



Wheelchair issues

Chatroom

3 September 2002

www.mstrust.org.uk

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3 September 2002 – 10am to 7pm

The experts:

- **Denise Middleton**
MS clinical specialist occupational therapist (10am – 2pm)
- **Liz Betts**
Physiotherapist (2pm – 7pm)

Simon (MS Trust): Welcome to the chatroom on wheelchair issues. Do you have a question?

Chloe: Hello.

Denise Middleton: Hello Chloe, welcome.

Chloe: I saw the chat room advertised on a magazine called open door. I don't use a wheelchair yet. Will I have to later?

Denise Middleton: Did you enjoy the article by Gail Townsend?

Chloe: It all made me think a lot about what might happen in the future.

Denise Middleton: Not everyone needs to use a wheelchair. People often use a wheelchair for convenience not just necessity.

Chloe: Does anyone here use a chair?

Sally: I use one occasionally - I might push the chair myself for a while then get into it. I think it's good to show that a wheelchair can be used as and when.

Denise Middleton: Using a wheelchair doesn't always mean that you can't you walk at all Sally's got the right idea. A wheelchair makes the best of your energy and allows you do the things you want to do not just the things you have to.

Chloe: Did you go straight to using a wheelchair, Sally, or did you use sticks etc first?

Denise Middleton: Chloe, people often use a stick or crutches before or as well a wheelchair it may depend on the activity.

Sally: One problem I do have is that I have a quiet voice and I find that when I do use the chair, it's difficult to converse with people. Does anyone have any ideas what I could do about that?

Denise Middleton: Do you feel that people are seeing the wheelchair and not you?

Geoff: Attitude is so difficult to cope with

Denise Middleton: Try talking directly to them. They probably need a nudge of encouragement from you. Attitude is very difficult but it can also a good way of educating people and used an opportunity to change.

Sally: Yes – I think that's right. Fortunately I can very often get out of the chair to chat to people - so in a way that's a demonstration that I am the same person in or out of the chair. But I usually would be doing this because of having this annoyingly quiet voice!

Denise Middleton: Sally a Speech Therapist may be able to give you advice on how improve your voice volume. Usually your GP needs to refer.

Geoff: Do you find they treat you differently when you're on your legs?

Denise Middleton: Geoff, have you experience a difference in the way you are treated?

Geoff: Standing up, some people seem to see me differently. The chair seems to frighten them.

Jill: Glad to be here really having only just located the chat room "tab".

Simon (MS Trust): Jill, we run four chatrooms a year, so the tab isn't there all the time. Transcripts of previous sessions are posted on the Information pages of our website.

Jill: Is there any advice about when to consider using a power chair as opposed to a manual wheelchair?

Denise Middleton: Generally my advice to people would be related to how tired they get using a self propelled wheelchair and whether or not they have the strength to go the distance they want to cover.

Denise Middleton: Jill are you considering a powered chair?

Jill: Denise, Yes I should like to buy a power chair so that I can walk along beside the people I'm with and where I live it is quite hilly! My MS is getting worse and I like to be as ahead of that as I can be as well.

Geoff: Do other people here use chairs at the moment?

Jill: Geoff, I agree that wheelchairs can be frightening for other people, and yes using a chair does single us out as different. But I have found that I feel more "normal" (not so different) moving around in my chair than when I'm walking about very inelegantly with my crutches. I can speak to people without having to worry about my balance or whether I need to sit down. And it gives me the opportunity to move around to speak to who I want to!

Eva: Hello this is Eva up in Scotland. I'm a pwms. Can I say I agree with Jill about feeling more "normal" in my electric powered indoor/outdoor chair (EPIOC).

Denise Middleton: Jill, do you access to a Wheelchair Therapist or OT? It's best to try and get an assessment rather than dealing with a company alone. Using a wheelchair on your terms puts you in control.

Jill: Hi Eva, I'm in the south east, so we're as far apart as we can be! I guess it's more hilly where you are than down here!!!

Eva: No, it's not too hilly here in Fife. I get around my village easily in my EPIOC.

Denise Middleton: Jill, using a powered wheelchair will definitely open options up to you in terms of independence and range of where you go ie up and down dale!

