



# **Employment and MS**

## **Chatroom**

**25 September 2007**  
**[www.mstrust.org.uk](http://www.mstrust.org.uk)**

# Employment and MS

**25 September 2007 – 10am to 7pm**

- **Jo Sweetland** – *research occupational therapist (10am – 1pm)*
  - **Brian Simpson** – *Working Life Service (10am – 3.30pm, 6pm – 7pm)*
  - **Gail Townsend** – *specialist occupational therapist (10am – 5pm)*
  - **Patrick Carroll** – *specialist occupational therapist (2.30pm – 7pm)*
  - **Janet Widdows** – *occupational psychologist (4pm – 7pm)*
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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 Team on 01462 476700 or [infoteam@mstrust.org.uk](mailto:infoteam@mstrust.org.uk)

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**Simon - MS Trust:** Good morning and welcome to the chat on employment and MS

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**Gail - occupational therapist:** Hello, Annie, do you have a question you would like to ask us about work?

**Annie:** I think I have sufficient evidence to take the matter to a tribunal. I have been retired on sickness grounds, my contention is that the managers made me ill by trying to reduce my hours without my agreement which was very stressful, I felt bullied and victimised and was signed off with stress exacerbating my MS symptoms

**Jo - occupational therapist:** Employment tribunals are one approach, Annie. Have you tried anything else, such as ACAS or the Disability Law service? Did your employers make any attempts to provide reasonable accommodations?

**Annie:** My employers who are a charity! They knew about my diagnosis three years ago, I have worked for them for seven years as a counsellor and social worker

**Jo - occupational therapist:** What was their response when you disclosed?

**Annie:** Reasonable accommodations? Not as far as trying to reduce my hours, as alternatives were not reasonable. I am seeking further advice through ACAS and Disability Law service. I have taken a grievance out about selection procedures to cut my hours, which seems arbitrary. I went to see Occupational Health who said I was fine to work last October but the consultation to reduce my hours occurred in April. By August OH said I was not fit to do that particular job because of dispute at work over my hours.

**Jo - occupational therapist:** Annie, it sounds as though your employer has been unfair to you. The DLS and ACAS are great and will offer you good advice and support - good luck!

**Annie:** Thanks folks, will do

**Jo - occupational therapist:** You have a strong legal case Annie if you can prove that no reasonable adjustments were offered or discussed with you - the DLS can support you through this process

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**Denise:** My statutory sick pay stopped in May. I had been attending Occupational Health and have since discovered they should have given me whatever I needed to claim Incapacity Benefit. I've been sent a completed form from Jobcentre Plus (very helpful woman I spoke with). Should I complain to my HR dept?

**Gail - occupational therapist:** Did you get any support to help you through this process; did you know where to go for help before it got to this point?

**Brian - Working Life Service:** If you feel that your workplace did not offer you the support you needed then by all means complain. It might stop the next person suffering as well

**Gail - occupational therapist:** Denise, it might be helpful to let HR know without necessarily making a complaint. They may have been unaware of what to do for someone with MS.

**Denise:** Thanks Gail & Brian will do.

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**Jack:** Good morning. Just had my first Copaxone injection. I have SPMS and Betaferon wasn't working. Despite the obvious limitations, I am determined to get back into the workforce but not sure how yet. I need to study and retrain. My previous employment was a general manager of a night club, which is not really suitable for me now.

**Brian - Working Life Service:** I usually try to find a way to use someone's existing skills when they are looking to change career. Try and think what skills, especially transferable skills, that you have eg I imagine you have good people skills which will be useful in a variety of careers.

**Gail - occupational therapist:** Hi Jack. What are you thinking of retraining to do?

**Jack:** My question is, can I seek funding to retrain, and how do I go about it?

**Brian - Working Life Service:** It depends on what you chose to do and what your income is. If you are on income support or have a very low income, many college courses are free or have a reduced cost.

There are also funded courses in some vocational areas. The Disability Employment Adviser (DEA) at your local job centre should be able to help. Also the Learning and Skills Council (check your telephone directory or visit <http://www.lsc.gov.uk/>) should be able to offer some advice

**Jo - occupational therapist:** If you do see a DEA, do remember they are not experts in MS but can offer you some good support. You may need to explain what MS is to them and how it affects you. Alternatively an occupational therapist should be able to work with you and the DEA in this process

**Gail - occupational therapist:** You might find it helpful to think through the kind of things you want to do in the future prior to any meeting

**Jack:** I was thinking of graphic design. Taking Brian's point about existing skills, I have always been interested in art, oil painting etc. Also working from home at a pace that suits my illness would be good. I am afraid to commit to full time employment

