

# **Work and MS**

## **Chatroom**

**24 May 2011**

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

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Reg Charity no 1088353

# Work and MS

24 May 2011 - 10am to 7pm

- **Gail Townsend** - Occupational Therapist
- **Gerry Tyrrell** - Working Life Service
- **Patrick Carroll** - Occupational Therapist
- **Sarah Ramsay** - Occupational Therapist
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This chatroom is an open forum and so the views expressed by participants are their own and are not necessarily those of the MS Trust

For further information on topics raised, please contact the  
**MS Trust Information Service** on  
0800 032 3839 or [infoteam@mstrust.org.uk](mailto:infoteam@mstrust.org.uk)

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What would be seen as reasonable adjustments under the Equality Act?	3
It's hard for me to distinguish between when I should keep trying and when I am having a day when I am really too ill to work	4
Since my diagnosis I was moved to a new post but it is very hard for me. Is this discrimination under the Equality Act?	5
I have recently asked to work from home on a permanent basis. I think my boss wants me to just leave	8
Talking things through can help you see different ways of solving issues	10
I know that my employer would be happy for me to work from home more but I am very resistant as I think that this would cause even more isolation	10
Is it sensible to tell a potential employer about MS when going for a new job?	13
I have to go through a formal assessment process to activate the permanent health insurance my company provides and am concerned they will downgrade or redeploy me	13
I'm self employed. Can I charge my services out from a limited company without taking a salary from this without it affecting my current benefits? Who is best to advise on office arrangements in order to reduce fatigue?	14
Do I tell future employers about MS and risk my CV just getting thrown out before they look at it or keep it quiet so I have a higher chance at getting a job?	15
I have been off work for a week and only get statutory sick pay. Can I apply for DLA?	16
I'd like to work but can't reliably commit to doing two consecutive days	16
Employers should be made aware of the symptoms of MS	17
Becoming an employment adviser is the best thing that's happened to me since becoming disabled	17

I'm feeling trapped in my current job. My employer has been very accommodating but it's time to move on	17
I've been told I can't receive ESA as am fit enough for work. But I know I'm not	18
Should I think of giving up working? Will choosing not to work affect benefits etc?	18
Reluctance of employers to grant 'medical discharge' to people with MS	19
When application forms ask if you have a disability should I declare that I have MS?	20
How can I tell if I'm being discriminated against in job applications	20
If a person is self employed should they be disclosing their MS?	21
Delayed phased return to and statutory sick pay	22
Worried that I will be made me do any work rather than something that uses my skills	22
Discriminatory effect of DLA cut of at 65	23
Is there anything really important for people who have MS to be aware of in the workplace?	23
How do I go about saying I can't keep up with work I'm asked to do?	24
Time limit and permitted work	24
If I work reduced hours or take early retirement how can I make up my earnings so I do not lose out financially?	24
Guidance on negotiating with an employer about reasonable adjustments	25
Questions about health during job interviews	25
Any hints on how best to talk about MS to others in the office?	26
If I were to work fewer days are my working or tax credits increased?	27
I have asked to change my hours but my employer would prefer I worked different hours. Does this count as a reasonable adjustment?	27
Blue Badges and knowing who to tell about MS	27
Knowing what reasonable adjustments may be available	29
MS Therapy Centres	29
What an OT can do for people with MS	29
Support for people in higher education or training	30
<i>MS Workbook Toolkit</i> and Working Life Service surgeries	30
I'm very unsure about going back to work and letting everyone down	31
Support with DLA problem and tribunal	31
Other work related events	32
Resources mentioned in the chatroom	33

**Simon - MS Trust:** Welcome to the chatroom on work and MS.

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**Pat:** Can anyone advise as to what would be seen as reasonable adjustments under the DDA [Disability Discrimination Act - since October 2010 replaced by the Equality Act] if I tell you what my job is?

**Gail - OT:** We can always try, but it can be quite a complicated answer. We might also be able to let you know who else may be able to help.

**Gerry - WLS:** There are some guidelines but nothing specific. It usually comes down to what you can negotiate.

**Pat:** I know. I am very aware of that as I am struggling to sort it out myself. I am a lecturer in Higher Education but my MS now means I have issues with walking and standing, eyes and fatigue.

**Gail - OT:** Based on my experience you could explore ways of reducing your walking - for example between rooms or meetings.

**Pat:** That was my main concern, as it might depend on my boss's view. I am having trouble knowing what to ask for?

**Gail - OT:** You could also think about whether a specialist Access To Work assessment might be useful with regards to any visual aids that could help. Visual aids are very specialised and they can offer very good advice.

**Gerry - WLS:** I would recommend Access To Work assessments, then look for ways with your employer to compliment the recommendations. The employer would usually send you for an occupational medical and together with both a support package could be developed.

**Pat:** I have a large 22" monitor that Access To Work helped with. It was more the sort of every day things like working at home and a reduced teaching timetable. Would that be considered reasonable?

**Gail - OT:** To help you with negotiating are you in a union? It can be quite hard to negotiate by yourself. You know your boss best, would they be open to someone like an occupational therapist coming to a meeting to support you while you talk about your difficulties and potential solutions?

**Pat:** That sounds an excellent idea - I have a meeting with Occupational Health next week. Yes, I am in the union.

**Gail - OT:** Occupational health can be useful, but their experience of MS is quite limited. If you could discuss ideas for what would make your work easier with an OT or MS nurse, they could write a 'to whom it may concern' letter to give to OH when you meet with them.

**Pat:** Brilliant - of course speak to my MS team and get a letter drafted for OH. Thank you so much I will try that.

**Gail - OT:** Working at home can often be helpful, as long as your employer agrees. However you need to make sure working at home doesn't mean you spend even more time working.

**Pat:** I work at home two days a week and yes, I find it hard to discipline myself.

**Gail - OT:** Pat I always agree the content of any letters relating to work before they are sent. Make sure you are happy with the content and that it discloses only what you are comfortable with OH knowing as it can vary as to what OH then put in their report to the employer.

**Gerry - WLS:** Any adjustment could be looked on as reasonable. The nature of your condition is that one change today may not be helpful tomorrow. A period of monitoring and assessment may be needed until all parties are happy to support each other.

**Ni:** I have a stool that looks like a horse's saddle but with wheels on and therefore I can move around on that. Perhaps this may help you as you could sit (height is quite good on the stool) move around the floor but not be as tired as if you'd be stood all the time?

**Karen:** After Access To Work came in and sent a report to my manager it took four months before any adjustments were made, but more needs to be done. He has lost the report (lucky I was sent a copy) and I don't feel I can approach him as I work in a small office and he has made a very clear point on how much has been spent!

**Gerry - WLS:** Karen, if you would you like me to speak with about your employers attitude you can ring the Working Life Service on 0151 298 3288.

**Pat:** Thank you so much for your help, I have to go to work now. This has been very, very useful I am sure so many of us working can relate.

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**Harriet:** I have recently started a phased return to work, and my company have been brilliant. But it's hard for me to distinguish between when I should keep trying and when I am having a day when I am really too ill to work. I really want to do more, but I don't think I physically can. Can you advise?

**Gail - OT:** Harriet, I think you're in a difficult place. What is your normal work pattern?

**Harriet:** 35 hours a week. I'm currently doing half that over three days.

**Gail - OT:** Are they consecutive days? We find that have a day between working days helps with fatigue and recovery. And that includes return to work plans.

**Harriet:** No, but I have been fixing my hospital appointments for rest days, which has been a mistake. But if I don't, I feel like I'm hardly there.

**Gail - OT:** Are you having lots of appointments that you need to fit in?

**Harriet:** Yes. It should calm down now though, as there were a lot of six month check-ups.

**Gail - OT:** If your return to work plan is being monitored and you're able to keep your hours stable for a couple of weeks before increasing, this might help you catch up in stamina terms.

**Harriet:** I hope so. I'm also feeling that being able to do more will be less stressful, but it's a fine line to doing too much.

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**Kristy:** I am having terrible time with work since my diagnosis in October 2009. I work in the NHS in Scotland. My post at time of diagnosis was community psychiatric nurse. However, due to safety concerns and poor sickness record I was moved to a ward post in November 2010. Even though I am part-time and don't work two consecutive shifts, this post is very hard for me - not least because a ward based post with frail elderly and demented patients is physically demanding even for someone in full health. The other concern I have is the temperature in the ward - this increases my fatigue symptoms. I guess what I want to know is, is this discrimination under the new Equality Act?

**Gail - OT:** Hi Kristy, when you were redeployed, was this through Occupational Health, and what other options might have been available to you? Was anything else discussed with you?

**Anita:** I have been off sick recently with work related stress due to the amount of pressure I was put under despite my pleas for help. After returning last week I was told I would have to move areas as my job was being covered by someone else now. This involves a round trip of 60 miles and three hours per day travelling. I used to travel between 10-20 miles and one hour travelling. Is this fair?

**Gerry - WLS:** Anita it doesn't sound fair. How does your employer expect you to manage your condition by increasing your stress and fatigue? Did you get support from anywhere before returning to work?

**Kristy:** Gerry, that is a very good point and pertinent to my situation where I have been put in a physically demanding role which increases fatigue not to mention the stress of numerous meetings with HR and management.

**Gail - OT:** Anita, was your return to work managed with any occupational health support?

**Anita:** When I asked them this they said they felt it was reasonable to ask me to move areas. Basically they didn't feel I was 'into my MS that much that they had to make many reasonable adjustments'. I have put in a grievance but don't hold out much hope really.