Eva: My question is - does the NHS invest enough money in EPIOCs? How can we quantify the enormous benefit an EPIOC has on our lives?

Geoff: I tended to find that they fitted me with wheels but not necessarily appropriate wheels.

Jill: I can arrange to have an assessment although it's hard to pre-empt things. Recently I had to really push for an OT to help us with plans for our home adaptations. They are apparently only able to respond to a crisis! And as I "don't look disabled" - I was not urgent. When we started asking about a private OT consultation, the department did respond pretty quickly.

Denise Middleton: Funding for EPIOCs is usually limited to a specific amount in each area. Often there is also an additional set criterion that you first need to be using an indoor powered wheelchair first.

Jill: So until I fit the set criteria I may as well go ahead and organise my own electric chair?

Eva: What are these criteria, who sets them and how do we, the users get involved in opening up the debate?

Denise Middleton: The criteria I described is specific to the area I work in. it may be different in other areas. Don't be put of by this always push for an assessment initially. Many more people than the allocated number could benefit from an EPIOC.

Jill: Could you describe an EPIOC chair to me?

Denise Middleton: EPIOC stands for electric powered indoor outdoor wheelchair

Jill: Yet another thing to have to push for. Eva's question has hit the nail on the head hasn't it? We really should have national standard criteria.

Geoff: Do you think that the problem with getting access adds to the negative image of chairs?

Jill: Geoff, I agree with you. Although there are more places we can get into with wheelchairs, they are still comparatively few. And people who hang out with us become restricted too. Hence the negative image.

Geoff: It's an image thing, isn't it. The way national health specs equate to raybans (?sp)

Denise Middleton: The PCT set the funding agreed in my area. The therapists who work in the service are constantly asking for more to allocated and often the only way a need is accepted for service development and new funding is for people to come forward for assessments and then go on a waiting list.

Jill: Waiting lists are an insult. When you have identified a need then it is a need. By the time you get to the top of the list you may not have time left to appreciate the advantages of the equipment. People don't volunteer for wheelchairs for fun.

Denise Middleton: Jill I completely agree we are bound by policy and processes to try to improve our services for pwms. Like interferon, wheelchair services are a victim of postcode lottery.

Marcus: I don't think that the 'chairs' have a negative image - it is more 'other people's' inability to deal with them. When has anyone been embarrassed by an electric golf buggy?

Jill: Golf buggies carry some status though.

Geoff: I agree, Marcus - I mean negative in the sense of 'society' (whatever that is). For me, realising that staggering about on a stick could be replaced by whizzing about in a chair was the best thing I ever did.

Jill: Geoff, you said it. The negative image comes from the people who don't use them. To us who do, they are our liberation.

Eva: Geoff, I wholeheartedly agree with the whizzing bit. I also like the contol/choice. I go where I want when I want – great.

Jill: But we can't quite get to everywhere we'd like to, can we? There are still obstacles like stairs to contend with. And we have to plan everything in advance.

Geoff: True, Jill, but with my sticks I probably wouldn't have even got to the bottom of the stairs :-)

Jill: I should like to be able to travel by train for example. In theory its possible but in practice its too risky.

Eva: Yes everything has to be planned. But at least our choices are increased. I can't go upstairs in a manual chair either.

Geoff: DDA etc has a long way to go to be truly meaningful.

Jill: Hear hear, Geoff (about the DDA).

Eva: Train travel - back to planning. I take a taxi to nearest accessible station and get on the train in my electric wheelchair. The planning bit comes in letting them know you are travelling and checking accessibility of station destination. They have a disability information telephone service to help you.

Jill: How far away is your nearest accessible station. And how often does the lift break down?

Geoff: Station lifts are a disgrace.

Jill: Denise, you said that health professionals are bound by policies and practices. And that provision of wheelchairs is victim to the dreaded postcode lottery. How can we speak up for our needs to bring them the same status as services for people with cancer or heart diseases etc? We are important too!

