise. Anything to get energy back. Can you and your partner afford a cleaner?

squiffy_admin How are you Jac?

jac_mod not too good relapsing at mo the lush named ms hug :(

jac_mod hia Stevie

squiffy_admin Oh no sorry to hear that Jac

steviebhoj hello everyone

squiffy_admin HI Stevie :)

rox hiya

squiffy_admin Welcome Rox, if you want to ask anything you type in the small green window at the bottom :)

steviebhoj you all OK

Anne Could afford it at the moment though I am seriously considering packing in my job which would make it less feasible. It's more that I feel I/we should be able to cope. I HATE the idea of someone cleaning up after me. Would probably clean before they came!!!

Judy_Graham Anne - Drop the guilt! Why overload yourself and risk your health? I haven't done any physical cleaning for many a long year and have grown to rather like people cleaning up after me

Anne Maybe it's another layer on the onion of accepting I have MS. If I can walk for miles then I should be able to clean the windows etc etc etc

Judy_Graham Why not conserve your energy for more enjoyable things

Steviebhoj got a question for Judy, but hey for anyone on DMD

Judy_Graham I've never been on any disease modifying drugs

Anne I am

Jac what are you on Anne?

Judy_Graham Whatever works for you

Anne Copaxone

Steviebhoj injection, on Avonex....oh injection problem I've got

Steviebhoj Think you've had the same problems Jac

Jac you're still having probs stevie?

squiffy_admin There is a new auto-injector just did the story on it today - see Latest MS News page on the website ;O)

jac I stopped rebif in January feel the same as when I was on them

Anne what sort of problem Stevie?

Steviebhoj can hover over site to inject for hours, sometimes very quickly. really infuriating, cause it's so irrational

squiffy_admin This new piece of kit might help Stevie :)

steviebhoj I know it's not going to hurt, don't THINK!! I have a needle phobia, because others injections aren't an issue

squiffy_admin RebiSmart

Anne I use autoinject. Forgot it when I went away recently and had to manually inject -had forgotten how hard it is -ended up missing 2 days injections. Can highly recommend autoinjecter

Jac I couldn't use the rebiject used to manual n still got panicky before injecting

Steviebhoj go on squiffs. what is it?

Rox all this talk of injections scare the cr** out of me I don't know how you do it

Steviebhoj have got auto-injector, but still got problems..... all in the head me thinks

squiffy_admin Hi Emma

jac hiya emma

Emma Hi all :)

Steviebhoj rox the injections aren't bad, just the thought of it

Rox yeah I think it is the though if it. Thank god I don't have to do that

Steviebhoj hey I've been on ANx for 12 months now, no real problems

Jac for me it was psychological

Steviebhoy all in the head

squiffy_admin Rox do you have MS?

Steviebhoy not at the refusal stage, nowhere near it...because hey have been relapse free for a while, is it the drugs, hey we'll never know

Rox yeah :(

squiffy_admin hug

squiffy_admin Stevie have you looked into CCSVI? As Tom G is in your neck of the woods?

Rox I hate it

Steviebhoy rox is this your 1st visit here

Steviebhoy waiting for appt

Rox yes

squiffy_admin You are very welcome Rox, do you know much about the MSRC?

Jac we all hate it rox

Emma Judy do you take any meds at all?

Rox nope

Judy_Graham Em - only desmopressin when on long car journey

squiffy_admin Ah, you have come to the right place :) Have a peek at the MSRC website and our message boards :)

squiffy_admin We produce New Pathways Magazine too.

squiffy_admin Are you in the UK, Rox?

Judy_Graham Thanks for the plug!

Emma Is that for the dizziness? Did you take them to start with or have you always gone down the natural route?

Rox Hertfordshire

Judy_Graham Desmopressin reduces bladder urgency - I can drive from London to Suffolk (2 1/2 - 3 hrs) no problem

Judy_Graham Always gone down natural route

squiffy_admin Goodo, then you can use all our services including our wonderful MS advisor and our freephone counselling line if you need them ever ;)

steviebhoj as you probably know by now, this is a great place for info, but a fantastic place for help & support when things aren't great, helped me when 1st diagnosed and eternally grateful for the people on here

Anne a neighbour to me then Rox

Rox I don't know anyone with ms

Jac that sounds like my kinda drug off for self catheterising next week:(

Judy_Graham desmopressin better than oxybutynin, its predecessor. Makes you very dry in the mouth

squiffy_admin Rox, you should pop in on our message boards then, we have the friendliest most supportive group of MSers anywhere :)

rox where are you Anne

Anne There's a great MS therapy centre at Letchworth - is that near you Rox??