**Anita:** No Occupational Health support at the return to work meeting, just my two line managers and prior communication about what they felt was reasonable from the HR manager. After travelling home yesterday, I could hardly get out of my car and had to go to bed early as my whole body was stiff and ached terribly.

**Gail - OT:** Anita, I would suggest you could ask for an Occupational Health referral. It is very difficult to advise in your specific situation from within a chatroom. You could contact me at the Working Life Service.

**Gail - OT:** Kristy, as you are in the NHS and we are fortunate enough to have in-house occupational health, you could request to see OH yourself for confidential advice.

**Kristy:** OH have been and are involved in my situation. The idea of me being moved to the ward was first suggested to me in my first week back at work post relapse in August 2010 (when I was vulnerable). It increased my stress levels so much that I ended up off sick again. When I did return to work in November 2010 it was to the ward. I don't feel I was given any choice in the matter. I agreed to give it a go very reluctantly as, since qualifying, I had never worked in a ward because I preferred a community setting.

**Gail - OT:** Are there other roles within your organisation that would work better for you - such as some outpatient type services rather than ward or travelling around the community?

**Gerry - WLS:** A lot of problems are caused by a lack of understanding from the employer. Sometimes occupational health reports that do not clearly state suggestions for support can make matters worse. There are ways for you get support locally within the UK.

**Gail - OT:** I think it would be reasonable to request a review or your redeployment, however this may make you feel more vulnerable about you job. Have you involved your union rep or MS team? A 'to whom it may concern' letter from someone in your MS team to give to OH can be helpful (perhaps you can see what I said in response to a question from Pat earlier on)

**Kristy:** I have both union rep and the support of an MS nurse. My MS nurse said at my last review last week that there is no reason why I can't work in a community post, so she has drafted me a letter to take to my next HR/management meeting saying so.

**Gail - OT:** Kristy, I don't know how large your patch would be in the community but you need to consider fatigue if you have to drive a lot. You could go through your old job description and honestly assess what bits might be harder for you, and identify some potential solutions so returning to that role is seen as more feasible. It also looks better if you show you have looked at the potential problems and have identified how to manage them.

**Gerry - WLS:** Was a risk assessment made and what did it include? The purpose of a risk assessment is to identify risk and explore ways of reducing the risk. If your employer did not involve you in the process, how did they know you were at risk?

**Kristy:** I don't think written risk assessment has been part of this process. If risk assessments have been done I haven't been party to them. Verbally, I was told that I was a risk as a 'lone worker' in the community and it would be safer to be in a ward environment where other staff are around.

**Anita:** I was diagnosed with MS two years ago and feel that I have had to fight to stay in my job since being honest with them. What they don't realise is that just because I can still walk unaided, it doesn't mean that I am OK. Far from it a lot of the time. I also have a hydrocephalus that I see a neurologist for, so have symptoms from that too.

**Gerry - WLS:** I have found that a lot of people do not have the confidence to initiate the procedures and steps being recommended. The stress of discussing the issues with an employer can make people even more ill. There are ways for people to get additional support. I have found that getting a union involved causes conflict when attempting to negotiate a support package as their role is to defend or represent through procedures.

**Karen:** Lack of understanding, from an employer is so universal. I also work for the NHS (at a GP surgery). It's wrong when you think about how much information is out there! If you are a manager and employing someone with a long term illness you would think maybe a little research on the subject wouldn't take to much time but would help with your understanding. Maybe I'm being too optimistic?

**Gail - OT:** Sadly my experience is that employers like to be told what they need to know but don't particularly want to go looking themselves. They also forget, not maliciously, but simply because it's a bit removed from them.

**Anita:** That's what I feel, Karen. If I employed someone with a health condition surely it would be beneficial to have an understanding, however small, of the condition and its affects.

**Gail - OT:** Anita, you're seeing this from the perspective of experience. Healthy people have little insight into the reality of living with a long-term condition.

**Karen:** You are so right. But I hate to approach a problem once, let alone have to keep asking whether anything is going to happen. I have to go to my manager, who then has to go to the GPs for approval. It's a small practice so money is tight - it makes me cringe every time I have to remind him.

**Anita:** How many reasonable adjustments is it acceptable to ask for? As Gail has mentioned, I feel like I am just a nuisance every time I remind them that I cannot or may not be able to do something in the way that they want me to.

**Gail - OT:** This is such a frustrating problem for so many people with MS. Sometimes involving a third party (OT / Access To Work / DEA) can sometimes help the process as there is an independent person supporting you.

**Gerry - WLS:** Good advice about the DEA (Disability Employment Adviser) at the job centre. This can sometimes be the key to any support available.

**Kristy:** That is so true. I can become fatigued with driving too. I will look at my old job description. It's terrible, but you feel you have to justify absolutely everything when you are in this situation. That in itself is tiring. I would still like to explore the possibility of returning to my old post, possibly on a job share basis. Am I entitled to request that they consider this and respond to it?

**Gail - OT:** Kristy, by looking at your job description you can make a good case for them to review your redeployment. If you have access to an OT it may be helpful to have support while going through your job description. If you can think things through before a meeting, you will feel more confident about your request and feel you have some evidence to back it up.

**Karen:** Access To Work came out and made a full report that has now been misplaced. They have made some adjustments but there are still some that need to be looked at but it's really difficult to keep mentioning it. I also work with other ladies in the office who dislike any change and offer little or no support, it's so frustrating. Even sitting here telling you all this makes me cringe.

**Gail - OT:** It's best to talk to someone - even this chatroom. It's horrible feeling that you are on your own. If you can, I would suggest you try getting some outside support. Being broadly in the NHS could make it hard for your manager to refuse to allow an OT to come to a meeting and to explain and support any negotiation. I have attended staff meetings to help explain fatigue and the condition (I also work with other neurological conditions).

**Karen:** The MS nurse suggested OT came out if things hadn't been done, but they are really stretched time wise. It's silly getting them out when Access To Work have already done a report. It's probably just me expecting people to do as I would do.

**Gail - OT:** Forget about worrying about how much time the OTs have - you have to think about yourself and if they can help, ask them. You are just as important as anyone else.

**Gerry - WLS:** It sometimes forgotten that MS can effect everyone even co-workers. At the Working life Service we would offer awareness training to colleagues. Ask your local Disability Employment Adviser at the job centre to speak to you about a program called Work Choice and how it can help.

**Kristy:** I will contact MS team and see if I can access an OT to help me look at the job description. I think I do need to look at things more closely to enhance my confidence and point of view. At the same time I feel compromised because I know if I fight to get back to my old job it will be very stressful.

**Gail - OT:** That's why it can be helpful to discuss beforehand, so you can also think about how to manage your stress through the process. I always agree beforehand what I'm going to say, and what I'm not. Don't feel you have to struggle alone.

**Karen:** I don't think for one minute I could make that happen! We all have issues and highlighting mine would just..?

**Gerry - WLS:** It is not about highlighting your condition - it is about supporting you with your condition. To succeed an action plan needs to address all the barriers. Your own confidence could be a major barrier to how you are supported.

**Gail - OT:** When I've gone to the workplace meetings, I've found it can take the focus and pressure off the person I'm supporting. I'm happy to tell people they are asking an inappropriate question (nicely) as well as helping them see there are solutions.

**Karen:** Wise words Gerry! Confidence is not my strong point. I'm all front but I struggle with the inner strength to carry out what I think I should say or do.

**Gail - OT:** Karen, we are often our own worst enemies with the 'oughts' and 'shoulds' - they so undermine our confidence in what we already do well.

**Karen:** Thanks to all for making me realize I'm not on my own! :)

**Kristy:** Thanks for your help. I need to get ready for work now... Bye.

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**Jo:** I have recently asked to work from home on a permanent basis due to not being able to cope with living in a house with stairs on my own. My house is for sale anyway, just waiting for it to sell. I think my boss wants me to just leave, which I don't want to do as I think it would be extremely difficult for me to get another job. I need some advice.

**Gerry - WLS:** Access To Work will pay towards transport costs of getting to and from work as well as if your job role requires you to move about the community in lots of cases.

**Gail - OT:** Hi Jo, can your job easily be done from home?

**Jo:** I think so yes. There are some things that can't be, but they are things I would have difficulty doing if I was in the office or not.

**Gail - OT:** The things you have difficulty with at the office, are they a big part of your job? Also is the workplace difficult for you to manage which is why you want to work from home?

**Jo:** No, it isn't a huge part of my job - I do admin. The difficulty is living on my own, looking after myself, getting ready for work, etc. My house is for sale due to the breakup of my marriage and not feeling I can cope with stairs, bathing, etc. I was staying at my dad's bungalow over Christmas and couldn't drive so had to wait for a mobility car. Now I have the car but still feel I can't or don't want to be living alone in my house. I can't afford to rent a ground floor flat or bungalow as it is too expensive. I want to move 100 odd miles away to where I have family and a partner I can live with.

**Gail - OT:** It sounds as though you could do with some general support from your local team, not just about work. As I said to Kristy previously, go through your job description and identify the difficulties and ways of overcoming them.

**Kristy:** I get the feeling that it would suit my bosses if I were just to resign. But you don't want to do this because what is the alternative? Benefits and the welfare state? So frustrating.

**Jo:** I have said I'm not going to leave my job. They can accommodate me as most of my job I can do on a computer. The things I can't do anymore, I couldn't do even if I was on site. I have been working from home since December but my boss says it's not working. He won't tell me why but says my role wasn't designed to be a work from home position.