Marcus: I'm not a wheelchair user (yet) and I am not aware of the difficulties involved in acquiring one. If there are difficulties and I required one and couldn't obtain one - I used to be in the motor trade and if you required 'wheels' (eg for racing), you would look for sponsorship - I wouldn't mind going around with a 'Tesco' badge on my top of the range wheelchair. Taxis do it

Geoff: Supermarkets and shopping centres do seem to be thinking about providing chairs and scooters more now and the thinking of the needs of customers who use them

Jill: Marcus, interesting idea - I wonder how the sponsorship idea could work within the NHS? Some people could find themselves advertising a product they disapprove of?

Geoff: wouldn't it be great if companies started vying for our custom :-)

Jill: And theatres and cinemas and museums provide wheelchairs and facilities for wheelchair users.

Denise Middleton: Wheelchair users are definitely important. The services for most types of equipment is always limited to budget restrictions and DLA is also supposed to count towards providing a means of mobility. If you need a car and an outdoor electric wheelchair you end up having to fund one or the other yourself. There just isn't enough government funding. Lobbying, is that the answer?!!

Jill: Denise, so I'm back where I started aren't I, regarding advice for purchasing my own EPIOC. I don't want to have to wait for an OT assessment so are there any tips you can offer?

Denise Middleton: If you ask your local branch of the MS Society for assistance with supporting your application for an assessment this may help. It seems to be effective in my area. Also some areas have Disability Info and Advice Centres where they often employ independent OTs who help. Some wheelchair suppliers also employ therapists who would hopefully provide an independent assessment and advice. I do agree that it must feel like a constant battle and as someone stated earlier 'they didn't chose to become a wheelchair user.

Jill: Re lobbying. I think society forgets that pwms and other disabling conditions lack energy and the wherewithal to lobby. I did go up to London for the beta interferon lobby a couple of years ago. That was an experience getting there and back by train :-). Fortunately my able bodied, long-suffering husband was supporting me. Otherwise I may have ended up in Dover.

Geoff: Sadly it's so often the case that people have to spend ages banging the drum before they get noticed - even if drum banging is not that easy. A thorn in the side seems to get quicker attention than a polite request.

Marcus: On the lobbying front, I emailed NICE when they had made a preliminary decision on the distribution of interferon - my question was simple. How many of the committee either had (or had a relative) who had MS - I asked this because I know of a senior government official in the Scottish parliament whose mother had MS and when I lobbied the Scottish parliament with a 'mass email' - I made sure that he was a recipient. I got a personal reply from Susan Deacon - result!

Jill: Good point. Incidentally do we know how many people have MS? 85,000 seems a bit conservative to me. If the figures were more accurate and the occurrence of MS known then maybe more would be done. A question for the next census maybe?

Simon (MS Trust): I think the figure is an educated guess based on prevalence studies (which only usually cover quite small areas). I've seen people refer to a range from 80,000 to over 90,000

[In 2009 the London School of Hygiene and Tropical Medicine published results of a study that suggest the figure is almost 100,000]

Marcus: I agree with the census idea but when I relate to figures when talking to people - their eyes 'mist' over. But when I recently referred to figures of people with a disability in the UK being 8.5 million with a calculated 'spend power' of £45 billion their attention seemed to perk up - maybe I must speak with the wrong sort of people?

Jill: Marcus, you have hit the nail on the head, people who use wheelchairs do so for different reasons and we have to join forces together. RADAR does this already. Does your local area have an access group?

Geoff: Has anyone been using a chair for a while? Is the situation re access improving in your experience?

Jill: I have been using a wheelchair since 1994, initially as a prop. When I wasn't in it I could use it to walk with support and my son was young enough to want to ride in it then. I definitely think access is improving, but as I said earlier you have to plan everything in advance. (No last minute holiday bargains for me I'm afraid)

Geoff: Yes, spontaneity doesn't do steps.

Denise Middleton: The whole issue of funding is extremely frustrating to pwms and health professionals. I am constantly advising and recommending people to use wheelchair for energy conservation and improved quality of life only to come across all the same obstacles time again.

Jill: Denise recommends wheelchair use for "Energy conservation and improved quality of life". Absolutely. Since the need for better funding is known to us ie pwms and the health professionals who care for us, where is the problem?

Denise Middleton: Your questions re access? I work in Milton Keynes. Being a relatively new city almost everywhere is wheelchair accessible.