Rox hmmm about 15 miles away

Jac I take ditropan as and when for bladder probs

Judy_Graham What difference does ditropan make to you?

Emma How would you deal with the dizziness Judy or is that a symptom that is eased with diet and supplements?

Rox I have to go now , can I come back in tomorrow

squiffy_admin Rox, we hold three chats a week, Tuesday Morning 10 - 12, Wednesday evenings 8 - 10 and Thursday afternoons 2 - 4 normally you will be very welcome

Judy_Graham Em - I used to get dizziness but don't any longer. So maybe diet/supplements do help. No harm in taking drugs for dizziness/vertigo.

Anne I met the manager there a couple of years ago when we used their premises during a charity event I took part in. I'm just down the road in Bedfordshire

Jac it helps when I go on long journeys but once I get there I need the loo quickly

Anne Judy can you give any advice about employment situations?

Judy_Graham Do you mean to tell or not to tell?

Anne No-been there done that. More about workload increasing and not being able to cope.

Jac I work 10 hours a week n find my employees useless

Jac I know you are protected under the DDA as far as I'm aware your employers are meant to make reasonable adjustments for you ... be it less hours

Judy_Graham Work overload a bad idea - risk of making MS worse. Feeling you are not able to cope is a sure sign of overdoing it. I think it's better to work at a lesser pace and not be stressed - but who am I to talk! A born workaholic!

Judy_Graham I do think it's important to keep working if you can without jeopardising your health because it's good for self-esteem and income. Also, whoever wins Election, it will be much harder to claim Disability Benefit

Judy_Graham I mean claim Incapacity Benefit

squiffy_admin If anyone needs benefit advice we now have a benefits advisor, Emma Rowe, at MSRC

Judy_Graham Anne - what work do you do?

Jac thanks squiffs wasn't aware of that

squiffy_admin you can contact her by email, or phone the office and they put her in touch with you Jac :)

Anne I'm not asking for adjustments in way of reduction - just want new promoted boss to accept that there is only so far I can stretch myself. Contracted to work 34hrs over 4 days -last month averaged 40 hrs over 4days. Am so stressed and tearful at times

Judy_Graham Because of the huge deficit, any new Government will try and reduce benefits bill by getting as many claimants as possible off welfare and in to work - including disabled

squiffy_admin Hug Anna :hug

Anne work in finance and admin in a private school Judy -so work all year round tho am supposed to work less hours during holidays (ha ha!)

Judy_Graham Anne - You need to have a quiet one-to-one talk with this person. You are obviously a valuable person to whoever employs you. If they understand your circumstances, they may be less demanding

Judy_Graham Anne - I think you need to negotiate more time off, even at the risk of getting less pay

Judy_Graham Or offer to do the work at home at your own pace

Anne he was one of the 1st folk to know I had MS long before I 'went public'. My immediate boss has told him and he acts as though he doesn't hear her.

Emma men have selective hearing Anne :)

Anne She put something in writing today -he commented on one point and ignored anything about her concerns about the hours I am working. Can't work at home -need specific computer system

Judy_Graham I still think you need to have a one-to-one with whoever the 'he' is who is causing you grief. He may hear if it comes directly from you.

Judy_Graham He's only interested in the finance work getting done well and on time. I'm sure you can convince him of that with you doing it but more on your terms

Anne I have mentioned it when trying to avoid taking on new things -he doesn't want to hear. His management method seems to be 'If I ignore it, it will go away'. Also I don't help as I always end up making time to provide what he wants. Own worst enemy!!

Judy_Graham Mentioning it by the way is not the same as requesting and getting a meaningful one-to-one with him. Do not be a doormat!

Anne Main concern is my 'nice' boss is leaving -then I have no-one to stand up for me at all. Finally got union involved yesterday as we are concerned that forthcoming 'restructuring' could put me in worse position.

Anne Am at point where I could just pick up my coat and walk out some days

squiffy_admin sorry to hear that Anna :(

squiffy_admin Anne

Judy_Graham You have to stand up for yourself! Getting union involved may help but could also brand you as a troublemaker, particularly if you work in a private school. You seriously need to win over the difficult man, which I think can best be done on a one-to-one human being basis

Judy_Graham Anne - you are obviously very good at your job. Hang on to that thought. They have no grounds to dismiss you, and you could have an unfair dismissal case if they tried

Emma I have a question. I suffer from anxiety and I understand that when my ms flares up it can make me anxious but I was wondering if ms and anxiety were more related than just being anxious about having ms

Anne That's what's so hard -have worked alongside him for 19 years and have always supported him at work and also through personal issues. Seems

power has changed him. No question of trying to dismiss me -I know far too much of use to them!!