**Gail - OT:** Do you get DLA (disability living allowance) to help you with things around the house?

**Jo:** I get DLA for my car but have found that there doesn't seem to be much help in the way of getting domestic chores done or things like laundry, etc. When you say my 'local team', who do you mean? Also, I'm now 100 odd miles away from my home, so it is difficult to attend any meetings. I would need to stay in a hotel as I can't stay in my house. My boss has asked me to list what I feel I can do from home and what I can't and he is going to do the same. Not sure what to do anymore.

**Gail - OT:** Do you not have a team local to where you currently live? Have you only been there a short time and so haven't had the chance to find local services? Sorry if I'm not understanding your situation properly. If you are having difficulty managing your daily activities you may be eligible for the care part of DLA as well as the mobility part.

**Karen:** DLA! That's another subject. I've been waiting for an appeal since December. I can't get to work without my car - I work basically to pay for my car and the fuel.

**Jo:** I don't have anything set up where I am now in Nottinghamshire. I have been here since Christmas but always with the intention of going back to my house in Berkshire once I get my mobility car, which I ordered in Notts. But now I have my car I have realised that I can't cope with going back to living on my own. It is a complicated situation and difficult to start from the beginning on here.

**Gail - OT:** Is your job in Notts or Berks? Regardless, I think it sounds as if you need support with where you are living at the moment. You need to ask you GP to refer you to a local service.

**Jo:** My job is in Berkshire and I'm now staying in Nottinghamshire. I'm not even registered at the doctors yet due to the intention to be going back to Berkshire. But I think I do need to talk to someone about my situation and what I need to do to protect myself, etc. I don't know whether I should be ringing someone on a disability basis or a work and the law basis.

**Gail - OT:** You can register with a GP as a temporary resident. It sounds as though you would benefit from seeing a local MS or neurological team where you are currently living. Gerry who was here earlier has offered to speak to people on the phone - he specialises in work and disability.

**Simon - MS Trust:** Gerry works for the Working Life Service - a service run by the charity Neurosupport. The service helps people affected by a neurological condition with work related issues - retaining a job, returning to work, job preparation or finding a meaningful alternative to work.

**Debra:** Working from home is GREAT where you can do this, but it can cause isolation from work colleagues, where you don't live close to work and you often end up working far longer hours. I do weekly planning (at home) on a Sunday, because I can and also work colleagues (in the USA in my case) can more easily contact you out of hours. You need to keep quite disciplined.

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**Ni:** I feel that I am in an extremely lucky work environment as the company I work for has been very supportive. However, they can only help with issues if I inform them that there is an issue. I found a good way of looking with 'fresh eyes' was to meet with my MS physiotherapist at home and just chat generally about my work, the environment, etc. Being relaxed allowed me to talk freely and allow my physio to listen and highlight potential 'fixes' without me even thinking about it.

**Gail - OT:** That's a good point. Talking things through can help you see different ways of solving issues.

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**Debra:** I work in a specialist role for a large employer. I informed my employer about my MS seven or more years ago, during which time my mobility has gradually deteriorated. My employer has set me up with a 'home office' allowing me access to work systems and I now try to work from home one or two days per week. However, I'm still not satisfied! Last year, my health deteriorated quite badly and my employer moved me to the ground floor (for safety reasons eg fire evacuation) I run a small department (four staff), which was split when I moved downstairs with my secretary. I now find it extremely difficult to run the department. As nearly all management meetings are on the first floor, I am unable to attend these, although I still receive the minutes. Generally, I am feeling a bit isolated. I know that my employer would be happy for me to work from home more, but I am very resistant to this, as I think that this would cause even more isolation. Am I being too ungrateful?

**Gail - OT:** Debra, no you're not ungrateful. I think most of us would feel isolated in that situation. Is there any scope for something like a stairlift to be installed?

Are there meeting rooms on your floor that could be used instead of first floor (this would be a reasonable adjustment)? Have you had an Access To Work assessment of the general environment in relation to your work?

**Gerry - WLS:** Debra, you may want to discuss this with your employer. On the face of it you are being excluded and may be being set up to fail. I am sure you are facing difficulties managing your team. Why can't the management meetings be held downstairs?

**Debra:** Our building was built in the 70s and has lifts, which I use (but can't in the event of fire evacuation). The work doctor has discussed my 'issues' and suggested various 'accommodations' - video conference, etc. Yes, we do have meeting rooms on the ground floor, which I try to use. The video conference room is on the ground floor, but it's out dated now. It's set up like University challenge and good for talking over video but terrible for discussions with other people in the room. The video conference room on the first floor is much more modern and better as everyone can sit around a v-shaped table so talking in the room and via video conference is possible.

No, I've not had a formal Access To Work assessment. What's involved and who does it?

**Gail - OT:** Access To Work is a government scheme, which you can apply to directly yourself. They carry out a workplace assessment and can make recommendations. Depending on the size of company and the recommendations they can offer some financial support to your employer. There is information on Access To Work on the DirectGov website (see the Resources section at the end of the transcript).

**Simon - MS Trust:** Also possibly of use, is the map of MS services on the MS Trust website which shows where MS nurses, physios and OTs are around the country.

**Gail - OT:** Debra do they exclude you from the meetings on first floor simply in case there's a fire?

**Debra:** No, I'm not excluded from any meetings. I have to go upstairs occasionally, eg recently for a staff leaving presentation and investigating a departmental IT problem. However, as discussed with my work doctor recently, no-one seems to be thinking about fire evacuation except me. I am sensitive to the issue as this is what caused my split from the rest of the department in the first place.

**Gail - OT:** I worked in a building where there was a wheelchair user on the third floor. They worked out an evacuation plan in the event of fire and he remained with his team.

**Ni:** I understand with regards to meetings, etc. Initially my office was upstairs as I hadn't told my employer about my MS having had a real bad experience with my previous employer. However, the stairs did take its toll and I finally admitted defeat. I was given an office downstairs which is much much better. However as a Purchasing Manager I do tend to have lots of meetings, which I find really tiring. BUT my MS nurse was wonderful when she simply asked me how many days a week I had meetings. I said "well, most days". The horror on my nurse's face said it all. I now hold meetings only on a Thursday (I don't work Fridays) and the maximum is four on one Thursday. This means that I have a more structured

time at my desk, don't have to get up and down all the time and although tired on a Thursday evening... it's the end of the week.

**Gail - OT:** Good point. Sometimes you have to be a bit more controlling over what you can control, and make things work better for you. It's frustrating and often exhausting, but you have to be the leader and perhaps be more focussed on your needs than you would naturally be. This means you may have to decide what works and making it happen.

**Debra:** I've looked at the DirectGov website and have used the Access To Work scheme in the past (they provided finance for my home office chair). However, their services appeared to be limited to applications for grants and funding and I found the whole process quite dispiriting, as the people just seemed to want to know 'what I wanted money for?' I didn't realise that they could carry out a workplace assessment. Is this right or is it an OT that I need to contact?

**Gail - OT:** Glad you got your chair out of them - you wouldn't now! They can do very thorough assessments, and are used to working with employers. OTs can do this but, some are more confident in this area than others, and because Access To Work is a government scheme, they can seem more 'official'. I'm happy to do workplace visits but the employer has to agree for me to go in to the workplace, and they are under no obligation to act on my recommendations.

**Debra:** Re: finance for the chair. I know that I was lucky. My application was submitted barely 14-days before they stopped this type of finance.

**Geoff:** Has this been a victim of the cuts?

**Gail - OT:** From October 2010 they changed the range of equipment that they would supply. Things like office chairs are now deemed as standard equipment and so are regarded as responsibility of the employer. Last year they said they were increasing funding to Access To Work, so this may just be a way of making the budget go further.

**Debra:** Ni, it's nice to know that "others" have had this problem too (and your meeting schedule sounds much worse than mine!) Something work did do, which is great, is that my department now has a dedicated meeting room next door to me, with computer and widescreen. I'm trying to encourage use of this facility as much as possible.

**Ni:** Yes, the computer, screen, etc has also been added to the meeting room I use and it saves having to carry lots of books and paper around. Although the room itself is over the other side of our site, I ensure that all my meetings run one after the other. The toilets are next door and the receptionist always ensures that there's tea and coffee for my visitors (and me!) so I don't have to worry about that. But if you want Debra I will swap my meetings for yours.

**Debra:** Goodbye all. I have to leave now, but I may try and get back later.

**Gail - OT:** Bye Debra, good luck.

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**Ruby:** I have a question and hope you can help. I have MS and problems standing, walking, fatigue, etc. I managed to secure a job as a resident manager at a retirement complex some five years ago which suits me fine apart from one part of the job. I am required to clean the guest suite after use. I can not do this due to my health, so I pay someone to do it for me. If I inform the company of my condition, would they be able to ask me to leave because I can not fulfil my role entirely or am I in a position to ask for assistance. The financial strain is becoming a burden but I would rather continue to pay than be forced to leave because I would also lose my home. I hope you can help advise me.

**Gail - OT:** Ruby, that's a tricky one. How often is the guest suite used?

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**Bill:** Is it sensible to tell a potential employer about MS when going for a new job? Day to day, my MS is fine and I haven't had a relapse since the start of last year.

**Gail - OT:** If you have to complete an occupational health questionnaire, you have to be honest. Beyond that it's personal judgement. The two tick symbol means that companies have to interview any disabled person who meets the criteria, but that requires you to declare. On the new info pages I think there is something about disclosing to an employer.

