



# **Staying active with MS**

**Chatroom**

**15 March 2004**

**[www.mstrust.org.uk](http://www.mstrust.org.uk)**

## Staying active with MS

**15 March 2004 – 10am to 7pm**

The experts:

- **Jo Kileff**  
*Physiotherapist (10am – 2.30pm)*
- **Gail Townsend**  
*Occupational therapist (3.30pm – 7pm)*

**Simon - MS Trust:** Hello Tim, do you have a question for Jo or a comment to make about staying active with MS?

**Tim:** I am very interested in the expert's opinions on exercise such as going to gym and especially pilates

**Jo - physio:** Hello Tim. Exercise seems to be very beneficial for people with MS but what exercise you do can be dependant on your physical problems

**Tim:** I usually go to gym three times a week then group physio once a week and have been doing pilates once a week for ten weeks. I am what they call at our local centre walking wounded and have primary progressive MS

**Simon - MS Trust:** Hello Sam

**Sam:** Hi. This is my first time in a chat - can I ask anything about physio?

**Simon - MS Trust:** Sam, feel free to ask

**Tim:** I am trying to start a pilates class just for MSers I have found instructor I just need to get others to join and them to see benefits.

**Simon - MS Trust:** How has pilates helped you, Tim?

**Tim:** I found it difficult and still do but it makes you more aware of posture and balance and helps core stability

**Sam:** Is pilates good for people with MS? I heard some rumours that doubt it. Is there a way to do pilates at home?

**Jo - physio:** Pilates looks at the small muscles that stabilise the centre of the body and so it is very beneficial if you have enough movement to do the exercises. If you have problems with balance, mobility, it can help to stabilise your middle. Even if you don't have specific problems at this stage, it certainly does help core stability - having a specific instructor aware of problems such as coordination of limbs and fatigue would also make a pilates class even more useful for an individual with MS

**Tim:** That is what I believe. Since being diagnosed two years ago, I have tried to stick to exercise and that in turn helps fight effects that MS has on muscles, if that makes sense. Pilates was recommended by physio at hospital a while ago so when class started locally I tried it.

**Simon - MS Trust:** Tim, whereabouts in the country are you? Would you like us to include your email address in the transcript so interested people can get in touch?

**Tim:** Yes you can do. I'm in Poole in Dorset

**Jo - physio:** I think there are increasing numbers of classes - they are well worth doing. As for your gym sessions, Tim, there is increasing evidence that this helps keep your heart, lungs and muscles strong

**Simon - MS Trust:** Hello Kimiko. Do you have a question for Jo or a comment about any activities you do or would like to do?

**kimiko:** I've been seeing a neuro-physio and she's given me some exercises for balance which are great. She's told me to start pilates which I will be doing next week

**Jo - physio:** Great - we were just discussing how pilates is also good for balance problems so hopefully you will find that useful too

**Tim:** Some my friends do yoga but that does not seem to deal with the issues of balance and posture so well

**Jo - physio:** Yoga can also be of benefit for people with MS but more for issues of tight, short muscles as it looks at flexibility and suppleness. I think posture may also benefit from yoga, but I have to admit, I know less about yoga than pilates

**kimiko:** I must admit my balance is awful so I'm willing to try anything. I find the gym ball has helped a bit

**Jo - physio:** A gym ball has all sorts of uses, one of which is balance. With all of these things, it is finding a programme of activity to suit your symptoms.

**Simon - MS Trust:** Sam, your profile says carer. Do you find exercise or activity helps the person you help?

**Sam:** I help my partner to do small exercises that make a difference, but we're trying to find ways to make it fun. Do you have any ideas?

**Jo - physio:** What sorts of problems does your partner have - how active is he?

**Sam:** He uses sticks mostly and sometimes gets a bit stiff - which is the main reason we try to do the exercises.

**Jo - physio:** Sam, stretching exercises can be good to stop the muscles getting any stiffer. Has he tried any more active exercise, like cycling?

**Sam:** Are there any exercises you recommend for stiffness?

**Jo - physio:** The important thing with stretches is to keep each of the joints moving through their full range. So hugging your knees into your chest, rolling your legs side to side. It does depend a bit on which specific muscles are stiff. Has he seen a physio?

**Sam:** Are there any exercise programmes that we could do as a couple?

**Jo - physio:** When picking exercise for yourself or for a partner, you can try any of them and if they are beneficial great and if you get any negative effects, then try another. You could attend a gym together - is that something you have considered? Or walking?

**Sam:** We like walking - our dog helps us to do that!!

**Jo - physio:** And walking is good. The important thing with exercise is to do it regularly so that the muscles don't get unused and so that you don't get unfit

**Tim:** What I am looking to do is set up pilates class after Easter just for MSers and hopefully our local Society will support it as for some it can be quite expensive

**Simon - MS Trust:** Tim, the Bedford Therapy Centre is producing a video on pilates and MS. It should be available from the end of this month. They say that many of the people who come to the Centre weren't able to get their on a regular basis for pilates classes, hence the video. It will cost £9.99. You can contact the Therapy Centre at [info@MS-selfhelp.org](mailto:info@MS-selfhelp.org).

**Tim:** Great I'll be interested in seeing that as pilates so much of the movements are similar to physio exercises

**Jo - physio:** It also means that it will have taken into account some of the specific problems that people with MS have so should be more user friendly

**Tim:** Yes, the group I attend is all older people except for myself and I am the only man and the two friends who also have MS go as well are younger

**Simon - MS Trust:** The MS Trust is also producing a book of exercises for people with MS. This is free and should be available soon (watch the website for info)

**Simon - MS Trust:** There was a report recently about tai chi and MS. Has anyone tried that? Any thoughts, Jo?

**Jo - physio:** There is some research suggesting tai chi can be beneficial. I don't have any personal experience but it is another option. I think exercise is about finding a way that you like and can do regularly - then you are more likely to persevere and get the benefits

**Simon - MS Trust:** Hi Alex. Do you have a comment on activities or a question for Jo?

**Alex:** How do I get physio in Derbyshire ?

**Jo - physio:** I don't specifically know the referral system in Derbyshire, but your GP is probably a good way. If you go to your GP, Alex, it is worth thinking beforehand what you want to work on with a physio - walking, fitness, balance.

**Alex:** Bye all. Will ask GP

**Simon - MS Trust:** Hello George. We've been talking about pilates and exercises for people with MS. Do you have any thoughts?

**George:** My problem is that I tend to find exercises a bit dull. It's too easy to stop doing them

**Jo - physio:** That is a common problem George. I was just saying, that finding something you enjoy is half the battle - then you are more likely to stick to it

**George:** That's true. I used to play football before I was diagnosed - hated training but loved the game

**Jo - physio:** And are you unable to play now because of your symptoms?

**George:** I get bad fatigue and can't really run anymore. Legs get weak quickly

**Jo - physio:** Fatigue is a problem affecting how much people exercise. However, unless it is really overriding fatigue, exercise may actually help.

**George:** I think I'm naturally lazy and the MS has played right into that instinct :-)

**Jo - physio:** George, if you started going to a gym, walking, doing something, you may feel more lively and stronger. It is a bit of a vicious cycle of inactivity.

**George:** I do like walking. Disguising the exercise in something else seems to work with me

**Heather:** Yes, walking and swimming have been a tremendous help to myself. I would recommend as much as the person with MS is able to do. I walk to work each day

**Jo - physio:** For sure - even just walking to the local shops to get a paper or some milk will reap some benefits.

**Simon - MS Trust:** Heather, do you do swimming as a class or do you just go along to the pool?

**Heather:** Simon, I am fairly fit and I do not go to a class, but swim at my local pool. Most local pools do run sessions for disabled though

**George:** I read somewhere that when someone without MS goes to the pool it's called swimming. If you have MS they call it aquatherapy :-)

**Heather:** George, I have found that inactivity makes me feel much worse, and therefore I try to do AS MUCH exercise as I am able each day.