Jill: Thanks for the advice about independent (private?) OTs. As I feared really. I have to leave the chat room now but it's been good to chat with you all.

Denise Middleton: Jill, I didn't necessary mean private OT. I was referring to centres employing their own ie not directly linked to NHS or SS. Sorry for the confusion. Nice chatting to you too.

Marcus: Other than public figures having experience (directly or indirectly) with MS. certain figures are in the 'public eye' as wheelchair users - I'm thinking of Mr Murray of Murray International Metals - If I were stuck, I would contact him for advice

Denise Middleton: Celebs and high profile people certainly do an influence on attitude towards disability

Marcus: My nearest city is Edinburgh (which must be one of the 'hilliest' cities in the UK. The council have gone some way to improve accessibility for wheelchairs but I don't know how much improved it is because I don't use a wheelchair yet. But I am struggling after 10 minutes walking about the city. When I sit to recover, I look with envy at electric wheelchairs, although I know that I shouldn't

Geoff: Have you tried using a chair or a scooter, just to see if it makes a difference?

Denise Middleton: Marcus, have you considered using a wheelchair if you struggle after 10 minutes? I imagine the hills are a nightmare

Marcus: No Geoff, I haven't. Yes, Denise, I have considered but all my DLA is used up on a car.

Denise Middleton: Scooters have a faster speed. More street cred?!?

Marcus: Must go to pick my wife up. First time on this chat room and it has cheered me up – see you next time. I don't really have a lot of experience with chat rooms but this has been fine - something to tell my MS nurse about next week

Linda: I have secondary progressive MS and I am steadily losing mobility. Soon I shall need a wheelchair in the house. I have seen ones advertised that rise up to allow access to kitchen cupboards - any advice about these?

Denise Middleton: There are a couple of manufacturers who sell wheelchairs that stand up. The one that springs to mind is called a Levo. These are either electrically operated or manually by lever and your own power

Linda: How stable are they?

Denise Middleton: They do provide another level of independence and are very stable. The wheelbase is wider to allow for stability so are difficult to use in small spaces. I would advise assessment by your therapist for suitability to you and your environment, as they are very costly

Linda: I have a folding electric scooter (which I think is the best thing since sliced bread!) and I am considering using it in the house when I finally need to, I also have a stair lift. What I have been wondering is - will I need a second wheelchair to use upstairs when I get to the top? How do people manage?

Denise Middleton: Yes you may need a wheelchair to use upstairs. If space is limited, some people use other wheeled chairs like office or shower chair. OT should be able to advise and provide suitable equipment. Community OT should also be able to advise on other adaptations ie ramped access

Linda: I am obviously going to have to get in touch with OT quite soon. It will be a bit late if I wait until I need all these things. My next question is about using my car. I have an automatic, adapted for me to drive left-footed and I am determined to keep my independence by using it for as long as I am safe to continue driving. My question is, I am going to be able to get into the car and somehow load my scooter and unload at the other end?

Denise Middleton: Again Community OT can advise. You can get special hoists for cars to lift wheelchair or scooters into the boot.

Linda: Thank you for the information, Denise. I had been concerned about lack of space in our bedroom and it had not occurred to me to think about other forms of chairs with wheels. I shall leave you all now for a while - I've managed to get my grandson to sleep, so I shall grab the opportunity to get myself some lunch!

Denise Middleton: Linda do you have a disability information centre near you? They usually hold a lot of info and leaflets on car adaptations. Has anyone found these centres useful in finding info on wheelchairs?

Linda: No, I have never heard of a disability info centre, so I presume we haven't got one - no MS nurse in my county either (Northants).

Denise Middleton: Linda we have a good centre in Milton Keynes - The Centre for Integrated Living. That's not too far from you?

Linda: Can you give me the address of the MK centre please? I live in Earls Barton (between Wellingborough and Northampton) so it would be quite a drive - but perhaps I could combine it with a shopping trip.

Denise Middleton: Linda the CIL is opposite the shopping centre (Marks and Spencer's) in the city church building, on left hand side if your back's to M&S

Simon (MS Trust): There's a list of centres (more than 40 around the country) on the Disabled Living Centre website at www.dlcc.org.uk

Linda: Thanks Denise. I'm off now for lunch. Bye everyone.