**Simon - MS Trust:** The MS Trust has a book called *At Work With MS* which has information on disclosing diagnosis.

**Lynn - MS Trust:** We also have further information in the Work Toolkit on our website (see the resources section at the end of the transcript).

**Ni:** I didn't tell my current employer (I've been there 11 years now) until six months down the line when I knew I was having a relapse. This was purely due to my previous employer handling my illness and requirements in an awful way. My current bosses were sympathetic although nervous of what MS actually was/is. They listened to my side of things, asked relevant questions about both me and their obligations and from then on have been nothing but supportive. However, thinking about it all again now, if I was going for another job I don't think I would tell them until I felt secure and knew the bosses a little.

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**Linda:** I have to go through a formal assessment process to activate the permanent health insurance my company provides. I am concerned about the potential for the company to use this as a way to downgrade or redeploy me. What can I do to protect myself? We don't have a union so, although I am allowed representation, I don't know who to ask.

**Gail - OT:** Linda, is this insurance process new, or is it because you're having problems? If you are managing your job with no problems, there should be no reason to change your job. In terms of representation, most employers allow friends or family, though beyond moral support they may not have much to offer. There is an organisation called the Disability Law Service which gives free advice.

**Simon - MS Trust:** You can find information and links to the Disability Law Service and the Working Life Service in the Resources section at the end of the transcript.

**Gail - OT:** You can also ask your OT or MS nurse to write a 'to whom it may concern' supporting letter which you can use as you want.

**Linda:** Thanks. My condition is getting worse and I am having difficulty with the stress in my job. Also due to change of ownership, the permanent health insurance is going to disappear as a benefit. I need to activate it now as once I am on it they can't take it away. I just don't want to lose out too much in the process.

**Gail - OT:** I think you have to weigh up the risks and benefits of activating the insurance. At a distance it's hard to advise one way or another. It might be helpful to discuss this with your OT or MS nurse. They may also be able to suggest things to help you in your work too. To help with stress it might be useful to see if you can access some support with stress management either through your GP or your rehab team.

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**Andrew:** I'm looking at a business consultancy role after a gap of two years not working. I have primary progressive MS, so things are very different physically. Two questions:

1. Can I charge my services out from a limited company without taking a salary from this without it affecting my current benefits? My reasoning behind this is because I really don't know what hours I'm capable of working any more and it is likely to be a fairly flexible arrangement with out set hours.
2. I'll work mainly from home at a desk. Who is best to advise on the chair / desk arrangement in order to reduce fatigue?

**Gail - OT:** Access To Work can give you advice, which includes where to get their recommendations. I don't know what financial support they now give to self employed people - you'll need to check. An OT could also give you some advice about your workstation.

As far as your first question goes, I think you would need to discuss this with someone who understands self employment and benefits. Again the Disability Law Service may be able to help, and also the Working Life Service may be able to advise.

**Lynn - MS Trust:** There is also more information about the things you might want to think about if you are considering self employment as an option in the focus on work pages on the MS Trust website (see the Resources section at the end of the transcript).

**Gail - OT:** Self employment can be tricky in that if you know what a job should cost, eg in terms of how long it should take, but find it takes you longer, you need to think about what that also means for your income. For example, if you only charge people for eight hours, but the work takes you 16 hours, you are effectively working for half the rate you advertise.

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**Lynz:** I was diagnosed with relapsing remitting MS six months ago. I have recently started a phased return to work, working from home as the last relapse affected my ability to walk. I am now facing redundancy. This is not due to the MS - my employers have been great about that - but due to work drying up.

I am now in a position where I need to start looking for work. I'm on beta interferon and having fluey side effects. It doesn't do anything for the symptoms, in fact, it makes me feel worse. I tried glatiramer acetate (Copaxone), which improved symptoms a lot but I reacted badly to it. I'm in a very uncomfortable position as I don't know what to do to ensure I can secure a new job and hide the drug side effects. Do I tell future employers about MS and risk my CV just getting thrown out before they look at it, or keep it quiet so I have a higher chance at getting a job? Then there's the issue of finding an employer who understands the condition.

I've already lost my health and now my job, and I'm worried about losing my home as well (mortgaged, not rented). The future is looking bleak so any advice on finding new employment would be great.

**Ellie:** Hi Lynz, I totally sympathise. I am dreading starting medication because of the side effects, but need to stop all my relapses. I am worrying about work, which is also very quiet. and fearing the worst next month when we are due to have a meeting. I have the feeling I'll be first to go. They understand about my MS have been great, but last in, first out etc. I have been worrying about my pay and have been off over a week now with just statutory sick pay. I'm also in the same position with my home.

**Gail - OT:** Telling employers is difficult. There is information about disclosing your diagnosis to your employer on the new Work Toolkit pages [see the Resources section below]. Having read through that I would suggest you talk it through with someone before deciding what to do. If you're asked in an occupational health questionnaire if you have a medical condition, you do have to be honest.

**Lynz:** Ellie, I completely empathise. I never thought I'd end up in a position like this either. I am currently awaiting pay day after being on statutory sick pay for a while. This will mean I can finally afford the prescription for the other medication and painkillers I should be taking which sick pay and DLA (disability living allowance) doesn't cover as they're eaten up by bills.

**Gail - OT:** Lynz, you could talk it through with either a health professional or Disability Employment Adviser (DEA). They both have strengths. DEAs don't know much about specific neurological conditions but will know lots about work. For health professionals the reverse is generally true! I have accompanied people to a DEA appointment if they thought it was helpful.

**Lynz:** I assume you would mean my MS nurse or GP to talk to and get advice? Or would I need to go to my local Jobcentre Plus for advice from an employment adviser?

**Ellie - WLC:** I found the DEA rather useless when I was wishing to return to work - suggesting jobs for me that were practically impossible in my new body. Rather frustrating. I was looked at in bewilderment when I said I was returning to work. I don't wish to drop out just because my body is less cooperative.

**Gail - OT:** As I said, DEAs don't have specific knowledge of neurology or MS, so can struggle. That is why I'll go with some of the people I support.

**Ellie:** I'm having a horrific week. I had a second relapse in eight weeks last week with IV steroids to treat it before I start medication. Anyway, I have a really sharp pain in back and been to the doctor to be told I've got sacroiliac joint dysfunction. They said it's nothing to do with my MS, just a coincidence. I have been off work for a week and a bit now and only get statutory sick pay. The pain is stopping me from sitting up, etc. Can I apply for DLA with MS and this other condition?

**Gail - OT:** I would think it's worth applying for DLA, it might be helpful to see if your local council have a benefits advice team who could guide you through the maze of benefits.

**Lynz:** If you don't already get it, DLA is worth applying for. In my case it has reduced the amount of debt I'm running up while being ill, though I would rather be using it to pay for the medication I need! Good luck with your DLA application. When I did mine I was mid-relapse and found it helpful to describe everything in my own words when I was feeling my worst. With MS, only you know how you will feel from one day to the next and it's not always easy to clarify symptoms on paper.

**Ellie:** Thanks.

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**Aled:** I'd like to work, but can't reliably commit to doing two consecutive days. I am a chartered surveyor and have been working for myself, but find it very difficult to have any pattern. Being self employed is no good as I just let myself down, and working for someone else is a non starter for the same reason.

If you are employed then it seems that your employer needs to be flexible but getting employed with MS is impossible as you just can't be relied upon. Fair enough, I think, as this is the minimum an employer requires. It just leaves you in a bit of a hole.

**Gail - OT:** You're in a really difficult position. Can you work more than one day per week on non-consecutive days, or when you work do you tend to do long hours? It might be helpful to think about discussing fatigue management (if you haven't already), although implementing fatigue management strategies can be very hard in relation to work.

**Gerry - WLS:** You might want to look at what you can do and what skills you have to offer. Access To Work will support self employed people. There is a programme called Permitted Work where you can earn up to £95 per week without losing benefit if you work under 16 hours. Your DEA (Disability Employment Adviser) will advise you. There is also supported permitted work where you can do a couple of hours work for £20 per week indefinitely. The permitted work programme is only for 12 months. The supported permitted work programme needs a recognised support agency to sign up to support. We at Neurosupport have done this for clients in the past.

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**Jane:** Employers should be made aware of the symptoms of MS. I was sacked for having MS. My mistakes at work were due to memory and stress. Neither of these were discussed or helped, in fact they piled on the stress which made it worse.

**Gail - OT:** Jane you've had a horrible experience. Are you trying to find another job? You can always ask to see the Disability Employment Adviser at the Jobcentre who can offer more support than the general Advisers.

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**Ella - WLC:** I have secondary progressive MS and work as an employment adviser in a charity supporting physically disabled adults. Since becoming disabled, getting this job as employment adviser here was one of the best thing that's ever happened to me and certainly the only good thing that came about by becoming disabled.

**Gerry - WLS:** Hi Ella, what does WLC stand for?

**Ella - WLC:** WLC is the company I work for - White Lodge Centre in Chertsey, Surrey.

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**Jim:** Can you tell me more about Disability Employment Advisers? I'm feeling a bit trapped in my current job. It's at a small place and they've been very accommodating about my MS and the surprises it can throw. Professionally it's time to move on, but I'm not confident that someone will be willing to make the same allowances as my current work when I'm battling for a new job.