**George:** It's true, I do tend to suffer for my lazy days

**Jo - physio:** I think lots of people with MS are afraid of exercise because they think it will make them worse. In actual fact, all the research seems to suggest that it'll make you certainly if not better, then no worse. Many actually see improvements

**Heather:** Despite being told to 'take it easy' by people after diagnosis, I have managed to improve my stamina considerably by walking and swimming regularly

**Jo - physio:** Take it easy is a very old school method of management that some doctors still say - activity is definitely important. The other thing to remember is that after exercising, muscle soreness is not uncommon for people with or without MS. So don't worry about that, as long as it only lasts a day or two

**Simon - MS Trust:** We've been talking about exercises and activities followed by people with MS. Do you do any?

**Ellie:** Are you familiar with the Terms scheme?

**Jo - physio:** I am not sure what you mean - tell me what terms is

**Ellie:** Terms is run by our local Primary Health Care and Leisure Services

**Jo - physio:** I think it must be a local scheme - I haven't heard of it, but is it encouraging you to exercise at your local leisure centre?

**Ellie:** I was assessed and do aquafit. You have to do two sessions a week for ten weeks. I think it must be a local thing, Jo, but the best is that the aquafit sessions are run by two neurophysios

**Jo - physio:** Ah, it is running around the country, just called different things. It is to encourage people to exercise and supported in slightly smaller groups within centres

**George:** What's aquafit? Exercising in water? Not heard of that one

**Ellie:** It is like either circuit training or a work out, in water. You can so much more than you can on dry land. I can run in water and jog. I fall flat on my face on dry land

**Jo - physio:** George, Aquafit is aqua aerobics - exercise in water. A good way of exercising if you struggle on land, or if you are fond of the water

**Ellie:** I really enjoy it. Every one in my class is a medical referral but we really work hard. I carried on after the Terms ten weeks. Also go to the gym once a week - a feeble programme for me but I try

**Jo - physio:** Ellie, That isn't feeble at all

**Heather:** Have you talked about yoga? I definitely found this was brilliant for regaining my balance after an attack, and improved muscle strength

**Jo - physio:** That is interesting to hear, Heather. I am not an expert in yoga, but we did discuss its benefits for flexibility. Interesting that it helped balance too.

**Heather:** It's not only the balance and muscle strength which benefits from yoga, but also the relaxational benefits

**Ellie:** I find that some yoga postures help balance. We do some in the water

**Jo - physio:** Ellie, I am a strong believer in doing as much as you can

**Ellie:** Has anyone done Pilates

**Jo - physio:** Over to you Tim!

**Tim:** Yes I do

**Ellie:** Is it good Tim?

**Tim:** I find it very good for balance and posture as my walking is c\*\*p

**Jo - physio:** Pilates is good for what we call your core stability, which is the muscles in the middle of your body, and so good for balance and all other everyday activities

**Ellie:** Yes, we do core stability in the water, that is why I wanted to try Pilates. I have put my name down for it at the Leisure Centre, but there is a waiting list

**Tim:** It also makes you very aware daily of your posture as you can practise the principles throughout the day. It's about how you move not about how far and breathing at the right time

**Ellie:** When I first tried it, I was really in relapse badly, and I couldn't breath at the same time!

**Tim:** No after ten weeks of it I still struggle as my coordination has always been bad but each week it seems to make more sense. It's no good doing it for a short period

**Ellie:** I agree. I had a trainer come to the house when I was really bad, but I gave up. I was just not fit enough to cope. My daughter does it and she said you just have to try again later

**Jamie:** Can you do too much exercise?

**Jo - physio:** Jamie, for someone with mild symptoms, the research suggests that your body will respond as a person without MS. No you can't really overdo it unless you suffer as a result. It is a bit of trial and error

**Heather:** I read some research from the 1970's by W. Ritchie Russell (prof Neurology, Oxford) who suggested that the more you do the better, and so I have done as he says!

**Jo - physio:** What is good in an exercise programme is to do some strengthening exercise and some cardiovascular exercise

**Simon - MS Trust:** David, do you follow any activities (we've been talking about exercise, pilates and swimming but any activities or sports at all would be of interest).

**David:** I am following the chat. I am interested in swimming - it might help me with my balance, which is a daily problem. Activities in water might help

**Ellie:** Jo what about horse riding? I used to ride years ago, but not since MS. I'm afraid my balance is not good enough, yet they do hippotherapy

**Tim:** Ellie, have you tried riding for the disabled – RDA?

**Ellie:** No Tim, I have not tried that. I believe there is a stables near us where they take disabled

**Jo - physio:** Horse riding is now available even for those with a severe level of disability. Maybe find a class for the disabled to start with and you may surprise yourself - you may find it helps your balance. Balance needs challenging to improve.

**Ellie:** Can't be worse than a wobble board I suppose!

**Tim:** My sister is a volunteer at her local RDA and says I should try it as I used to ride years ago

**Heather:** Ellie, What about cycling? Can be dangerous if your balance is very bad though. I fell off this summer, but I'm not letting it put me off.

**Jo - physio:** Cycling is a great way of exercising - if your balance is really bad, there are the recliner bikes to lean against.

**Simon - MS Trust:** We had an article in our newsletter last year from someone who uses a hand cycle - an attachment onto a wheelchair that allows her to pedal with her arms. I think MS Matters also mentioned this

**Ellie:** Oh Heather! I did try on a campsite in Spain. I borrowed a bike, felt very proud of myself for a few minutes then fell off in a heap. Every one was cheering

**Heather:** Ellie, I'm sorry about that. At least no one was looking when I fell off - but I was embarrassed none the less

**Jo - physio:** I've just realise you mean push bikes - how about a static bike?

**Tim:** I would have the same problem but I do use bike in gym

**Ellie:** Oh yes, I do that at the gym, half an hour at 70

**Heather:** That sounds impressive. I did the Tweed Valley cycleway this summer, which was 120 miles, but then I fell off at home

**Jo - physio:** I did some research with a small group of people with MS and they found they improved physically with regular cycling. If you haven't cycled before though, build up your amount slowly and just watch for a negative effects

**Ellie:** Heather that is really impressive. I'm terrified of the roads now. A few years ago in Germany I hired a bike and went all over on it, but I was not so bad then

**Heather:** Yes I am worried about the fact that I may get worse, and on the whole I prefer to walk as briskly as I can each day

**Ellie:** You are lucky. I can't do the brisk walking bit any more. I have a scooter. Funny I can manage on the treadwheel at the gym

**Jo - physio:** Jamie, Did I answer your question - can you see benefits from your exercise?

**Jamie:** I believe so - certainly mentally. What terrifies me is I play games like cricket and golf where I will be able to see my deterioration very rapidly if it happens.

**Jo - physio:** Jamie, you can't predict your course at all, so you must just enjoy what you do and keep as fit as you can.

**Vicki:** My gym membership is suspended (dodgy legs). Should I keep paying £50 a month? All I can do now is swim and pilates. Should I carry it on? My legs are so weak and I'm only 30.

**Jo - physio:** Any exercise is good - if you can still swim then do, including aquaerobics. The others were saying they can do more in the water than on land

**Heather:** Vicki, yes, you should carry on with the swimming. Does this mean a costly gym membership, or could you just go to ordinary sessions at local pool?

**Jo - physio:** And as for pilates - I think this chatroom has lots of converts to pilates.

**Jim:** Vicki, keep on with as much exercise as you can

**Ellie:** Vicki, I do aquafit, and my legs are dreadful, yet in the water I can jog, even run (slowly)!

**Jo - physio:** The less you do, the weaker your legs will get, even without any effect of MS, so do keep as active as you can.

**Jo - physio:** I have a couple of patients who struggle to walk yet go to aquaerobics twice a week. Also if you can't get in the pool, many have hoists.