Caroline: Hi all. The time is rapidly coming when I am going to need some mechanical assistance to get around. How do I proceed? I'm in Oxford.

Denise Middleton: Usually there are specific Wheelchair Services in most areas with qualified therapists who assess and advise. You can often refer yourself or ask any health professional to refer you ie physiotherapist. I believe the wheelchair service in Oxford is based at the Nuffield Orthopaedic Centre.

Nichola: Does everyone know about Shopmobility schemes, run by most big towns? You don't actually need an orange badge. They are great. They loan electric or manual wheelchairs for the day, which means you can shop without fear of dropping. I used them before I used a wheelchair full time.

Denise Middleton: Trying out a wheelchair from Shopmobility is a good way of 'having a go' especially if you're a shopaholic too

Caroline: Thanks for the info. May I ask a second thing? Must one pre-warn travel companies if one wishes to take a scooter/wheelchair?

Denise Middleton: Yes it is probably advisable to inform them. Space may be limited and you'd may get VIP treatment if they know your specific needs in advance

Anne C: How often do you have the Chatroom? I found it by chance.

Simon (MS Trust): We are doing them quarterly now. If you email me your email address, I can send you a reminder of when the next one is coming. Or if you send me your postal address, I can put you on the mailing list for Open Door, our quarterly newsletter, which will have announcements of forthcoming rooms

Simon (MS Trust): Denise has now left. The expert for the rest of the session will be Liz Betts?

Liz Betts: hello Paul, do you have a question?

Paul H: Not sure really, Liz. Trying to find out all I can. I've been diagnosed with primary progressive MS four weeks ago. I am only 33.

Liz Betts: I am sure at the moment you feel as if the rug has been pulled out from under you. Have you any particular symptoms that are causing you problems at present?

Paul H: Not really, Liz. I am going for physio next week. I've seen an MS nurse. everything that can be done is being done. I think I am teaching myself to use this computer at the moment but I do wonder what job I will be able to do. I was a lorry driver. My main problem is walking

Liz Betts: I think you will find the computer very useful to access information. It is difficult to predict on the job front. Hopefully your physio will help

Paul H: Will physio help me to walk much better do you think?

Liz Betts: It will also be helpful to talk to both nurse and physio about coping with fatigue and physio should certainly help with walking problems

Paul H: I see, thanks.

Simon (MS Trust): Paul, if there is information we can supply from the MS Trust's Information Service, please let me know (my email is simon.webster@mstrust.org.uk)

Paul H: OK, thank you

Simon (MS Trust): We also have a discussion list on our website - communicating via email. The people there will be supportive and you might find that helpful

John Major: Liz, any ideas how you stop people talking to the pusher rather than the person in the wheelchair?

Liz Betts: Good question to which I'm not sure there is a right answer. Just sit up tall and get assertive I suppose. I wish I had a better idea

Geoff: Hi John. It is a case of finding a solution for the other person's problem (ie they can't cope with your chair)

John Major: Liz, my preferred solution is to get an electric chair and do without a pusher and to be politely assertive! And thanks Geoff

Liz Betts: Unfortunately we need to keep educating people. I do my best when I have kids on work experience and put them in chairs -hope for the future

John Major: Liz, how useful are stabilisers? I used to do without till I managed to tip my chair over and cut my head open!

Liz Betts: Bad luck I think you have answered your own question

John Major: Thanks Liz. How good are they at stopping the chair tipping over?

Liz Betts: The answer to that is up to a point. But there is, as I'm sure you are aware, a point of no return. It depends on angles etc.

John Major: Thanks, Liz and Simon, time for my tea! Hope to chat again later tonight.

Liz Betts: Hello Neil. Have you got a question?

Neil: I was just interested to see what a chat room looked like and to listen for a while about wheelchairs etc. My physio told me about this website. I was diagnosed five months ago and don't use a wheelchair yet

Liz Betts: Do you have mobility problems that make you think you may need one? Not everyone with MS needs to use a chair

Neil: No, but when I'm tired I feel really dizzy and my eyesight isn't great all the time. I don't go out much when I'm not feeling good because I don't want to fall over. Is that normal?