**Ella - WLC:** It's a tricky one. What's making you feel trapped? I think you've got the right word with 'battle'. Even those individuals who aren't hampered with a condition such as MS are battling to find work currently.

**Jim:** Ungracious as it sounds, I feel trapped by the supportive nature of my current job. Here they have been very accommodating and have adapted to cope with my MS. But professionally it's time to move on.

**Gail - OT:** Disability Employment Advisers work in the Jobcentre and are there for people who are in work, as well as those looking for work. As you say "professionally it's time to move on", is there an independent person you can get confidential advice from with regards to your specific job so you can talk through the options? At the end of the day you'll have to weigh up whether you want to take the risk. However, never resign from a job until another one is completely settled.

**Jim:** Quite right, Gail, don't move on without having somewhere to go. It's just I have restless feet at the moment (career wise)

**Gail - OT:** Having MS doesn't mean you lose your ambition. It's important for all of us to have a positive challenge. That's why I suggested talking about your specific career might be helpful as different professions have different demands, which can be more or less flexible.

**Jim:** Thanks, that's good advice. I think it may be a comfort zone thing and although I think it's time to change, I may be putting up barriers for myself. I shall find people to help me explore my options. Thanks.

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**Linzi:** I was working self employed as a hairdresser until I gave up in January due to my symptoms. I have eyesight loss, which as returned, have real bad fatigue, and trouble with walking and balance. I got diagnosed with MS in April. I'm a bit confused by it all. I was claiming ESA (Employment and Support Allowance) but I've now been told I can receive it no more as am fit enough for work. But I know I'm not. Can you claim any other benefits for MS? I'm so confused.

**Gail - OT:** ESA seems to be a widespread problem for people with neurological conditions. If you are in time, you could try appealing and ask for your medical to be carried out by someone with expertise in neurology, rather than a general person. You could also go to a tribunal. In my area our local welfare benefits team support people through this process, but you could ask Citizens Advice or the Disability Law Service for help.

**Ella - WLC:** In terms of benefits, I would have a word with your MS nurse. If she's anything like mine she'll know the way to go. You should be absolutely entitled to Employment Support Allowance - after all it's not your problem that they don't understand the condition.

**Linzi:** Thanks for your advice I shall look into it.

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**George:** Some days work can be a real slog, with my mind growing fuzzier and my legs heavier. Should I think of giving up working? Will choosing not to work affect benefits etc? Where can I find out more?

**Gail - OT:** Have you had any help with fatigue management? Or other symptom management support?

Before you give up work you need to think about whether you could carry on with support, changing your hours, changing your duties etc. You could talk to a number of people - OT, MS Nurse, Disability Employment Adviser (DEA), Access To Work, Occupational Health. Who you start talking to depends on your personal situation. Access to benefits if you voluntarily stop work is complicated and you should take specialist benefits advice. However benefits generally mean a lower standard of living than working.

**George:** Thanks. Some days you find yourself thinking that the effort of working isn't worth it. Bad days I guess.

Another thought - if your performance at work is not what it should be, you need to ask for help from a disability perspective sooner rather than later, particularly if disciplinary processes are raised. Sometimes rearranging what times of the day or week you do things can help. Also there are specific strategies or equipment that can help you, for example using a dictaphone or digimemo to help you remember things, using your phone to remind you, etc.

Some of the other people who took part earlier have used some different ways of managing their work which has helped, have you had a look at these?

**George:** Thanks I'll have a read.

**Gail - OT:** And another thought - sometimes if it feels like you're just living to work, try and find some small things to look forward to each day or each week. This could be listening to or watching a favourite programme, spending half an hour on a favourite activity or hobby, and making sure you prioritise it.

The StayingSmart website also has some useful suggestions for working with cognitive problems.

**Simon - MS Trust:** We also had an article in the May 2011 issue of our Open Door newsletter from someone who appears on StayingSmart and who was affected by cognitive symptoms at work.

**Lynn - MS Trust:** The recent World MS Day also had some examples of how people managed their cognitive problems in the workplace.

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**Simon - MS Trust:** This chatroom is happening during MS Awareness Week. The MS Trust is using this to focus on employment issues. The focus on work webpages include links to more resources about working with MS and some videos of people with MS talking about how their own experiences. There's a video of Gail there too. See the Resources section below.

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**Patrick - OT:** Reading through it strikes me that it remains a struggle to get the most useful information to people at the best time, especially around work.

**Gail - OT:** Accessing information seems to a constant problem.

**Simon - MS Trust:** It does seem to be a problem in so many aspects of MS, but particularly so with work issues.

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**Judy:** One of the significantly difficult issues regarding work with MS has been the reluctance of employers to grant 'medical discharge' to people with MS. This related predominantly to statutory employers and state organisations. They try as hard as possible to get out of paying their dues and in this connection people with MS really need help. Do you have thoughts on this?

**Gail - OT:** Medical retirement has become more difficult over the years for all problems, not just MS. Larger organisations often have more capacity for redeployment in theory, and probably try and explore all other routes first. It's very tough though when people are really struggling and seem to get taken down the capability route.

**Patrick - OT:** It's an interesting suggestion but my experiences (anecdotal) don't support the contention. One police service retired a person with whom I was working with indecent haste! The settlement package meant it wouldn't have helped using employment law.

Where the NHS is concerned it partly depends on the manager and also there are more redeployment opportunities, so accessing ill health retirement and the pension is more difficult assuming that's what someone wants to do.

Ultimately being employed is better for anyone's general health, though I've had some very successful outcomes for people whose jobs couldn't be adapted.

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**SK:** I was made redundant back in January. The work / life balance was good, I was in a full time office based job where I worked from home two to three days every week.

Now I am struggling to find even a part-time role. When application forms ask if you have a disability and if so what and does it affect your work?, should I declare that I have MS? Naturally I am feeling down about this. It seems that having a child and MS does go against you in the work place.

**Patrick - OT:** Although it can feel difficult, I advise people to declare their diagnosis simply because if you don't and then get the job, you are even more conflicted if you have a problem. There is quite a lot of protection under the declaration process and it may even improve your chances of interview.

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**Les:** I've applied for a number of jobs recently and got nowhere. In my darker moments I'm torn between thinking I'm not good enough for the jobs and feeling that my MS is being used against me. Although no sensible employer is going to say that they turned someone down because of their MS, is there any recourse under the Equality Act, or should I be less paranoid and just have to keep plugging away with applications?

**Gail - OT:** At what point are you being turned down, or does it vary? In our local vocational rehab service we've found that, as the job market has got harder, even getting people voluntary jobs is becoming harder due to all the competition from the 'well' unemployed.

**Les:** Sometimes at the application form, a couple of times at first interview.

**Gail - OT:** Did you ask for some feedback from interview? This can be hard as you're already feeling rejected, but if there is something you could have done better it would be really helpful to know.

**Patrick - OT:** At first interview I'd want to ask what I could have done to be considered for the next stage. At least that way you'll get some feedback on your performance. It's very hard when the job market is so competitive.

**Gail - OT:** The advice we give to people when completing application forms is to make sure it sounds as though you're applying specifically for that job, rather than copying and pasting into multiple applications. You can tell if someone hasn't shown they've read the information about the job. It's about making the best possible first impression and standing out from the crowd - and some days there is a huge crowd to stand out from.

**Les:** I always ask for feedback and try to take on board the lessons. But I have failed to get further than a first interview for some time. It's the nothing specific 'high quality of candidate, etc' type of feedback that makes the dark side of me wonder if the MS has been a factor.

**Gail - OT:** That sounds like not particularly helpful feedback. It takes guts to give honest feedback (speaking from experience) and I expect an awful lot of people don't want to do it. How do you feel the interviews went? Were there things you thought weren't too good?

You could try approaching the Jobcentre to see if you can go on a course to help with interview skills (if they have one) and use this to get some feedback on how you are in interviews.

**Patrick - OT:** I'd come back on that type of generic statement and ask for specific advice on what would have made you that 'high quality candidate'. What was the main factor that differentiated the successful person?

**Les:** Thank you - useful advice both. Trying to be objective, I suspect it's a double battering of my fragile confidence - not getting the job and having MS. Maybe being more proactive would help.

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**Sue:** May I ask, if a person is self employed and works on an invoice only basis with companies, should they be disclosing their MS? I have not had an actual diagnosis to date. I am under a MS specialist who I don't need to see for another two years due to no further relapses.

**Patrick - OT:** It really depends if it is affecting your work or ability to meet the external deadline.

**Sue:** No it's not, Patrick. I haven't had to complete any forms of late but in the past I have had medical forms which ask if you have any medical conditions. I feel that I can legitimately say no as I haven't formally been diagnosed. I have had all the usual scans and lumbar puncture, which did show proteins in the spinal fluid.

**Gail - OT:** As Patrick says, it depends if it's affecting your work. If it isn't, there isn't really any reason to tell them. Particularly if you don't yet have a formal diagnosis.

**Patrick - OT:** I wouldn't necessarily disclose. Your way of working is effectively as an independent contractor, so you are your own company. Customers don't need to know how the job's done, only that it has been done. Perhaps if you took on a big bit of work with critical deadlines you might want to have a conversation, but again if your MS is settled and managed then it shouldn't have that much influence.

**Sue:** That's great, thank you both. I feel a bit better thinking that I haven't mentioned 'it'. I would hate to be discriminated against as I am very fortunate to be able bodied and, aside from fatigue, I manage my symptoms well I feel. I just feel a little guilty for some of the colleagues who I haven't disclosed to as I have a really good working relationship and almost feel like I'm lying a little.