**Ellie:** We have a lady, her problem is heart, but she is grossly obese, she is in a wheelchair. They take her in in it, and help to the edge and she sort of flops in, they have a hoist but she won't use it

**Vicki:** Thanks. Maybe I should keep the membership. The gym is only five minutes from home and very nice people. Local pools are further away. Just trying to justify £50/mth. Think I need to keep my legs active. Better go for now. Thanks for the advice.

**Heather:** Must get back to work now - keep up the exercise all of you!

**Ellie:** What was that horse riding thing mentioned again?

**George:** That sounds interesting. Have you done that, Ellie?

**Jo - physio:** There are riding for the disabled clubs where they will assist people onto horses.

**Tim:** Ellie try <http://www.riding-for-disabled.org.uk/>

**George:** Tim, have you tried riding? Did it help?

**Tim:** No. My sister is a volunteer at her local centre and has asked me to try as I used to ride years ago

**Jo - physio:** I know people that have tried it and love it - even with quite bad levels of activity

**George:** Are there particular exercises or is it like pony trekking? I've never ridden a horse

**Jo - physio:** Doesn't matter if you've never ridden, they will teach you - it is riding though, not exercises

**George:** That sounds good. Something fun that helps rather than just 'doing exercise'

**Jo - physio:** Did you hear the cycling discussion - that is another way?

**George:** With weak legs, I feel wary of doing something that I might not be able to do quickly. Riding a bike is something where I might look silly if I can't go on. No one would expect me to be able to ride, so I'd be better able to be bad at it :)

**Jo - physio:** You may struggle on a push bike, but not necessarily on a static bike. Have a go at the riding. Any exercise is a bonus - you need to enjoy it

**George:** I think the idea of going to a gym full of fit people worries me too, hence something to disguise my limitations

**Jo - physio:** There are now gym sessions organised for people with disabilities to help with that fear of looking silly. It is called exercise on prescription - your GP can refer you. But if you don't fancy the idea of gyms at all, don't worry. There are plenty of other ways of exercising

**Simon - MS Trust:** A question emailed in before the session. Margaret asks 'Can you suggest exercise that I could do that would not aggravate the tightness round my middle, nor worsen my painful legs? I do walk about during the working day and walk the 15 minutes home

**Jo - physio:** Pilates may well be a way to work on the muscles in the 'middle'. As for the pains in the legs, I would suggest Margaret saw her doctor about that, as they may be able to give her something for it. When reading the previous discussion, Margaret may also consider aqua aerobics or cycling too - they shouldn't aggravate the tightness in the middle. I wouldn't rule out any exercise, but try it and see the effects - if it helps continue. The only reason to stop is if you get negative effects. That goes for everyone really.

**Simon - MS Trust:** Hello Kate, do you have a question or a comment about activities for people with MS?

**Kate:** I've only been diagnosed a year and am lucky to have not too bad symptoms

**Jo - physio:** And do you exercise regularly to keep yourself fit and strong?

**Kate:** I used to run a lot and still do shorter jogs. I play badminton too. Are there precautions I should be taking? Should I not do certain things or am I OK until I'm no longer OK?

**Jo - physio:** Not at all - regular exercise is good for you. The only reason not to do something is if you get a negative effect from it - so as much as you can is good. In the past people used to get told to take it easy and got weaker from doing less. So keeping active is good

**Kate:** I used to run till I was exhausted. Then I found it started taking ages to recover, not just a few minutes. This was before I was diagnosed. Now I take it much more gently

**Jo - physio:** What is ages? And do you mean to get your breath back or recovering from achy legs?

**Kate:** No, I'd be useless for the rest of the day - flaked out and feeling like I'd just finished hours afterwards. Not out of breath, but feeling drained

**Jo - physio:** It is normal to feel tired after exercise and to get aching muscles, because you have used them. But that is a bit extreme, so tapering it a bit is probably good. If you can still run great, but perhaps run until you are tired, rather than exhausted and see how your body responds to that

**Simon - MS Trust:** The literature tends to suggest that exercise that builds strength is good but that exercising to exhaustion can have a negative effect

**Kate:** That does seem to have been better for me

**Jo - physio:** And that is the thing to judge - how your body responds. A bit of tiredness is okay but not exhaustion

**Kate:** Thanks

**Simon - MS Trust:** Hello Brian. Do you have a comment on activities for people with MS or a question for Jo?

**Brian:** Hello. I used to be moderately sporty before MS. Now I'm in a chair. I have physio but would like to find a sport

**Jo - physio:** There are groups that arrange sports for people with MS who use wheelchairs - Simon may have some more info

**Simon - MS Trust:** Brian, what sort of thing might you be interested in?

**Brian:** Hard to tell. Never done anything sporty since I've been in the chair.

**Sue - MS Trust:** The MS Trust is collecting information from people on accessible sports that will be produced as a CD later in the year.

**Brian:** Almost need a menu to pick something from that I could try

**Jo - physio:** We have a local group that arrange sporting activities - where are you based?

**Brian:** North Wales

**Sue - MS Trust:** Some examples are sailing, gliding, fishing, canoeing, powertriking

**Brian:** What are powertrikes?

**Sue - MS Trust:** A Powertrike is a way of adapting your wheelchair to give it extra speed and power so you can take it off road, along paths. Their website is [www.pdqmobility.com](http://www.pdqmobility.com)

**Sue - MS Trust:** The British Wheelchair Sports Foundation is the umbrella body for 17 different wheelchair sports associations. Their website is [www.britishwheelchairsports.org](http://www.britishwheelchairsports.org)

**Kate:** Are there things for people not in wheelchairs but who might be looking for some a little gentler than previous?

**Jo - physio:** If you are still able to participate in non-wheelchair sports, then cycling, swimming, walking are all good

**Sue - MS Trust:** Yoga and tai chi could also be good

**Mike:** I was using equipment in my local hospital neuro gym until I was found to have high blood pressure, which has put a block on that for now

**Jo - physio:** Presumably they will bring that under control and you can get back to it

**Mike:** More incentive than home exercises

**Jo - physio:** We were saying earlier, it is really important to enjoy whatever form of exercise you do, because then you are more likely to keep going with it

**Sue - MS Trust:** Jo, what do you think of toning tables?

**Jo - physio:** Interesting question - from a physio point of view, it is not something I know much about. If you can activate the muscles for yourself, then that has to be better but if you can't and have a muscle imbalance because one group is active, we have tried the stimulators. I have not seen any specific research on toning tables and so am hesitant to come down too strongly either way. Sorry to be a bit vague

**Sue - MS Trust:** I had an email from a lady who recommended using mechanical beds - they either move by themselves or you can work out with them. She said she used them regularly for movement and found they helped her mobility as they helped to loosen her joints

**Mike:** Is tiredness and constant fatigue to the point of breathlessness after doing very little a normal or common MS occurrence? Or might there be something else going on as well

**Kate:** Mike, that sounds a bit like me. Stuff I used to be able to do now would wipe me out

**Mike:** It seems that 99% of people I see at the local MS centre have more "go" in them than me, even though I am still mobile after eight years. In fact the get up and go went years ago lol

**Jo - physio:** Do you do any exercise, because some people find that their fatigue improves if they exercise regularly

**Kate:** Does this change from day to day, Mike. Some days I can almost keep up with my get up and go. Other days I can't even get up

**Mike:** I do see physio at centre, but find it hard to motivate myself to do exercises at home due to feeling weary

**Jo - physio:** If you have a real problem with fatigue, there are some fatigue management programmes being run - that might help.

**Mike:** Most days are not good ones but then again there may well be others who would class them as great ones? Suppose its all relative

**Brian:** Oh yes! Compared to a few years back, most days are not great. But they are OK for now and I make what I can of them

**Jo - physio:** Is it a feeling of overriding exhaustion with all activities or do you just get more tired than you did before your MS?