Anne

Excellent question Emma!!

Emma

ty :)

Judy_Graham

Em - once you have MS, you do tend to become more anxious. Also more likely to become depressed. The stress hormone cortisol involved in these feelings of anxiety. So good idea to do things like relaxation, meditation, yoga. Prozac etc also OK

Judy_Graham

Relaxation techniques lower cortisol levels so lower feelings of anxiety

Emma

I am on anti depressants. I've noticed recently that when I'm anxious lately it isn't like before. My ms has been flaring up so now when I get anxious I get different symptoms that I would relate to ms such as burning, fuzzy legs etc.

Judy_Graham

Anne - this man is a challenge. If you have previously had a mutually supportive relationship, there is a chance you can get back to that.

Emma

I wondered if it was anything to do with nerves

Emma

hi ellie :)

Judy_Graham

You are expending a lot of energy and grief over this work relationship.

**Judy_Graham
Anne**

Em - more to do with stress hormones than nerves I feel my work is what keeps me going -that and my walking! I was diagnosed with depression some months back and going to work is what gets me going each day.

Emma

ty Judy, it is hard to break out of the vicious circle but I'm trying :)

squiffy_admin

Emma don't forget the MSRC's Counselling line if you need to talk :)

Judy_Graham

Am not suggesting for a moment that you give up work! But this relationship at work problem does need to be resolved. It may be contributing to your depression

Anne there's no doubt about that in my mind

Emma ty squiff

squiffy_admin all part of the service, em :)

Judy_Graham Anne - with your finance skills, you could work at another private school

Emma I've wondered for a while, when you have a lumbar puncture what is it that they're looking for. I have a friend going through diagnosis and I couldn't answer this for her

Judy_Graham They are looking for something in the cerebrospinal fluid which gives away that you have MS

squiffy_admin Protein Bands

squiffy_admin A lumbar puncture (also known as a spinal tap) is a procedure where a sample of the cerebrospinal fluid is taken and analysed to test for any abnormalities that can indicate MS. CSF is the fluid that supports and protects the brain and spinal cord.

Judy_Graham These protein bands have a particular pattern when you have MS. If you Google this, you should be able to see photos with these bands

Anne Got through to final 3 for a job recently - an organisation that oversees finance in most of the linked private schools in this area-went to an internal candidate! Very difficult to get in there. Looking at other areas of work just to move

squiffy_admin sorry to hear you didn't get it Anne :(

Judy_Graham Good for trying Anne! Most jobs advertised have already been given to somebody - usually an internal candidate. It's just that they have a duty to advertise openly. No harm in trying for other jobs, even so.

Anne you and me both brother. My nice boss had almost started a leaving collection she was so sure I'd get it when she saw job description!

Judy_Graham You'll get another job.

Emma So those for those people that aren't diagnosed with a LP does that mean the mri showed more lesions?

Ellie I refused a LP.

Judy_Graham MRI can look at 'lesions' in brain and spinal cord - they come up as white patches on the scan photo. Completely different from what they see in spinal fluid.

Emma wish I had lol

Anne I agreed to one cos I thought it would be negative and so throw doubt on the diagnosis already made. Got THAT one wrong!!!

Emma I just wondered why there is two methods of diagnosis that are used separately or together

Judy_Graham MRI is much more modern and far less invasive than lumbar puncture

squiffy_admin LP is a good indicator for most people with MS (no false positives) BUT there are a sub-group of peeps who have MS but negative protein bands.

Anne LP on its own won't get you a diagnosis -it confirms there has been inflammation in CNS but that's not necessarily caused by MS =could be other neurological condition. However with MS symptoms and MRI it is another piece in the jigsaw of diagnosis

Emma So they look at the mri to see for possible lesions and then if need be or if they're unsure go for the LP too

squiffy_admin and evoked potentials as well

jac my diagnosis was MRI LP & Optic neuritis..... so LP was just a formal ok

Anne My consultant diagnosed on MRI, symptoms and reflex changes, didn't so EP. Oh and his reputation (world renowned specialist). LP was an additional to convince me I think

Anne Don't you just HATE it when a man's right.....

squiffy_admin My MRIs , EVPs and symptoms were all "highly indicative of demyelinating disease" but LP kept coming back negative

Emma I wasn't diagnosed with mri, was diagnosed after LP so was just wondering if maybe there weren't many lesions or something like that

Judy_Graham Hard to comment

Anne Maybe your consultant can answer that for you when you next see him??