**Gail - OT:** Don't feel guilty. Your health is a private matter and there are no rights and wrongs over who and when you tell. Good luck with your ongoing business!

**Patrick - OT:** There are no hard and fast rules about disclosure. There may come a natural point where you want to tell a colleague but I wouldn't feel guilty in any way. Our health is very personal.

**Patrick - OT:** Looking at Gail's simultaneous responses I'm worried OT training has somehow cloned us!

**Gail - OT:** Patrick, I think we differ in some important ways! But it's good we're not contradicting each other.

**Sue:** Thank you once again to you both. I'm off to do some paperwork now!

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**Jane:** I was diagnosed in January and have been off sick since then. Been trying to get back with a phased return since the end of April but my employers have delayed this and said I couldn't go back until they had an occupational health (OH) assessment report. I saw OH in early May and have just been told I can go back next week. I have not been paid since the middle of April but not been allowed to work. Is there anything I can claim as I will be receiving statutory sick pay only this month despite being delayed by my employer?

**Gail - OT:** You can't get ESA (Employment and Support Allowance) until your statutory sick pay has run out, and that isn't a lot of money either. If you are worried about money and debt you can always get advice from the Citizens Advice Bureau.

In one way it's positive that you've had an OH report that says you are fit for work. The down side is the length of time it takes. I hope you have a good return to work plan that allows for you to increase your hours at a pace that works for you.

**Patrick - OT:** Although it is frustrating it sounds like your employer is trying to give you the best chance of a return to work and thus being paid again.

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**Tracey:** I am a qualified dentist and physically can't work anymore as I can't feel my legs and feet and so I feel it is a bit dangerous to drive a drill. I find myself in a position where everyone looks at my qualifications and then doesn't know what to suggest about a move to a new job. Can you help at all?

**Patrick - OT:** Have you thought about seeing if there are any management opportunities with the local PCT or health provider that runs dental services?

**Tracey:** I have tried that, but as you probably know, apparently there isn't that much money kicking around in the NHS! I'm just a bit frustrated and not sure which way to turn.

I've got to go for another ESA (Employment and Support Allowance) assessment and I think they may say that I can work, and make me do anything rather than let me use my skills. Does that make sense? Really worried about what they'll make me do.

**Patrick - OT:** It's a balance of being realistic about your MS in the assessment. Most people want to give a good account of themselves but need to describe what they can do reliably in the context of work.

A document on the Tameside council website shows the way the ESA assessment is scored [see the Resources section below].

**Tracey:** I guess I just go along and not pretend I can leap around like I used to. I now have to drive an adapted car as I can't use the pedals, so I don't feel it

would be that safe to drive a drill turning at 100,000 rpm in someone's head!  
Fingers crossed they see that logic.

**Patrick - OT:** It is an awful dilemma that to get what you need out of the system you have to 'turn up the contrast' on your condition and think that it is getting worse. Although work is good for us it has to be something we like doing. I'm also using the term 'work' in its broadest definition and really mean occupation or doing stuff. Even if your income is benefits, that doesn't preclude doing something useful in other ways.

**Tracey:** Thank you! I hate to moan, but do worry! I'm sure I'll find the right thing to do. I guess I just keep smiling and be glad that I'm not looking into grubby mouths anymore!

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**Simon - MS Trust:** A comment sent in in advance talked about benefits and the aging workforce.

"Primary progressive MS is not usually diagnosed until people are in their mid to late 50s. As the name suggests, the problems associated with primary progressive MS usually get worse as you get older. The mobility grant, of the Disability Living Allowance, has a fixed cut off at 65, whilst the primary progressive MS may still be progressing along quite nicely."

Attendance Allowance is the equivalent benefit for people applying over the age of 65, but this has no mobility component.

**Patrick - OT:** I wouldn't attempt to defend the vagaries of the grant, which are unfair and, I suppose, based on the previous assumption of society that someone over 65 with a disability won't need to go out independently. It's a way of containing costs and is unfair to everyone over 65.

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**Lynn - MS Trust:** Is there anything you think is really important for people who have MS to be aware of in the workplace?

**Patrick - OT:** I think the biggest issue for me is the assumptions people make about MS - and I include the person with MS, usually their GP and their employer.

The default thought is 'I / you, will have to give up work' because it's the same process that the lay public go through. If people could seek advice and support as early as possible, even before they have symptoms that affect work significantly, then they can plan how to manage their employment and use the legislation in the most effective way. It is much, much easier to remain employed than to get back into employment and large organisations often have redeployment processes that can work well.

**Lynn - MS Trust:** Thanks Patrick. Gail also addresses this in a video on Focus on Work pages (see the Resources section below).

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**Sharon:** My problem may be silly. My work place has been very good with me since I found out I have MS. They have let me change my hours, so I can afford time off to go get my Tysabri medication. But the new hours I have mean that they shove lots of work on to me before I leave. This is making me so tired. Now they know I will try and do everything as I did before, which I do. They also know I struggle with tiredness. I can't afford to lose my job. How do I go about saying I can't keep up with it?

**Patrick - OT:** It doesn't sound like it is 'I can't keep up with it' but more that the way the work is coming to you that is making it more difficult than it needs to be. I would broach the issue around the idea of pacing and that it doesn't help to give you lots of tasks towards the end of the day. There needs to be an agreement about what is doable in a day and that if work is given to you after a deadline in the afternoon it may/won't get done until the following day.

**Sharon:** Thank you - I'll go check that out.

**Gerry - WLS:** Some of your problems are in your doing. I understand that you are a conscientious worker but it is about your condition management now so you can continue working. In order to have a chance you must manage your condition during work and outside work hours. In my experience, one can't work without the other.

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**Denise:** I am currently claiming contributions based ESA (Employment and Support Allowance) and have been doing permitted work off and on for nearly a year. Apparently, after the year, I either have to give up the job or ESA. I am in the work related group, despite having primary progressive MS. I want to continue working as and when. I am working for the NHS in a very assisted and supported environment, which gives me a focus, but there are times when I do not feel well enough to work, so it would be good to stay on ESA. My doctor supports me on this, but the DWP say that the rule is that you can only do this for a year. Can you suggest anything please?

**Gerry - WLS:** As stated earlier, permitted work can only last for one year but supported permitted work can go on indefinitely. The draw back is that you can only earn £20 per week and must be supported by a recognised support body.

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**Jill:** I have been diagnosed for 18 years and am still working full time. In the future, if I'm in a position where I need to work reduced hours or take early retirement through ill health, how can I make up my earnings so I do not lose out financially?

**Patrick - OT:** There isn't really a way to completely mitigate the financial impact of reduced hours or early retirement as both reduce income. If it falls below a certain level then there is the benefit system and tax credits but that is a safety net. As you are still working full time and it is an 'if' question, my advice would be to use independent financial advice to plan for different scenarios and points in your working life.

**Gerry - WLS:** It may be a good idea to speak with the pension people and ask about retirement criteria on ill health grounds. Not all pensions are the same. To discuss reduced hours should be no more than speaking with the employer. It might be a good idea to speak before it becomes critical.

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**Lynn - MS Trust:** Do you have any guidance on the most successful way to approach negotiations with an employer, for example around reasonable adjustments?

**Gerry - WLS:** I have found that introducing support from the likes of the Working Life Service to the employer as support for them as well as the person with the condition opens doors. The employer either lets us in or starts to take interest in the client. It is always good to remember that the employer could be a loss as to what to do.

**Patrick - OT:** I agree with Gerry. Often the biggest problem is the ignorance of both managers and even high level human resources. At best it is theory to start with and there is a lot of basic education needed about the diagnosis.

**Gerry - WLS:** I find that once discussions have started, I can develop a degree of control of the support and take the lead. Clients will start to become less stressed and manage things a bit better. It is a bit more complex than that in reality but basically I find it works in a lot of cases.

**Lynn - MS Trust:** Can you tell us more about the Working Life Service and how people might get in touch with you?

**Gerry - WLS:** We are not OTs or medical but have lots of experience of talking and educating employers around working with people with neurological conditions. Also we speak to people about alternatives to employment, something that has shown itself here today. People can contact me on 0151 298 3288 or [gerry@neurosupport.org.uk](mailto:gerry@neurosupport.org.uk).

**Simon - MS Trust:** Does the Working Life Service cover the whole UK, or are arrangements different in England, Wales, Scotland and N Ireland?

**Gerry - WLS:** We cover all the UK for advice but our direct contact with people is based in Merseyside, North Wales and Cheshire. We are in discussion with other charities, including the MS Society, to see if we can offer service physically on a national basis, so watch this space.

**Patrick - OT:** I think the role you describe is critical since it opens up a proper dialogue with the employer. If that relationship is managed well it pays off for both them and the person with MS.

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**Diana:** I live in a small town on the Isle of Man and recently went for a job. The first question I was asked was "Do I have any illnesses?" I thought it was strange to ask me that question as I thought they were not allowed to put it so blatantly. I would have told them anyway as I feel I have nothing to hide. Surprisingly I didn't get the job. Because it is a small place, I think they had been told before hand. What is the law across there?

**Gerry - WLS:** My understanding is that the job centres have DEA (Disability Employment Adviser) provision on the Isle of Man. I have been asked before to speak to people on the island who have Parkinson's, so feel sure there must be some provision. The DEA will have access to agencies paid by the job centre to assist you with this barrier.