**Mike:** What are fatigue management programmes?

**Jo - physio:** Fatigue management programmes are where they look at your lifestyle and suggest ways to adjust life to reduce fatigue

**Mike:** For me its usually overriding exhaustion, and sometimes just tiring more easily than pre MS

**Jo - physio:** Maybe ask at your centre about fatigue management programmes in your area

**Mike:** I know exercise gives a feel good factor, and when blood pressure is reduced I fully intend to get back to the gym

**Jo - physio:** The literature does suggest that regular aerobic activity, such as gentle cycling can reduce tiredness. But it may not work for you, so you'd have to try it and see.

**Brian:** What sort of things do you do, when blood pressure allows?

**Mike:** Exercise cycle, upper body exercise machines involving weights, leg weight exercises

**Brian:** Were these things your were doing before MS?

**Mike:** Never set foot in a gym before, was just trying to maintain what fitness I had/have

**Jo - physio:** The literature recommends that we do 20 plus minutes of aerobic exercise, such as the bike - this is good to try and work up to

**Brian:** What exactly does aerobic mean?

**Jo - physio:** Exercise for your heart and lungs - so raising your heart rate, rather than strengthening which serves a different purpose

**Brian:** Did someone mention exercise on prescription earlier? Did I see that? Can you get exercise on the NHS?

**Jo - physio:** Yes! I think it is a national scheme. You get your GP to refer you to your local leisure centre, where they give you a programme of exercise and then you have 10 sessions at a reduced rate.

**Brian:** How do you qualify? Is it by assessment by the GP or do you just turn up and ask?

**Sue - MS Trust:** Brian, there are more details about exercise on prescription on [www.birmingham.gov.uk/leisure & tourism/sport & leisure centres/disability sport](http://www.birmingham.gov.uk/leisure%20&%20tourism/sport%20&%20leisure%20centres/disability%20sport)

**Jo - physio:** Thanks Sue, and you do need a referral - from any health professional but check it out. There is no 'qualifying' - you are entitled to it.

**Brian:** Great - thanks Sue and Jo

**Mike:** At what blood pressure reading would it be considered OK to exercise? Diastolic down to 100?

**Jo - physio:** Blood pressure is individual and it depends on your normal. It is more important that it is stable than the figure, but 100 is probably ok - be guided by your doctor

**Kate:** Is your blood pressure the result of MS or was that a problem anyway?

**Sue - MS Trust:** I received an email from someone who was asking about concessionary rates at leisure centres. He said they did not apply to him yet but that they probably would when he was too ill to use them

**Jo - physio:** Sue, I think you can get a disability badge to get concessionary rates - but not at all centres

**Mike:** I wasn't impressed with my local sports centre for the prescription exercise. They weren't used to people who suffer MS fatigue

**Vicki:** Is it ok to swim if your legs are weak. Sometimes I can't walk much when I come out of the pool. I feel a bit embarrassed.

**Brian:** Do you find that people think you odd for having MS and still wanting to remain active? They seem to think anything above vegetable state is somehow wrong

**Vicki:** I think people look at you differently when they know you have MS. They think you shouldn't do anything!

**Mike:** Most people wouldn't know there's anything wrong initially

**Vicki:** Until you fall over in class or wobble out of the pool

**Mike:** Until I walk too many steps that is

**Kate:** I've found that. I have few symptoms and nothing 'obvious', but as soon as I say MS they change their approach

**Mike:** Which is why I don't mention it, Kate

**Vicki:** We're just special. We know the truth

**Jo - physio:** Who changes their approach, Kate?

**Kate:** Just people. Some are fine, some seem affronted that I don't have spots or need an iron lung. Some seem to back off as if I'm unclean. Suppose I'm just experiencing ignorance and fear of the unknown from the other side

**Jo - physio:** Which is just ignorance, but I know that doesn't make it any easier. The disability discrimination act should make awareness better as everything should become more everybody friendly rather than disability being different.

**Simon - MS Trust:** That's a point a local councillor made when she contacted us about the room. Accessibility should mean opening services to everyone not considering it the making of adaptations for a few because the law tells you to.

**Mike:** I need to go now, thanks for your time each of you and best wishes

**Simon - MS Trust:** Thanks for your input Mike. Look for the transcript next week

**Simon - MS Trust:** Hello Geoff. Do you have a question for Jo or a comment about activities for people with MS?

**Geoff:** How do I find out if I can get hold of equipment that will allow me to do things? You see the London Marathon and these people have special chairs and so on

**Jo - physio:** Equipment is generally provided by an occupational therapist - you can get a referral by asking your GP to refer you to the social services OT

**Geoff:** Are there places where you can borrow these sort of things to try things out or is it a matter of investing up front?

**Jo - physio:** For more swish stuff - it may be you need to go privately, but an OT can arrange for a rep to come and show you what there is

**Geoff:** Will they have things for more than day to day living?

**Jo - physio:** I am sure there are places that loan items - you probably have a local aid and equipment centre - try ringing them

**Simon - MS Trust:** We will have an OT in the room later on who may be able to help with this question. And if there is no standard equipment available, the charity REMAP may be able to help with adaptations

**Jo - physio:** Jo, do you have any questions or comments about activity and MS?

**Ginger Jo:** I participate in triathlons and have recently been diagnosed (Nov 03), I just wondered what else people do?

**Jo - physio:** We've had various discussions- pilates, yoga, swimming, cycling - there is no shoulds or shouldn'ts - more what works for you

**Ginger Jo:** Jo, The only problem I have is the fatigue, it mostly hits me after a 24 hour shift at work, but I try not to train too hard on these days - not always poss.

**Jenny:** Wow triathlons! What do they include?

**Ginger Jo:** Swim, bike and run all back to back no stopping. It's a real endurance sport but becoming more popular. They come in different distances. The ones I do are only little! 750m swim, 21k bike and then a 5k run.

**Jenny:** And you do this with fatigue? That's impressive

**Ginger Jo:** At the moment I am planning on doing five possibly six this season and a swim only event. If you want more info on triathlons in the UK try the British Triathlon Association at [www.bta.org.uk](http://www.bta.org.uk)

**Jo - physio:** Don't feel you should stop the triathlons - the comment we did make earlier though is not to work to exhaustion

**Ginger Jo:** Everyone's MS is different and I can continue at the moment. I'm even going to buy a horse to ride in the winter. My hubby's a fitness instructor so I do have an unfair advantage - my own personal trainer.

**Jo - physio:** Excellent - the fitter you are, the better for your body

**Ginger Jo:** The fitter you are the further you have to fall

**Jo - physio:** Psychologically I am sure that is true, but it also means your muscles, heart and lungs are in a better state of repair

**Ginger Jo:** True. I also think exercise can help those patients who are more disabled than myself. Rob (hubby) has shown a couple of MSers round the gym he works at. They appear to be improving in their general well being and flexibility.

**Jo - physio:** For everyone, I recommend keeping your body as active as your MS allows, because inactivity is a vicious circle, where the less you do, the less you can do. And it has been shown that it can improve fatigue levels too

**Ginger Jo:** I've found that Ginseng helps too - whether that's just psychosomatic or is a real benefit - who cares!

**Jo - physio:** That is interesting - I haven't heard that used before. Is it taken as a tablet?

**Ginger Jo:** Yes you can get it in most health food shops, I've heard that acupuncture can help too

**Jo - physio:** For some it does - but again it is individual.

**Jenny:** I think my involvement with triathlons would be as a spectator. I used to ski but feel wary of it now. Tend to swim a bit and go for walks

**Ginger Jo:** Jenny, that's what got me started but they are great to watch. I'm doing a triathlon as a fundraiser for the MS trust in June. Will anyone out there sponsor me? I have a website to donate on [www.justgiving.com/weardaletriathlon](http://www.justgiving.com/weardaletriathlon)

**Jo - physio:** Are you wary of skiing because your balance is a problem Jenny?

**Jenny:** It's the tiredness as much as anything. And I'd be wary of getting stuck halfway up a mountain feeling knackered and unable to get down

**Ginger Jo:** Jenny, you get skiers in the paralympics. There must be a way. Try asking at a local dry ski slope?

**Sue - MS Trust:** Have you heard of monoskiing?

**Jenny:** No. What's that?

**Ginger Jo:** Sue, what's that - skiing on a snow board?

**Sue - MS Trust:** Basically you're in a sitting position on a single ski in a harness and your ski poles have skis on them as well for stability

**Jo - physio:** They do do single skis in bucket seats for paraplegics - don't know if it would help the fatigue, but you could just do a shorter day and have a rest for a drink more often

**Ginger Jo:** Jo, is fluid intake a problem for MSers or just good idea generally?

**Jo - physio:** Definitely good to keep fluid levels up - dehydration can mimic fatigue

**Ginger Jo:** That's a problem for me as I can't drink little and often as I'd like cos they don't let you drink in a lab!