Liz Betts: Yes, it may be you need some advice on coping with fatigue - your symptoms will always be worse when you are fatigued and also if you are anxious. No adult ever wants to fall, as you tend to feel self-conscious

Geoff: Just dipping back in again. Hi Neil

Neil: Hi Geoff. I fell over on Friday but it wasn't too bad - I was in the pub so my mates thought I'd had too many!

BePe: I have ppms Liz, (diagnosed 4 years ago) and my walking has deteriorated to the point where I use elbow crutches all the time, and it's getting worse. Should I start using a wheelchair for work to reduce fatigue, or should I carry on with the "sticks"? Hi Geoff and Simon too. Like Neil, I have been falling over every month or so!

Liz Betts: I feel that wheelchairs can be very useful in fatigue management. It saves you using all your energy just to get where you want to go and stops you falling in the pub!! You can also use a chair as a walking aid and just sit down when you need a break

Neil: But then my mates will know there's something wrong won't they?

Geoff: Which is more important - being on your feet or avoiding fatigue? When I answered that for myself (I chose to minimise fatigue and use a chair) opportunities opened up again

BePe: OK but what about the use it or lose it approach? Or can you maintain use by doing exercises? I use a wheelchair quite often on holidays, but am worried about using at work, until I am really forced to. Stupid eh? I think for the same reason as Neil, although they know I have MS at work

Liz Betts: I would always try to keep on your feet if you can but that could be more as your daily exercise and use the wheelchair to live your life. People can be more understanding than you think

Geoff: Fair point - but I found I expended so much energy keeping up appearances that I had no oomph to do much worthwhile (and I do exercises and manage without the chair over short distances)

Liz Betts: Geoff I think you have got a good balance

BePe: Good points Geoff and Liz, thanks, food for thought.

Neil: How much does your MS affect your holidays, BePe?

BePe: Just got back from two weeks in a wheelchair adapted villa in the Algarve. Brilliant. Take good mates who share the pushing. It does affect practicalities, but can get round most. Have a look at the wheeling round the Algarve website, Neil, that guy is an inspiration

Neil: Thanks BePe

Vanessa: Does anyone have any objections to me asking about a legal problem I have?

Simon (MS Trust): It's worth a try but we may not be the right people to answer it. What's the problem?

Vanessa: Well - to cut a long story short, I am taking my ex-employers to the Industrial Tribunal for Disability Discrimination and Unfair Dismissal. Originally, they had acknowledged that I have a Disability but now are backtracking, saying they don't believe I am disabled. The Tribunal have accepted this and now I have to find expert witnesses. Has anyone heard of such a thing happening before?

Liz Betts: I don't have any experience of this myself. Would your consultant not help?

Vanessa: Yes - he will be on the list of "expert witnesses". We have to forward 3 names to the other side and they will pick one to attend the Hearing in January.

Liz Betts: The only other suggestion I can make is have you tried the MS society?

Vanessa: Yes, but they are not really able to help. I have legal representation, I just wondered if anyone has had this kind of experience before (just to reassure me :)

Liz Betts: I'm sorry I can't be of more help

Simon (MS Trust): If people reading the transcript have any thoughts on Vanessa's situation and would like to email comments to me at simon.Webster@mstrust.org.uk, I shall pass them on to her.

Vanessa: Thank you

Simon (MS Trust): Hello Caroline, do you have a question for Liz?

Caroline: Hello. Yes, how does one access a physiotherapist who knows about MS and the limitations of fatigue?

Liz Betts: Unfortunately there's no easy answer to that. It depends where you live and if there are any specialist physios in your area.

Caroline: I'm in Oxford. And what would the physio offer?

Liz Betts: It may be worth contacting the local hospital to find out or the GP to see if there is a specialist centre in your area. Physios or occupational therapists can give you advice on fatigue strategies and relaxation and the physios should be able to advise on suitable exercise programmes

Caroline: Many thanks.

Ploughman 77: Can you suggest a folding electric wheelchair that can be used both indoors and outside. I don't need it yet but the way things are going...

Liz Betts: Not specifically, but have you tried your local wheelchair service – at least for advice, even if they don't have exactly what you want. There are also scooters, which come apart for easy storage and lifting into a car

Ploughman 77: Thanks. I'll start with the Occupational Therapy Dept.