Anne or her (shame on me)

Emma I looked into the Elisa test and was unsure of the prices. I think it said for the first one it was £9.99 and that would tell you if you had an allergy and then you'd need a second one to find out what your allergic too costing £200+

squiffy_admin worth ringing the MSRC office Em, they will be able to explain costs etc

Emma is the MSRC discount for the first or second one

squiffy_admin I don't know em :)

jac you'd best phone em

Judy_Graham The expensive one!

Jac what does the test involve?

Emma well that's a bit of a relief lol Will the test give you an area of foods your allergic to or specific ones?

Anne Fraid I'm going to have to go-been staring at screen all day and am getting weary eyes now. Thank you SO much Judy for doing this evening session and for all your advice.

Judy_Graham They send you a testing kit. You get some blood from a finger and send the blood back. They test this blood for dozens of different foods to see if you have any sensitivity, and if so, how much

Jac night Anne good luck with ya boss let us know how you get on :heart

Emma Night Anne, good luck with everything :)

squiffy_admin bye Anne

squiffy_admin there will be a transcript of the chat available

Anne Thanx Jac. Must try to get on boards more often. By the way if you haven't read Squiffs Gordon Brown joke suggest you go to humour section on the boards -it went down a storm at lunch today!

Judy_Graham No. Looked up Ditropan. It IS oxybutynin. Desmopressin considered better

Judy_Graham I mean oxybutynin

squiffy_admin Judy, given that CCSVI MAY be very significant in MS, where do you see the whole field of MS in 10 years?

Nutty Good evening Squiffy and everyone else:ch

Judy_Graham CCSVI might be very significant for some - but not everyone. It seems more effective in some than others. I would like to see conventional doctors in the UK routinely sending their MS patients to vascular experts to get tested. I hope it won't take 10 years for that to happen!

squiffy_admin Agreed, it seems to be the sooner along the MS road you have the ccsvi treatment, the bigger the benefits, I guess because there is more damage with progressive forms. I guess IF CCSVI live up to expectations, the pharmas really need to work on remyelination therapies to augment the ccsvi treatment

Emma good question squiffy

Nutty It will be interesting to see how the oral therapies take off too

Emma Do you think with the introduction of CCSVI there could be other areas that need to be explored to find the common denominator

squiffy_admin some of the oral therapies have scary side-effects

nutty it seems the theories change all too quickly

Judy_Graham Yes - let's see all avenues explored. But it may turn out to be a simple vascular abnormality, perhaps from birth.

squiffy_admin wouldn't it be great if it was

Judy_Graham I would not like to go on any of the oral therapies. It seems possible for remyelination to take place without the use of drugs.

Nutty Some of the not for ms but take this drug have scary side effects too....It would be fabulous

Emma Maybe because MS is so complex they've been too complicated in trying to find the cause

squiffy_admin I think it may be possible they have been barking up the wrong tree for 40 years! Only time will tell

Judy_Graham I can't believe that there is only ONE cause. I back the idea that several things come together. In my case, Epstein-Barr virus at age 15 a major factor

squiffy_admin yes, true, and peeps have said for some time that MS is NOT just one disease so could explain why the difference

nutty scary me too - I blame glandular fever when I was 13

Judy_Graham Also, let's not forget vitamin D and lack of

squiffy_admin link with Vit D and blood vessels too...

nutty sunshine!!

Judy_Graham I was born in winter of 1946 - snow drifts for months and no sunshine. Maybe this had effect too

Emma Yeah I think the Vit D thing is a factor

squiffy_admin this new study out yesterday points to heavy environmental factors on the genes too

Judy_Graham I look forward to getting tested for CCSVI - not booked anything yet

squiffy_admin Even though I have now been told I have another neuro disease I still want to get CCSVI screening to see...

Judy_Graham

The Oxford Prof George Ebers been saying for a while that MS caused by interaction between genes and environment. He's a clever bloke!

Judy_Graham

PS: Can I please go and watch Election Debate on TV?

squiffy_admin

Judy, yes by all means :)

Judy_Graham

I'm a bit of a news and current affairs freak

squiffy_admin

Thank you very much for doing this Judy :)

Emma

Thank you again Judy :)

Judy_Graham

You're welcome, everyone!