**Jo - physio:** Jo, could you not use the DDA to say you need to have a drink, or need to be able to go out for a few seconds at regular intervals?

**Ginger Jo:** What's DDA

**Jo - physio:** Disability Discrimination Act

**Jo - physio:** I'm off now. Bye all - do keep active!

**Sue - MS Trust:** Thanks Jo for all your help

**Simon - MS Trust:** We've been talking about different sports and activities that people take part in. Do you do any, or have you any comment?

**Ginger Jo:** All, do you have problems finding places to exercise in the community?

**Jenny:** I'm mostly walking, so that's available everywhere there's a path

**Ginger Jo:** Jenny, what about swimming, that's non-weight bearing so might be good

**Jenny:** Yes I try to swim once a fortnight

**Ginger Jo:** Jenny, fab, I find it really relaxing – when I'm not going for personal bests! I can think through all that's gone on and unwind

**Geoff:** I tend to find I don't like places that seem to treat my needs as something special and unusual - probably my own barrier

**Ginger Jo:** Geoff, when you say needs does that mean wheelchair access and help getting into pools etc

**Geoff:** Yes. When people seem excited because they can use the special kit it puts me off. I just want to be treated like a normal bloke and have no big deal made of things. Suppose that's just my pride as they are only being helpful

**Ginger Jo:** I can understand that. When I was first diagnosed, people kept molly-coddling me - I told them to stop. Just pick me up if I fall over! My hubby's a fitness instructor. He tries really hard to treat MSers in the gym the same way as 'normal' people. He finds they get on much better that way. But finding a good gym instructor is hard if you're not married to one!

**Geoff:** That's what I want really. Finding one, not marrying them that is :-). See if I can do stuff or not do stuff, but don't prejudge me based on the letters MS

**Ginger Jo:** Geoff, I agree you are still the person you were before the diagnosis

**Ginger Jo:** All, does anyone do pilates or yoga? And do they find it helps flexibility

**Jenny:** I saw tai chi mentioned in the paper recently

**Ginger Jo:** Yes I think I saw that too - have you tried it?

**Jenny:** No, but I think there are classes nearby. Maybe I should try. It looks very gentle. Have you?

**Sue - MS Trust:** there is a website called [www.taichifinder.co.uk](http://www.taichifinder.co.uk) to find a group in your local area

**Jenny:** Thanks Sue

**Sue - MS Trust:** You can also do tai chi exercises from a sitting position

**Geoff:** Maybe I should have a go

**Sue - MS Trust:** I also have heard of someone who does karate. She says it improves her balance, strengthens her legs and challenges her short term memory

**Simon - MS Trust:** Have people found any barriers to their following activities that they would like to take up?

**Julie:** re walking, difficult to get distance right ie when you have reached half way and so able to return! Any suggestions?

**Jenny:** I've been bothered by that myself though luckily it's never happened to me. I've relied on a mobile and a husband. Have you been stranded ever?

**Ladywolf:** I have no problem during any kind of physical activity except for after I have finished (mostly the day after) my legs and arms just stop wanting to bend!

**Julie:** The mobile and husband is OK if the terrain is accessible by vehicle! I've been stuck in countryside waiting for power to return to legs before retracing steps!!

**Jenny:** How horrible. How long were you there?

**Julie:** Took a good couple of hours to get sufficient strength back to make it home!

**Jenny:** Not nice. I used to ski and that was the sort of thing that put me off carrying on

**Julie:** Very wise - perhaps I should go for circular walks but that's not so interesting and since my main purpose is birdwatching, not likely to be too successful!

**Jenny:** Suppose birdwatching does mean going to quite remote places. Are you able to gauge your range with walking or do you only know you've gone too far when you've gone too far?

**Glyn:** What are people's views of taking medicinal cannabis ?

**Sue - MS Trust:** Hi Glyn - the MS Trust has a useful factsheet about cannabis - you can contact us if you would like to receive one

**Julie:** Any info on exercise bikes?

**Simon - MS Trust:** Jo the physio, who was on earlier, was very keen on bikes as a way of exercising. She also felt they helped with balance

**Ed:** I use a tricycle. Look like an overgrown school kid but I'm balanced and can get about

**Julie:** Know you can't brand advertise but what features are recommended as seems it like a minefield. Guidance needed as price range enormous

**Simon - MS Trust:** If you see a physio, it may be worth asking them what they suggest. A couple of places that may have advice are the Disabled Living Foundation ([www.dlf.org.uk](http://www.dlf.org.uk)) or the Disabled Living Centres ([www.dlcc.org.uk](http://www.dlcc.org.uk))

**Julie:** OK thanks for that. Will give them a try. Signing off for now. Tks and Bye

**Gail OT:** Hi there everyone

**Simon - MS Trust:** Gail, an occupational therapist, has now joined the room. We're talking about access to sport and activities for people with MS. Do you have a comment?

**Ken:** How can an OT help with getting access to special equipment that might allow people to do sports?

**Gail OT:** Ken your question is quite tricky

**Ken:** Oh dear, thought it might be

**Gail OT:** OT equipment as supplied by social services tends to be just for daily independence not leisure activities. Do you have a specific item of equipment that you were thinking of?

**Ken:** Well that's it really, no. I use a wheelchair, so a lot of sports would require special kit for me. As I don't know if I'd like the sport it's tricky to get hold of the right equipment on the off chance

**Gail OT:** Has your local council got a sport for all advisor?

**Ken:** Don't know. What does that person do?

**Gail OT:** They should be looking at making sport facilities accessible to all people in the area. In some places they are more visible than others, and some focus on particular groups such as older people

**Ken:** And that's through the council?

**Gail OT:** yes

**Ken:** I'll check the phone book, thanks

**Gail OT:** Do you have any disabled sports groups in your area?

**Ken:** Again, I'm not sure

**Gail OT:** Most councils, as part of their websites, should have some pages which list local community groups, they may be able to help.

**Simon - MS Trust:** Ken, the MS Trust is putting together a resource that may help with info on national sport organisations for people with disabilities and how to find local groups

**Gail OT:** Different Strokes which is a charity for younger people who have had a stroke and they are quite active re sport it might be worth contacting them. They might know of some resources locally that you could use

**Ken:** Sounds good

**Simon - MS Trust:** It's the sort of information that local branches of DIAL might have - Disability Information and Advice Line - [www.dialuk.org.uk](http://www.dialuk.org.uk)

**Gail OT:** Ken do you see a physio? They may have some local contacts

**Ken:** Had not thought of asking the physio (how daft). What I'm looking for is something to make exercise interesting, not just a chore

**Gail OT:** Do you know what sort of things you might like to try? - Gym, swimming, archery?

**Ken:** I've been wary of the lack of support so have really not dug too deep

**Gail OT:** Did you do any sport in the past?

**Ken:** Archery sounds good - not thought of that. Not much - but have more time on my hands now I don't work and would like something to get me out of the house

**Gail OT:** Archery is quite popular, people with spinal injuries often take it up to improve their upper body strength. Do you enjoy watching any sport as one way of getting out of the house might be to see about what you could go and watch

**Ken:** It's a case of knowing what I can do and what the MS will allow. Will I be bad because I can't do it, or will I be bad because of the limits of MS?