**Patrick - OT:** In the UK it isn't acceptable to use the question 'Do you have any illnesses?' in an interview. It is obviously discriminatory and there is strong

employment legislation to ensure people are treated as equally as possible. Having an illness isn't an automatic disqualification for a job.

**Gerry - WLS:** If some research is done on the company before the interview, it may be clearer if they are disabled friendly or equal opportunities employers. My understanding is that employers cannot ask direct questions in this manner unless it has a direct effect on the role. Some charities recommend that you don't disclose until you are offered the job. It is a good idea to ask questions in interview that can help the person form an opinion on the prospective employer.

**Lynn - MS Trust:** Was this one of the changes that the Equality Act brought last year and is there anything else it would be useful to know about this legislation that replaced the Disability Discrimination Act?

**Patrick - OT:** I'd have to check. I was more coming from the general principle and spirit of the law. I would correlate the question about illness with asking if someone was planning to have children or how they would look after them while at work.

**Nazia - OT:** The Disability Law Service have published a summary of the Equality Act along with other helpful material which might be of help. They have a whole section on MS which is very useful. You can find this on the factsheets page of the DLS website.

**Simon - MS Trust:** The Equality and Human Rights Commission also has good information about the Act (see the Resources section below).

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**Mike:** For me, the more formal side of things - talking to my employer about MS, getting changes in hours and a few other adaptations - went fine. The difficult bit was talking to my colleagues, who saw me as getting preferential treatment for no obvious reason. Had I had a wheelchair rather than fatigue and a dodgy bladder, it might have been easier. Any hints on how best to talk about MS to others in the office?

**Gerry - WLS:** Depending on where you live and what services are available, it may be a good idea to discuss awareness training with your employer with the focus on general disability and to introduce MS within the training. Let me know and I will look to see if I can develop something for you.

**Patrick - OT:** It's a problem when the main effects of a condition are invisible. I'd start with colleagues you trust most and give them gradual information if they are interested. Depending on how open you are, you could leave a basic what is MS leaflet around. It's amazing what gets read in idle moments.

**Simon - MS Trust:** The MS Trust's *MS: What Does It Mean For Me?* or *MS Explained* might fit the bill.

**Patrick - OT:** One person I worked with used raising money for the MS Society through sponsorship as a way of raising the issue, rather than it being specifically about his diagnosis. When people talked about what he was doing that was his in to talk about MS.

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**Laura:** I have primary progressive MS and currently work 40+ hours per week. I work these hours as I have bills to pay (most importantly mortgage) and a family to keep. If I were to drop one day (due to exhaustion), are my working or tax credits likely to be increased?

**Patrick - OT:** Best to talk to the benefits people but I would expect that if you already qualify for tax credits, it would increase to compensate for the reduced income. Best to check as this is not my area.

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**Sharon:** I work full time in the NHS as a school nurse. I have asked to go term time, which means I will have regular set holidays and unpaid leave while still working full time but being paid for 33 hours a week. My employer has said no and that they think I would get more benefit from annualised hours, where I get paid 33hrs and essentially work flexi time but without school holidays. Basically, I want to know if by making an offer that they as managers feel is best, does this count as a reasonable adjustment and that's it?

**Patrick - OT:** That's a difficult one as they need to run the service and I guess don't want term time contracts. From a pacing point of view, they are offering a solution which should work. It is best to have an even spread of work rather than episodes of higher demand. I am not sure how you'd argue that a term time contract was more reasonable as it effectively has less flexibility?

**Sarah - OT:** In your Department is there available cover when you want to be off?

**Patrick - OT:** Sorry, another question - is heat and summer worse for you?

**Sharon:** Colleagues I work with have term time and there is cover via other full time staff for holidays. Also, yes, my symptoms are worse in the heat. I don't know if that counts in Scotland though. 😊

**Patrick - OT:** It may give you a bit of leverage with the employer in that the warmest months under a term time contract are when you wouldn't be working. It doesn't feel like a particularly strong argument but may work. From the OT and pacing point of view, I would be likely to recommend the annualised hours contract as it spreads work out and offers flexitime. This doesn't mean it is a better solution for you as there will be lots of other factors like child care that will impact on which strategy is best.

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**Stephen:** Been diagnosed for less than a year so everything is still quite new. I wonder if anyone can help.

I am still OK to work full time and I'm paid quite well. All the books say that as soon as you are diagnosed with MS you are automatically classed as disabled. Is there somewhere I should register as being disabled? My MS nurse says I should get a Blue Badge. I have tried and been refused. What next? It would be a help on the days that I am bad. I have kids so most of the time I can park in parent and child bays anyway.

**Nazia - OT:** When you say 'on bad days this would be helpful', what would a bad day entail for you? Is it fatigue that is impacting your ability?

**Stephen:** Mainly it is my legs that give up. They feel like lead and I can hardly move them. If I do have to struggle back to the car while in this state I end up in bed tired out and sleep for four hours.

**Sarah - OT:** Have you seen anyone else but an MS nurse and where was she based?

**Stephen:** I'm in limbo at the moment. I was with a Nottingham nurse but care transferred to Derby from April. I'm seeing my new nurse and doctor for first time on Friday.

**Sarah - OT:** It would be helpful to get a referral to see a neuro-physiotherapist and occupational therapist. They should be able to assist with appealing the blue badge decision with your GP.

**Patrick - OT:** Being diagnosed isn't a passport as, quite rightly, things like blue badge assessments are based on the functional impact of the condition. I usually discuss with people with MS how they would manage on a bad day rather than a good one and then trust they'll use the badge when needed.

There is no reason to register as disabled. Local authorities have tended to abandon the practice.

**Stephen:** Like I said this is all new still and there appears to be loads of information out there. People tell you lots too, but I wish there was a form that said, if applicable,

1. Inform Local Council.
2. Inform DVLA.
3. Inform employer, etc etc.

Most of the time we use parent and child parking anyway and we hate it when we see people pull up without kids and use those bays. So I would not abuse a blue badge. I just wish it was easier to get because I've seen other that have them and really shouldn't.

**Patrick - OT:** Sorry, I didn't mean to imply any criticism or judgement. I think you need the badge from what you've said but people find it difficult to describe their worse days at assessment.

**Sarah - OT:** I think it might be useful to go to your Friday appointment with a list of either questions for the nurse and doctor and work from there.

**Stephen:** I was recently having physiotherapy at my local hospital but stopped while I had issues which changing from gabapentin to pregablin. But I will be starting up with them again soon as I'm now OK with the dosage. I will talk to them. It's good to know that, as I just thought that they would have asked my local GP. I'm not sure if he even knows that I am with the physio team, so that could have been a factor for being refused.

Thanks for advice.

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**Carol:** Part of the thing with looking for reasonable adjustments is knowing what is available. I realise that part of it is identifying the specific problems and working from there, but is there some resource that suggests the sorts of things that may be available in different circumstances?

**Patrick - OT:** Reasonable adjustment is hard to define as it depends so much on the job. It is reasonable to adjust a sedentary office based job in a large company quite a lot. It isn't reasonable to adjust a job such as a pilot's since you have to be physically able to get into the plane and use the controls.

**Carol:** Fair point. But for instance, there are things like fat pens that are easier to hold. I wouldn't have known there were such things to ask for had a friend not had one. Not major readjustments, just little things that make the job a bit easier.

**Sarah - OT:** That sounds like you could have benefited from seeing an OT! I have had people who have been to our local MS Therapy Centre and tell me how much they learn about gadgets, or useful tips for sometimes dealing with the small things, which all mount up to help!

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**Debra:** You mention the benefits people have had from seeing an OT and your local MS Therapy Centre. We have an MS Therapy Centre in the town where I live and I've never been - too busy at work during the day - but maybe this is something that I should investigate further.

**Sarah - OT:** Some of the Therapy Centres do evening sessions or meetings just for this reason. It's maybe worth giving it a try.

**Simon - MS Trust:** To help you find if there is an MS Therapy Centres near you, they are included on the map of MS services on the MS Trust website.

**Debra:** Yes, I only found out that my local therapy Centre have some classes on a Saturday. I work about 45 minutes away from home and I'm always frustrated that so many events, etc take place during the day or early evening. I really must find out what's available and accessible for those who still work.

**Sarah - OT:** Good luck with your searching. It sounds like you have got your work-life balance right. It does take some practice, doesn't it, and definitely discipline as you say!

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**Simon - MS Trust:** I'm not sure people always know what an OT can do for them. Presumably it's not all about major changes and adaptations and often smaller items, such as Carol's pen, can make a difference.

**Sarah - OT:** We can do so much more! It is usually beneficial for an OT to look in detail at someone's life-work balance, their fatigue levels and the impact of all types of activity on function. We can also help to analyse what the physical demands of living and functioning have on someone's abilities, and address their routine, their environment and of course what specific goals and attainments a person has.

**Nazia - OT:** As OT's we look at how people with MS are managing all aspects of daily living from the small, like doing your shoelaces or handwriting, to the bigger

picture such as identifying reasonable adjustments at work. We also usually take a lead on fatigue education and its management.

**Debra:** I've just been to the map of MS services and it looks like there's no OT service in Swindon, but we're quite close to lots of other centres (and I work in Oxfordshire). How can I get referred to an OT?

**Simon - MS Trust:** The map shows MS specialist OTs, but there will probably be general OT services.

The map depends on people locally telling us about services. If you are aware of existing services that are missing from the map, please let us know. Similarly if you spot errors in existing entries, let us know so we can keep it as up to date as possible.