**Jo - occupational therapist:** Working at home is a good option. Once you have a work at home job, Access to Work can help you with set up. I had a client who started her own business recently and AtW paid for a new computer screen and chair for her home office

**Gail - occupational therapist:** I'm not trying to discourage you, Jack, but you will need to think about the demands of a training course and how you will manage while it is going on. Courses don't always take account of conditions, especially as I would imagine that graphic design is quite a competitive field. While there are more remote access courses now available, they will still have

deadlines for assignments. These are things to bear in mind. This isn't meant to be off-putting

**Jo - occupational therapist:** Most colleges do have a specific person assigned to support people with disabilities - it maybe worth finding out who they are and talking to them about the course you are interested in doing

**Brian - Working Life Service:** I think working from home can be a good idea as you can work around the variabilities of your MS. However, you need to think carefully about your finances as you could end up poorer than you would on benefits. You need to take advice from a reputable welfare rights adviser before committing yourself to this course of action

**Jack:** Thanks for all your comments

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**John:** I was employed by the Department of Work and Pensions in a Jobcentre in the signing section doing face to face interviews with fortnightly claimants.

In March last year I went sick. In September 06 I returned on reduced hours slowly building up to full-time.

In the November I was sent home because I needed help to get on and off the toilet and in and out of my car. I get recurring bladder infections.

Last week I had an interview with a doctor from Capita Health who will determine if I am fit to return to work. I want to - I cannot afford not to. Half pay stopped six months ago. Now I live off my savings.

If I cannot return, is there any help for me? I have about £30,000 in an ISA. Do I cash that in to live?

**Jo - occupational therapist:** Again DWP need to offer you reasonable adjustments to maintain you in work - my experiences with doctors from occupational health is that they do not always understand MS and the impact it can have. You can seek a second opinion or ask for your neurologist to write and support you. Do you feel you could manage your job?

**Gail - occupational therapist:** It seems that a step has been missed out. You don't mention whether you had had any form of assessment from occupational health or even the disability employment advisor who might have been able to get you some support to continue to work.

**Brian - Working Life Service:** You should be able to claim Incapacity Benefit, which is not affected by your savings. Other benefits, like Income Support, are affected by savings. If you are retired on medical grounds and are offered a pension then this will affect you Incapacity Benefit. Take professional advice before agreeing to anything. You may also be eligible for Disability Living Allowance. This is not means tested ie you can get it despite any other income or savings.

**Gail - occupational therapist:** I don't know how old you are but your bladder infections may not just be MS related. It may be that getting a referral to a continence nurse or a urologist might help look at your bladder problems and make sure nothing is missed

**Jo - occupational therapist:** Your employer should do all they can to maintain you at work; look at alternatives within the DWP, look at what reasonable adjustments could be made. You need to think about whether you feel you can manage the job or if not is there another job you think you can do? I would recommend the support of an occupational therapist to help you establish what roles you feel confident and able to do, and how best to manage your symptoms in the work place. I would also agree with Brian and Gail's comments above. If your symptoms can be managed at work then I would encourage you to remain in the workplace

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**C:** All Job Centre literature seems to be directed at getting people off Incapacity Benefit and working 16 plus hours/full time albeit within 52 weeks. What if working 16 hours is never likely to happen but you'd still like to be able to do something?

If your MS means you can't work at the same professional level as you once did, it's likely any job you do might be relatively poorly paid, so working say, 10 hours a week wouldn't be enough to live on if you're single.

Is there a way of someone with MS working part time without being pressurised to up the hours, but still have enough money to eat?

**Gail - occupational therapist:** I think this is a common dilemma faced by people with MS. As Brian has already said about working from home, you would need to weigh up the pros and cons of any decision you make and from a finance point of view. That might be best done through a welfare rights organisation.

**Brian - Working Life Service:** You might be interested in 'permitted work'. This is work you are permitted to do whilst on Incapacity Benefit. There is a lower rate whereby you can earn up to £20 per week for as long as you like. The higher rate allows you to work up to 16 hours a week and earn up to £86 per week for 6 months (usually can be extended to 12 months.) There is also supported permitted work but that is a long story. Remember the word 'permitted'. You need permission from Jobcentre Plus before you can start this type of work

**Jo - occupational therapist:** It is a really tough issue that many people in your situation face. It would be good for you to think about what your current skills are (perhaps in relation to your previous employment), think about how you could use these, maybe on a freelance basis? Think about how many hours you think you could do a week in light of the symptoms you need to manage. Are there any contacts you still have from your previous employment or through friends? Could you manage a part-time job, say, with a support worker to help you? (This can be provided through the Access to Work scheme). Just some thoughts. We all need a certain amount to live on and benefits often aren't enough to meet our needs

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**Chris:** I think confidence is my thing. I'd been relatively OK for a while and then a relapse really knocked me over for months at the end of last year. 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.