**Gail OT:** That's why having a chat to your physio might be helpful, they could look at how you can use your strengths. Having MS doesn't mean you can do anything, you just might have to be more selective. Ryder Cheshire volunteers is a group that can offer support in doing hobbies. They try and match people up with similar interests. Thinking about things to get you out of the house - how about something like birdwatching? Some football grounds allow "pushers" in free, as do some other activities, which makes the cost of going a bit cheaper

**Jenny:** Hobbies? Is this more laid back than sporty things?

**Gail OT:** I was thinking of staying active physically and mentally - we need both?

**Jenny:** Someone mentioned birdwatching a while ago

**Gail OT:** Gets you out in the fresh air

**Simon - MS Trust:** By way of an aside to Gail's comment on keeping the mind active, a year or so ago a researcher in America was looking at the role of bridge as a way of keeping healthier. The idea was that the mental activity was good for people

**Gail OT:** There's been lots of studies in older people that those who have hobbies that exercise their minds stay more active and involved in life

**Ken:** Think I may go for the football ground option

**Gail OT:** That would be a good chance to get together with other people who have a shared interest

**Ken:** More like counselling at Northampton :-)

**Gail OT:** LOL. Ken do you have an OT?

**Ken:** Not seen one. Unless an OT did my chair at the hospital?

**Gail OT:** Probably was an OT. OTs should be able to talk to you about what interests you and perhaps come up with ways in which you could do them. Do you see your physio at a rehab centre? Perhaps she could ask the OT to see you?

**Ken:** I go to the therapy centre. That's a good idea.

**Gail OT:** Ken I hope you can get to see an OT who will help you

**Simon - MS Trust:** An OT student sent in a question concerning tai chi and MS. Do you have any thoughts on that, Gail? Or anyone

**Gail OT:** Tai chi has been proven to reduce the incidence of falls in the elderly because it improve balance and flexibility. People think that because it's slow it's not very challenging, but it's good at helping you focus on control

**Jenny:** I've tried yoga - is the principle the same (though different in practice)?

**Gail OT:** I would think so - I've done both and there are certainly some similarities in terms of focus and using your breathing as part of the whole thing, which means it helps you relax as well as exercising the body. I would have thought that something that looks at the quality of the movement, rather than how many and how fast it quite therapeutic and you don't try to be competitive and get worn out. Pilates is also quite good, as that focuses on what they call core stability. If you have more control over your pelvic and back muscles it can improve walking

**Ken:** Can any of these be done when you're in a chair?

**Gail OT:** The Yoga Foundation runs courses for people with MS. They're in Bedfordshire.

**Simon - MS Trust:** They have a website at [www.yogaforhealthfoundation.co.uk](http://www.yogaforhealthfoundation.co.uk)

**Gail OT:** I think our local MS Therapy centre here in Bucks runs yoga groups

**Simon - MS Trust:** And there's info on the therapy centres all over the UK at [www.MS-selfhelp.org/html/therapy\\_centres.html](http://www.MS-selfhelp.org/html/therapy_centres.html)

**Simon - MS Trust:** Hello Ian. We're talking about sports and activities for people with MS. Do you have a comment or a question for Gail?

**Gail OT:** We've been talking about yoga and tai chi

**Ian:** Does tai chi help?

**Gail OT:** Studies have been done with older people, and it reduces falls. I don't know of any studies in MS. Tai chi is thought to help with balance and flexibility

**Simon - MS Trust:** Hello Keith

**Keith:** Hi. Saw the link below the one to this room was for parachuting - that's not a thing for MSers is it?

**Gail OT:** Depends how brave you're feeling!

**Simon - MS Trust:** Could be. We've had people with MS who've done fundraising jumps for us (see [www.mstrust.org.uk/jump](http://www.mstrust.org.uk/jump))

**Gail OT:** Even strapped to someone who knew what they were doing - I'm not sure I could do it

**Keith:** Oh! Maybe something closer to the ground :)

**Gail OT:** I didn't mean to put you off, I don't like flying so jumping out of a plane would be a step too far!

**Keith:** I'm with you on that. I used to play football and cricket, but now walk with a stick so they are out. I play snooker, but nothing much more energetic

**Gail OT:** Do you support a local (or otherwise) football team?

**Keith:** I go and watch Blackpool occasionally

**Gail OT:** How do find getting into the ground and the facilities?

**Keith:** It's a bit of a maze of steps, but I can take it gently if I avoid the crowds - I get there early, leave late

**Gail OT:** That can make it a long day, do you have a long journey to the ground as well?

**Keith:** Brother in law drives me there. Can be a long day but we only go a few times a season. Loos were a problem until I was given a personal solution to that. Now better off than most as don't need to queue

**Gail OT:** You knew there had to be something positive about MS - now you have it -no queue for the loo:)

**Keith:** Funny thing that. I'd have died had you told me about that that sort of thing a few years back. Now it makes things so much easier it's a wonder everyone else doesn't do it

**Gail OT:** I think it would mean that we would be even more a nation of couch potatoes

**Keith:** LOL I think you're right

**Gail OT:** Do you find you get bored and would like to do more activities?

**Keith:** Doing something myself would be good

**Gail OT:** Do you have any other interests - not necessarily sport?

**Keith:** I read. Not very active thing

**Gail OT:** We were talking earlier about keeping mentally active to stay healthy as well as physical activity. Simon mentioned a study about bridge as an activity, and I mentioned birdwatching

**Keith:** Oh yes, without anything to do I'd just waste away

**Gail OT:** I know what you mean. I always have my head in book. I also potter about with painting and crafty things. But not basket weaving

**Keith:** I've avoided that as well

**Gail OT:** LOL. Wet cane makes your fingers bleed. Never touched the stuff since college in the Jurassic period

**Ellie:** Hello all

**Simon - MS Trust:** Welcome back Ellie. We've been talking about parachuting (not much support) and then mental activities such as reading

**Gail OT:** Not much support sounds like no parachute!

**Ellie:** Oh, nothing, not even MS trust would get me to jump out of an aircraft, my worst nightmare!

**Simon - MS Trust:** I'm told parachuting is very exhilarating. Though am happy to go with second hand experience

**Ellie:** I had a look at the disabled riding website, but they are all too far away. We have Hope in The Valley here, but that is just for children. I may ring one or two stables

**Ken:** I play chess. Though find that sometimes I can't concentrate. Hot weather etc

**Gail OT:** I find that making erratic moves in chess annoys the heck out of the opponent and sometimes results in a win. I work on confusing the opposition

**Ellie:** My hubby does crossword puzzles all day sometimes, says it keeps his mind active

**Gail OT:** Crosswords are one of the recommended activities to keep the brain active

**Ellie:** I'm too impatient to do them

**Gail OT:** Do you get fed up with all types of crossword or just some sorts like cryptic ones? What do you do while your husband is buried in his puzzles?

**Ellie:** Mostly Paint and draw, or watch TV or listen to a talking book

**Gail OT:** Ken does your concentration fade or is it just sometimes harder to concentrate, or both

**Ken:** I find if I'm OK that day, I'm OK. If not, the mind won't settle and so chess is a non starter

**Gail OT:** Have you found anything that helps your mind settle?

**Ellie:** Meditating is good for settling your mind

**Gail OT:** Ken have you tried meditation like Ellie suggests?

**Simon - MS Trust:** Suzy, do you have a comment - we've been talking about less sporty activities like reading, chess and crosswords

**Suzy:** Much more my sort of thing! Seriously - my only problems are with tiredness and I'm really bad at 'managing my fatigue'!