Liz Betts: Good idea

Ali: Can I ask you a question about home DIY?

Simon (MS Trust): Ask away

Ali: OK! I have MS and my husband's quite tall (6 ft 3). He finds my wheelchair handles too low for him, and he's always at risk of hurting his back when pushing me. A disaster for us both! He's modified my manual wheelchair - raised the handles (against the strictures of the NHS) but it's not completely solved the problem because that'd require longer new handles to be made. I wondered if anyone else had had this problem? At present I use a small electric scooter whenever possible but it's less flexible than a wheelchair for steps etc. Advice?

Liz Betts: There is an organisation called REMAP, whose website is www.remap.org.uk. They will often do changes to conventional items to make them more user friendly

Ali: Liz, thanks. I'll have a look at the website and point my husband in the right direction.

Liz Betts: I wonder if an outdoor wheelchair with kerb climbers might be better for you. Unfortunately I think you would have to fund it yourself or by charitable donations

Ali: Thanks, Liz. I'll have a think about that one too.

Ginny: Liz, can you recommend a walking aid that is suitable for a young person? Is there a remotely trendy walking stick?

Liz Betts: There are folding sticks, which aren't too bad, but you could always customise a conventional one to your own taste. It's amazing what a coat of paint can do

Ginny: Where do I get a stick from?

Liz Betts: Your local physio department should be able to supply one but you may need to go thro' the GP

Ginny: Thanks!

Liz Betts: I hope you're successful

Kath: I use my wheel chair on a part time basis but I most often use it in handcycle form. Since not many people seem to know about handcycles I thought it might be worth commenting on their value.

Liz Betts: I have seen what I think you are talking about when on holiday in Holland. A wheelchair powered by hand. Although I have no direct experience I was impressed with what I saw and am interested to find out more.

Kath: The first question people might have is what is a handcycle? Basically it is an attachment to the chair through an under seat socket. It takes the form of a single wheel with attached frame, chain wheels providing 21 speed derailleur gears and handlebars. Turning or cranking the handlebars provides forward motion for the whole machine. In mobility terms it is just so much more efficient than pushing a wheelchair with the hand rims. I use mine in all sorts of situations and feel quite evangelical about it

Liz Betts: I'm sure you do I think it seems much more ergonomic than a conventional chair. Do you have any supply details?

Kath: Supply details can most easily be obtained through the Handcycling association of the UK (HCAUK). They have a web site at <http://www.handcycling.org.uk/>. There are about six manufacturers in this country although some of them probably import.

Liz Betts: many thanks I'll have a look!

Sally: Hi, I was wondering whether using a wheelchair indoors would be better than trying a frame as I am used to a wheelchair or would it worsen things a lot?

Liz Betts: It sounds as if you are currently using a wheelchair. There is no reason why you cannot use a frame to exercise further providing you are safe and have the physical strength. You may want to alternate between the two so as not to get too tired.

ladywolf777: How many members does the trust have? Do you meet up (conferences etc)? I came here from Jooly's Joint. I had not heard of it before.

Simon (MS Trust): The Trust isn't a membership organisation. We produce publications, newsletters and have an information service - all of which is free to all

ladywolf777: That's good - do you do your own research?

Simon (MS Trust): We fund applied research - we are currently supporting a couple of cannabis studies, work looking at the value of MS specialist nurses and an information needs analysis. We also run education courses for health and social care professionals

ladywolf777: Cannabis studies?

Simon (MS Trust): Yes, one is looking at the effect on bladder symptoms, the other looking into psychological issues.

ladywolf777: How do they think that cannabis can help with bladder functions? And what psychological issues? Sorry for all the questions. I was diagnosed three years ago but not much info since (denial on my part more than health care professionals)

Simon (MS Trust): The bladder study has been looking at whether cannabis can have an effect of frequency. Results should be published later this year. I believe the psychological study is looking into the effect of taking the drug (though I'm not sure if this is in tablet or spray form - not smoked)

ladywolf777: I will keep lookout will it be on this site?