**Nazia - OT:** The best way to get referred to an OT is via your GP. Ensure that you ask to be referred to a neuro-specialist team.

**Debra:** Thanks, I'll ask whether I can be referred to a neuro-specialist team next time I contact to my doctor. Thank you all and good bye.

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**Lynn - MS Trust:** On a separate, but related area is there any support that might be available for people who are in higher education or training?

**Gerry - WLS:** My understanding is that colleges and training providers must assess people's needs and look to support them as if in work.

**Nazia - OT:** I also work with people with MS who are at university or in higher education. Often a good point of call is the disability officer within colleges or universities. They can be a great resource.

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**Lynn - MS Trust:** Is there anything that hasn't been covered today that you think it is important for people with ms in the workplace to be aware of?

**Sarah - OT:** I have been looking back over the days chatting and I think it is worth also mentioning Gail Townsend's excellent *MS Workbook Toolkit* to support people with MS in employment. It is a resource file that gives specific guidance on considering all aspects when working, from the journey to and from work, to the stresses when working and recognising these. It then gives detailed contacts or website links to look up more information. I would highly recommend it.

**Lynn - MS Trust:** Gail's *Work Toolkit* is now available on the MS Trust website. See the Resources section below

**Gerry - WLS:** Could I also mention to anyone who lives in North Wales or Chester that I do a four hour surgery at the MS Therapy Centre in Saltney near Chester. Just drop in, no appointment needed. It occurs on the last Friday of the month.

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**Sam:** My MS has undermined my confidence. I had a relapse at the end of last year that really laid me low. Even though I'm OK again now, I'm very unsure about going back to work and letting everyone down again should I have another relapse. It's only a small place and it must have been difficult to lose someone for a few months.

**Gerry - WLS:** It's not unusual to hear this. We at Neurosupport have designed a specific confidence building course - one day per week for four weeks. We also offer service to all people affected by neurological conditions. I would imagine in a small place as mentioned, the staff would need to be supported too.

**Nazia - OT:** That is a tragic statement. I'm sure you add a lot of value to the organisation. You should think about a graded return to work (escalating hours and duties) and build up your confidence.

**Sarah - OT:** I wonder if you would benefit from reflecting back on what your problems were with the relapse. Write this down with the solutions you found helped you as you came out of the relapse, including the personal comments about feeling that you were letting down team members. Present this write up at work to help the rest of the team see what the varying symptoms and transitory pattern is like so as to be ready to help prepare for the next relapse.

**Gerry - WLS:** Good advice, Sarah. I think it is important to get all concerned on board in supporting people. A friend or mentor can work as natural support can be priceless. It can be difficult for the person with the condition to facilitate this. Speak to the local Disability Employment Adviser, who can recommend a Work Choice provider who can help.

Work Choice replaced the Workstep provision from Jobcentre Plus in October 2010. It is designed to support people with disabilities in finding work and retaining employment. There are a number of designated providers throughout the country. They will negotiate with employers and monitor and review regularly. An important aspect of the provision is the development of the person with the disability within the workplace, not just to keep them in the position the hold. This should ensure the people we support actually get opportunities to progress the same as others. The provider will discuss reasonable adjustments and identify ongoing support. A drawback, as has been identified earlier, is that it may be pot luck getting someone who understands the condition. The Working Life Service is a designated specialist support for the provision locally.

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**Caroline:** From January 2007 until January this year I was getting DLA for my depression and anxiety as I was in a clinic in 2006 for clinical depression. In November 2008 I was diagnosed with MS. I received a renewal document in August 2010 and sent it off. In January my DLA ceased as they are claiming non receipt of the August form. The DWP turned down my application and my appeal and I now have to go to a tribunal to plead my case. The appeal date will not be before October 2011. I feel totally stressed out about the whole thing and don't know which way to turn. It says in the info pack that I have to get my GP to write and it is down to me to get as much evidence as I can. I have just come off the phone to him and he is surprised that the information is saying that I have to do this.

**Gerry - WLS:** If you want to give me a call on 0151 298 3288 I can refer you to our benefits advice person who would advise you.

**Nazia - OT:** The Disability Law Service offer a special service for people with MS. They have a dedicated MS Legal Officer who is the first point of contact for people affected by MS and who are seeking legal advice. They don't have the resources to respond to written enquiries immediately but will endeavour, but not guarantee, to respond to an enquiry within seven working days. You can reach the MS Legal Officer at 0207 791 9800.

**Caroline:** I have rung the Disability Law Service three times and over a couple of weeks and they have not come back to me.

**Sarah - OT:** This sounds so stressful for you! I wonder why the appeal date is not before October. I was unsure if the GP is saying he will write in support or he won't. Are you known to any other neurological specialist team or services?

**Caroline:** I have spoken to the Maidenhead MS Society and they are saying that there are not enough resources for the amount of people who are appealing. She has said that a case due to be heard in July has been put back to October. So I feel there will be no hope for me. I am under Dr Nicholas at King Edwards in Windsor. My GP is sending me all the paperwork from the hosp appointment. He has not said that he will write himself.

**Sarah - OT:** Maybe Dr Nicholas can help by getting you reviewed by his team. Then, in the time you have to wait, there can be constructive reports written to explain how you actually are, ready for your tribunal?

**Nazia - OT:** As Sarah says, I would speak to the consultant and see whether he can support with a letter, etc. Also the same with other allied health professionals who can comment on the difficulties you are having.

**Caroline:** I will try the MS nurse I had when I was first diagnosed. Thank you.

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**Simon - MS Trust:** There are other work related events happening this week. Tomorrow (25 May) is World MS Day, which is focussing on removing the obstacles preventing people with MS from getting or staying in work.

And the MS Trust's Awareness Week activities will include focus on work, featuring a collection of videos and links that look at employment issues (see the Resources section below).

It's 7 o'clock now, so I'm afraid we will have to end the chatroom.

Thanks to Sarah, Nazia and Gerry, and to Gail and Patrick who were online earlier in the day.

Also many thanks to all the people with MS who asked questions and shared their thoughts, both today and by sending comments in in advance.

## Resources mentioned in the chatroom

Other than our own publications, the MS Trust can not vouch for the content of the information listed



### MS Trust

#### Publications

- **At Work With MS**
- **MS: what does it mean for me?**
- **MS explained**

**Open Door article** (Open Door is the MS Trust's free, quarterly newsletter)

- A new chapter - May 2011 pp6-7

#### Web pages

- **A to Z of MS** - [www.mstrust.org.uk/atoz/](http://www.mstrust.org.uk/atoz/)  
Brief information about a range of MS related topics
- **Map of MS services** - [www.mstrust.org.uk/map](http://www.mstrust.org.uk/map)  
Includes MS Therapy Centres and MS nurses and therapists
- **Work Toolkit** - [www.mstrust.org.uk/professionals/work/](http://www.mstrust.org.uk/professionals/work/)  
A resource for health professionals working with people with MS who are looking for help to retain or regain employment
- **Focus on work** - [www.mstrust.org.uk/msawareness/focuswork.jsp](http://www.mstrust.org.uk/msawareness/focuswork.jsp)  
A collection of videos and links about working with MS
- **StayingSmart** - [www.stayingsmart.org.uk](http://www.stayingsmart.org.uk)  
A website about the effect of MS on thinking

### Contact the MS Trust to order publications or to join the Open Door mailing list

MS Trust, Spirella Building, Bridge Road, Letchworth Garden City, SG6 4ET  
01462 476700 / [info@mstrust.org.uk](mailto:info@mstrust.org.uk) / [www.mstrust.org.uk](http://www.mstrust.org.uk)

## **Other resources mentioned**

### **Working Life Service**

A service run by the charity Neurosupport to help people affected by a neurological condition, to assist them in retaining a job, returning to work, job preparation or finding a meaningful alternative to work.

The Neurosupport Centre, Norton Street, Liverpool, L3 8LR

0151 298 2999 / [www.neurosupport.org.uk/support-services.html](http://www.neurosupport.org.uk/support-services.html)

### **Community Legal Advice**

A network of organisations in England and Wales offering advice about legal rights - including information on benefits and employment law. Participating organisations include legal aid solicitors, Citizens' Advice, Law Centres, local authority services and other organisations.

0845 345 4 345 / <http://legaladviserfinder.justice.gov.uk>

### **Disability Law Service**

An independent charity providing legal information and advice to people with a disability, their families and carers. Has factsheets on the Equality Act.

0207 791 9800 / [advice@dls.org.uk](mailto:advice@dls.org.uk) / [www.dls.org.uk](http://www.dls.org.uk)

### **Equality and Human Rights Commission**

Also has good information about the Equality Act.

0845 604 6610 (England) / 0845 604 8810 (Wales) / 0845 604 5510 (Scotland) / [www.equalityhumanrights.com](http://www.equalityhumanrights.com)

### **DirectGov**

A website collecting government information and online services. Includes information on benefits and employment issues, such as Disability Employment Advisers, Access To Work and Permitted work

[www.direct.gov.uk](http://www.direct.gov.uk)

### **ESA assessment**

The document describing how the ESA assessment is scored can be found on the Tameside Metropolitan Borough website

[www.tameside.gov.uk/esa/wca](http://www.tameside.gov.uk/esa/wca)

### **World MS Day**

An annual event led by the MS International Federation. In 2010 and 2011 the Day has included a focus on employment and MS. World MS Day takes place in May.

<http://worldmsday.org>