**Ellie:** How long have you had MS Suzy

**Gail OT:** Well Suzy you're in very good company - managing fatigue is a real challenge

**Suzy:** Diagnosed 2002 - but first symptoms way back in 1980 something!

**Gail OT:** Is there a particular bit of managing fatigue hard or is it all of it?

**Ellie:** I started in '83 I find I have to try really hard, bed regularly after jobs in the house

**Suzy:** Gail - how do you know when you're overdoing it? On a good day I just think 'excellent!' and then wipe myself out for the next two...

**Gail OT:** you're obviously psychic you've just answered the question I was typing. That is overdoing it!

**Suzy:** On a bad day even washing my hair is too much to handle!

**Gail OT:** Do you work Suzy?

**Suzy:** Part-time - although not for much longer as my contract isn't being renewed

**Gail OT:** Ouch

**Suzy:** So it's back to full time house-slave! and chauffeur for the kids

**Gail OT:** Have you seen an OT about how to manage your fatigue?

**Suzy:** Not yet - I live in a very under-resourced area

**Gail OT:** One of the principles of fatigue management is to try and balance everything out -not fit it all into a good day. Easier said than done. Do you have an MS Nurse?

**Suzy:** Sort of - but she's across the Irish Sea in Liverpool!

**Gail OT:** Can you explain that - do you live a long way from where your MS nurse is based?

**Suzy:** I'm in the Isle of Man

**Gail OT:** You could see if your MS Nurse could help with fatigue management. You could try looking at all the things you do or want to do and spend time planning and prioritising

**Suzy:** I'm trying to get referred to the MS nurses special fatigue clinic in Liverpool - but if I can't then I'll have to pay

**Gail OT:** Suzy try and enlist your MS nurse's support in getting you some help without paying. Surely there are some OTs in the Isle of Man?

**Suzy:** There are, but there's no 'joined up thinking' knitting together the 'experts'

**Gail OT:** That's so frustrating for you.

**Suzy:** The MS Society here is campaigning for an MS nurse here so we don't have to keep going to Liverpool

**Gail OT:** MS Nurses are great for focussing the mind and drawing attention to what should be provided

**Suzy:** I can't really complain - I walk my dog for half an hour to an hour every morning!

**Gail OT:** Walking the dog is really good exercise

**Jill:** Trouble is Gail, it is often we the people with MS who end up doing our campaigning and as we all know we get tired enough without having to fight our own corners

**Suzy:** Too right Jill - I have to schedule in a sleep before I go to an MS Society meeting!

**Gail OT:** I know Jill, I hope that with the National Service Framework as well as the NICE guidelines things will start to improve, but it takes so long

**Jill:** Gail I too hope that the nice guidelines will achieve some results for us all

**Simon - MS Trust:** No mention of activities and sport in the guideline, but it is an important part of life

**Gail OT:** Leisure activities are in the NSF

**Jill:** So remind us about the difference between NICE and the NSF

**Gail OT:** NICE was about what should happen now, and the NSF is about how things should develop over the next ten years and is broader than the nice guidance

**Jill:** Have you talked about swimming/exercising in the water yet?

**Ellie:** Yes we did this morning. I think its wonderful. I do aquafit

**Suzy:** Is that good Ellie? Might be able to fit it in when I've stopped working!

**Jill:** I just do a weekly swim with a few lengths backstroke and some exercises - don't know much about aquafit?

**Suzy:** Anyone know about acupuncture? I've had three sessions and it seems to be working

**Ellie:** I do it twice a week, referred by GP

**Keith:** Have a friend who does acupuncture and swears by it. Does it do any good?

**Suzy:** Well it's either doing some good or I'm convinced that it better had be as it's costing me 30 quid a session!

**Ellie:** That seems an awful lot of money Suzy

**Keith:** Is that the usual price? Is it available on the NHS?

**Jill:** Is that £30 for acupuncture?

**Gail OT:** Acupuncture can be through the NHS. Some physios do it and some GPs as well, but it's very variable

**Ellie:** We are lucky here, over 65s get full Gold membership of the Leisure Centre, including any classes, the gym, two pools so I think that is a good deal. I started with a GP referral, and also physio referral from Hurstwood Park Neuro centre, then when I had done my 20 sessions I joined the club

**Jill:** Have you had MS for a long time Suzy?

**Suzy:** About 17 years but only diagnosed two years ago

**Jill:** Have you had the fatigue for a long time?

**Suzy:** On and off for years, but now I know why!

**Jill:** It gets really soul destroying doesn't it? I just wanted to say that exercise is often the last thing I feel like doing but when I do my exercises or go swimming I always feel better for it.

**Ellie:** Me too, Jill

**Gail OT:** Exercise is really good for releasing hormones that make up feel better

**Jill:** I'm glad you schedule in a sleep Suzy. I find it really "boring" having to schedule rest periods in to my day.

**Suzy:** Forward planning.....so do I!

**Gail OT:** But it should help. Bit like nasty tasting medicine

**Jill:** Sleep is like nasty tasting med you mean?

**Gail OT:** Scheduling in rests and being more organised is a bit like nasty tasting med - unpleasant but necessary

**Suzy:** Jill - if I'm going out socially I plan a sleep for before I go and then schedule an entire day in bed to recover!

**Jill:** Organised! That is something I was not before MS.

**Suzy:** My problem is that I've never been sporty in my life - so trying to keep fit now when I'm so tired really goes against the grain!

**Jill:** Me too, Suzy, but swimming is really relaxing. Have you a friend who would go with you regularly?

**Suzy:** My doctor thought that just getting into the water would relax me and make me feel better I didn't have the heart to tell her that just the thought of getting in and out of my clothes was too tiring! It WAS a particularly bad day!

**Jill:** Water is amazingly good for balance too

**Gail OT:** Swimming is great you just need to make sure you don't do too much as the water helps keep you cool until you get out of it

**Jill:** When is do my lengths on my back my heart really beats fast and no it is not fear it is because I do not move very quickly with my crutches!!!!

**Suzy:** Gail - how do you know when to stop? Once I get going I'm always 'just one more length'

**Gail OT:** Suzy you should try and set your self a number of lengths and stick to it

**Jill:** Knowing when to stop comes with experience - I find that some weeks I can do more than others

**Suzy:** I suppose I know that really! It's frustrating though

**Gail OT:** If you stop before you get tired you can start to build up gradually not all at once, but have a minimum that you know you can always achieve

**Suzy:** OK - sounds sensible

**Gail OT:** Suzy I think it's about trying to make sure you don't get stuck into a pattern of feeling a failure because by doing one length more you're too tired after

**Jill:** Gail, what do you think about hydrotherapy for people with MS?

**Gail OT:** Hydrotherapy pools are usually very warm so they don't suit everyone

**Jill:** I agree that has been my experience. However the perfect leisure pool with the just right temps are hard to come by as well!!! Anyway I have to go now but it's been a great fast moving chat.

**Sally:** I used to be a keen tennis player, but now am not really able to do that

**Gail OT:** Bye Jill

**Jill:** May I just remind everybody about the MS echat group – MS People UK. Maybe speak to some of you there?

**Simon - MS Trust:** Thanks Jill

**Suzy:** I've got to go too

**Gail OT:** Take care Suzy and good luck with getting an OT

**Suzy:** Gail, I'll try and follow your advice. Thank you!

**Gail OT:** Hello Alan

**Alan:** I've had MS since Sept 93. Looking back on my 61 years, I now know what caused my body to break down. In 1991, following my second divorce, I decided to escape from England for three months and to cycle from Atlanta to Nova Scotia. My fitness was tops, but I was worried about the lack of vitamins in American food

**Gail OT:** That's amazing how many miles was that?

**Alan:** I started taking vitamin supplements to boost my auto immune system. The guys I was with noticed the difference. It was the extra vitamin B that made me more relaxed and a better rider. Other ways of recovering from MS - First realise what caused your body to break down and be positive, do something about the problem. And avoid the build up of adrenaline - I use meditation to do this

**Gail OT:** Alan do you still cycle?

**Sally:** I just wanted to say that I used to play a lot of tennis, but can't do that anymore as I couldn't keep up my pre MS standard, I lost interest in playing.