Simon (MS Trust): We will certainly advertise the results when they are available and also cover them in our newsletter - email your postal details to me at simon.webster@mstrust.org.uk if you'd like to go on the mailing list for that.

ladywolf777: Liz, do you recommend a particular exercise for decreasing neck tension - I have terrible problems with mine

Liz Betts: You need to look at your posture. You may be poking your chin forward so look in the mirror and sit up straight keeping your chin tucked in. It may also help to use gentle heat on your neck and resting regularly

ladywolf777: I can't do heat though anything else

Liz Betts: You could try cold maybe a cold flannel

ladywolf777: I will try that thanks

Sally: I use a wheelchair outdoors but I'm desperately holding on to my independence and do not want to use frame but realise I am getting weaker. My house is not very wheelchair friendly.

Liz Betts: Sally if you use a frame you may find it helps to save a lot of energy. You don't have to pick it up if you get one with wheels you can also get them with seats to help you rest in between

Sally: Would using my wheelchair indoors create many extra health problems though as I am still only 32.

Liz Betts: The trick with the wheelchair is to make sure you walk some of the time or at least stand regularly. There are also exercises you can do sitting down to help keep you fit

Sally: I think I would rather use what I'm used to (wheelchair) as I could do more but in a way it seems like the end of the road.

Liz Betts: Try to think of it as you managing your symptoms to live your life rather than your symptoms managing you. Wheelchairs are gadgets like dishwashers you use them to make life easier

Sally: that is a good point it's so easy to get fixed on what a wheelchair implies to other people

Liz Betts: I hope that's helped. It's not all negative!

Sally: Liz, thanks for your help. I shall try and think of it like a dishwasher from now on and see if it changes my perspective!!

Liz Betts: I'm glad to hear it you may just need to look on the wheelchair as a gadget to help out now and again

Monique: Hi, can I ask you if you have any advice/experience in how to present MS to my boss? I like to work four days a week so I can use one day to exercise and rest, without getting fired?

ladywolf777: Monique, he cant fire you - get as much info on MS and take it with you

Liz Betts: Monique, it may be worth looking into the pattern of your day to incorporate a rest time eg don't go out at lunch sit down and take a break. It might help to keep you going longer and be less of a problem to the boss. If he sees you coping with your symptoms it may help his attitude

Monique: OK thanks for the suggestions.

Simon (MS Trust): The MS Society have people who can help with employment right issues. Contact them on 0808 800 8000 or email info@mssociety.org.uk.

jay: Hallo! Were you talking about cannabis? I'd love to try it especially for pains in my legs

ladywolf777: I don't think they are looking into it for pain relief

Liz Betts: Hopefully in the not too distant future you will be able to. I believe the trials are going well

Simon (MS Trust): There are a number of studies looking into cannabis in relation to a number of symptoms. Some have been looking at pain

ladywolf777: Oh OK well I might try for that!

Simon (MS Trust): There is information on some of the trials on the Medicinal Cannabis Research Foundation website at www.helpcannabisresearch.org

Monique: Do you perhaps know about any financial benefits available to MS sufferers that work full time or four days? I read some brochures on disability allowance but it was mainly for people that only worked a few hours and hence had hardly any income

Simon (MS Trust): I'm not an expert on benefits but I believe Disability Living Allowance is based on medical rather than financial criteria

Monique: ok thanks

Simon (MS Trust): It would be worth talking to your local Citizen's Advice Bureau.

Simon (MS Trust): Hello John and Stuart. The theme of this chatroom is wheelchair issues, though conversation has started to range quite widely

Liz Betts: I have to say I've enjoyed the variety

Stuart: My main problem with wheelchair is MY pride. I still won't use outside home. Fortunately, just now I don't need wheelchair often. I'm one of the lucky ones, interferon has really slowed down my progression

John Major: For what it's worth, I had to choose between using a wheelchair or never going anywhere. I use mine now but I still wish I didn't have to

Geoff: Very much my feeling too, John

Stuart: I have accepted that, more than likely, eventually I will have to use more but I live my life one day at a time

Liz Betts: I don't know anyone who likes to use them but sometimes it's the only option or you miss out on too much

Simon (MS Trust): We need to close the room now. Thank you to everyone for their contributions and especially to Denise Middleton and Liz Betts for acting as experts