**Gail OT:** Do you do anything else to keep fit and / or active?

**Sally:** Luckily I've met up with a group of people who are all equally bad at badminton and that helps no end. Because none of us are any good we're not competitive and just have fun. And they don't mind when I need to sit down and just watch

**Gail OT:** I think badminton is harder than tennis - I'm impressed. It's good that you've found a group - the social side is just as important as the exercise

**Sally:** At our level it doesn't go so fast and you don't have to move as far. And yes, it's the fun with others that's good now, not the winning that used to drive me

**Gail OT:** Do you do any other activities such as swimming?

**Sally:** I do swim. Always did, but am just a little slower now

**Gail OT:** sounds like you're doing a fair amount of active things.

**Sally:** I'm fine so long as I set aside part of the day to rest afterwards. Otherwise this would knock me flat

**Gail OT:** Finding the right balance for you is what's important.

**Sally:** Swimming is once a week, badminton maybe once or twice a month. Not hectic, but I think I'd feel despondent without activity

**Gail OT:** I think to be healthy you have to prioritise time for things that you enjoy, whatever that may be

**Sally:** That's true. I have to be careful with how much of everything I do, whether it's the laundry, going to the shops or going for a swim. But all laundry is no life, so time for fun is important too

**Gail OT:** It's really important that the day to day things don't take everyone needs to have fun too

**Sally:** I agree completely

**Gail OT:** I'm all for a spot of delegation - share out the chores and then everyone can enjoy something together. Obviously you have to have someone to delegate to....

**Sally:** I am fortunate in that, yes. Mind, I wouldn't want to give up all the chores. Much as I dislike ironing, giving it up would be an easy failing

**Gail OT:** Ironing is probably less tiring than hoovering - so there is a trade off

**Sally:** Ah, my secret rumbled :-)

**Gail OT:** Now housework doesn't generally come up as a sport (apart from extreme ironing) but it does take up a lot of energy

**Sally:** That's really the problem, isn't it. With the cost of managing your life day to day it's easy to make fun sporty things seem unimportant or at least less of a priority. And then you find you do nothing at all and feel much worse for it

**Gail OT:** That's why I always encourage people to prioritise time for themselves. Otherwise you feel like a hamster in a wheel

**Sally:** I made that mistake for a while and rather let MS take me over instead of trying to carry on being me, even if in a slightly different way than before

**Gail OT:** It's really easy for that to happen. You can think that by ignoring it and working hard that the MS is not affecting you, but in reality it's taken over. But it's really hard to find the way through that issue

**Sally:** It almost feels selfish at first. You only have so much energy and the housework's still there. But the other stuff is just as important. I think Jill was talking about priorities before. That's it. Different days, different things. But looking after yourself is definitely one of them

**Gail OT:** I don't think housework should be the top priority. It doesn't matter if your house is immaculate if you have no energy to enjoy time with your family and friends

**Tony:** I agree about what's important. When you have MS, things are in a different perspective. Stuff that had to be just so doesn't get done to quite the same level and yet the world goes on

**Gail OT:** Yes, I think you have to think about what you really are irreplaceable in and being part of your family and friends is where you can't be replaced. Anyone can Hoover or dust

**Sally:** Sorry, seem to have been pontificating for a while :-). But anyway - my comment is play sport with non competitive people who are as bad at it as you are :-)

**Gail OT:** Too right. I have a perverse competitive streak myself.

**Sue - MS Trust:** Hi does anyone have any thoughts on diet? eg when is a good time to eat to improve energy?

**Gail OT:** Some people find they feel tired after eating. Generally it's recommended that you don't eat for 2 hours before exercise. You need to eat things that give a sustained release of energy like pasta and cereal not a mad sugar rush which can drop quickly

**Tony:** Is there anything in that vitamin B thing that the earlier chap was on about?

**Gail OT:** Too much vitamin B can have a bad effect on the nervous system, just as much as too little. It's important to have a healthy balance. You should try and get the recommended daily dose through ordinary food, and only take multivitamins if you are not able to have a varied diet

**Sue - MS Trust:** What about chocolate?

**Gail OT:** Chocolate is a sugar rush. But it does have tryptophan, which is supposed to make us feel better. And fat. Or did you mean something else?

**Sue - MS Trust:** Just wondering about timing a sugar rush to get some exercise in!

**Gail OT:** The endorphins from the exercise should mean you don't need the chocolate to feel better!

**Simon - MS Trust:** Do you have a comment on activity for MS or a question for Gail? We've been discussing different activities that people have tried and also the need to be careful of controlling fatigue. Has MS affected the activities you have been involved with?

**Marilyn:** Hello. Fatigue is a major problem so what exercise to do?

**Gail OT:** There's all sorts you can try. We've talked about yoga, tai chi, swimming and badminton. With exercise it's more about finding something you enjoy and finding a level at which you can do something.

**Marilyn:** I don't drive any more so getting places relies on a bus

**Gail OT:** Buses can be a problem, have you got a friend or member of your family who would like to do something with you?

**Marilyn:** Only feel active mornings when people tend to be at work

**Sue - MS Trust:** Marilyn - have you tried Pilates? You can get videos to try at home

**Marilyn:** Would pilates help my balance?

**Gail OT:** Pilates is really good. It works on strengthening the muscles in the back and pelvis which can improve your stability

**Sue - MS Trust:** The Bedford Therapy Centre video shows their pilates exercises and has been made by people with MS

**Gail OT:** That's really good. The MS therapy centre in Halton, Bucks runs classes in yoga. Marilyn, do you tend to do all your household things in the morning?

**Marilyn:** Yes housework in the morning. Have stopped paid work recently

**Gail OT:** If you don't do housework do you have more energy in the afternoon or do you feel bad if you don't do it?

**Marilyn:** Doesn't help energy level any afternoon

**Gail OT:** Some people find that they get a second wind in the early evening, even after feeling tired in afternoon. Have you seen anyone about fatigue management?

**Marilyn:** I take modafinil which was great at first, probably still helps

**Gail OT:** Perhaps you could try having an easier day and going out in the evening with a friend and see how you go.

**Marilyn:** Pilates video sounds helpful. I do liven up in the afternoon.

**Gail OT:** Pilates is good for your pelvic floor - which can help with some bladder problems

**Marilyn:** Other things always seem more important

**Gail OT:** We were talking earlier about the importance of making time for ourselves

**Alison:** Hi. I am new to all of this...

**Gail OT:** It's only my second time in a chat room so don't worry

**Alison:** I was told by my MS nurse that pilates is excellent. Making time for yourselves is VERY important, but sometime difficult to do.

**Gail OT:** I think if you have children it's very easy to put yourself last

**Alison:** Definitely!!

**Gail OT:** But if you're too tired from all the running around you're not able to concentrate on your family either. We all need a bit of sanity time

**Alison:** I have just returned to work today after 5 weeks off, and I am shattered tonight. I NEED some sanity time now I think!!

**Simon - MS Trust:** Do you do any sports or activities, Alison?

**Alison:** I swim when I can.

**Simon - MS Trust:** Alison, did you always swim or is it something you've taken up more recently?

**Alison:** I have always done it in the past, but I have let it slip of late! I will be getting back to it next week.

**Sally:** I swim too when I can and find it makes me feel better in myself

**Simon - MS Trust:** It's 7 o'clock I'm afraid and we need to wrap things up. Thanks to Gail and to Jo who was on earlier for their help with this room and being online for longer than was originally billed, and also thanks to all the people with MS who shared their experiences and thoughts on this topic