**Jo - occupational therapist:** Chris do you have a job to return to? Do they know you have MS? We have been running a service supporting people with MS in the work place and loss of confidence is often the biggest barrier to return to work. The attitude of the employer is often key in this...

**Gail - occupational therapist:** Do you have a pattern of relapses, or is it just the uncertainty that really worries you?

**Chris:** Work has been supportive and given me plenty of time, but I'm worried I'll let people down if I have to be off for a long time again. It's only a small place and it must have been difficult to lose someone for a few months

**Gail - occupational therapist:** Have you discussed your worries with anyone about going back to work?

**Jo - occupational therapist:** Again a common concern. The unpredictability of MS is so difficult to manage especially in the work place, but it sounds as though you have a supportive employer and they want you back. Remember you bring skills they want you for - this hasn't changed and legally they have a right to support you in your role

**Brian - Working Life Service:** There are good business, legal and moral cases for your employer to take you back. Your employer has paid to recruit and train you to the level of experience you now have. If your employer lets you go, then s/he has to go through that expense and time again. It may make better business sense to retain you rather than go for a new worker.

Also there are legal issues around employment law and the Disability Discrimination Act that the employer has to consider before getting rid of you

**Gail - occupational therapist:** Brian is so right you need to remember the contribution you make to your company, not just what the future may or may not hold

**Jo - occupational therapist:** Doing a SWOT analysis can help with this loss of confidence - Strengths, Weaknesses, Opportunities and Threats. List your strengths and the skills you have, any weaknesses you feel you have, what opportunities there are (eg have supportive employer, good team, flexible hours) and list threats (eg difficult line manager). Then you can objectively look at the weaknesses and threats and see if there is a way to work through them/remove them. Sometimes just getting back to work is what someone needs to restore confidence

**Gail - occupational therapist:** Although if you have been off for a while going back on reduced hours at first might be something to consider and gradually build up

**Jo - occupational therapist:** I agree with Gail and graded return to work can sometimes be a good idea - rather than jumping in the deep end!

**Brian - Working Life Service:** Like Jo, at Neurosupport in Liverpool we recognise that loss of confidence is often the biggest barrier to going back to work. We run a number of confidence building measures that help people regain some control over their life.

Think about what you have put into the company in the past and don't take all the blame on to your self

**Chris:** Work is fine about things. It's more on the personal level with colleagues (who are also being very kind) and me letting them down. I think the problem is with my own confidence. The relapse was a shock, taking me from normal every day person to someone housebound and barely able to get about (thankfully only for a short time). Maybe small steps first would be a good idea

**Gail - occupational therapist:** Taking small steps is a good way to build up your confidence. Also if you find something is a problem you can tackle it early on before it gets out of hand

**Jo - occupational therapist:** It is a huge knock to confidence. Small steps and beware of fatigue - this can often knock people on a return to work. The MS Trust have a good booklet called Living With Fatigue with guidelines on managing fatigue.

**Gail - occupational therapist:** Also your local occupational therapist or MS nurse can talk through fatigue management strategies with you on a one to one basis which might be helpful

**Chris:** That would be helpful as this is something that has been an issue

**Jo - occupational therapist:** Good strategies to manage your fatigue can really help and make work viable

**Brian - Working Life Service:** I think you have provided the answer in your previous comment. Work and colleagues see the issue differently to you. It seems that you are the only person being unsupportive!

Again, following what Jo and Gail have said, just take it a little bit at a time. If you succeed in small things that will give you the confidence to take a bigger step. If you take a big step first and then fail, your confidence will take another knock. Think about what you are able to do and then go and negotiate with your manager.

**Gail - occupational therapist:** I think Jo's comment about the deep end is a really good one. Even after a holiday, when you get back to work it seems like there is so much to do. I think there is a skill about saying no to yourself, and not pushing yourself too hard too soon.

**Chris:** Good advice that I was never any good at following :- ) Thanks

**Gail - occupational therapist:** Good luck Chris

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**Linda:** I have an MS-like condition without a diagnosis. I have been on sick leave for over six months and intermittent in the three months before that.

I am hoping to return to work part time in the near future but would need to ramp up to full time fairly quickly.

My employer is very supportive and I would like to stay, but am concerned about managing my existing job with fatigue, memory and multi-tasking problems.

The company occupational health doctor previously said he would like a diagnosis before planning to return and at that time my GP was against it. Now my GP feels I am ready. Can the OH still prevent me from returning?

**Jo - occupational therapist:** Linda, we see many people at our hospital who do not get a diagnosis. It would be unfair for your OH to determine your ability on returning to work or not on whether your symptoms have a name. It should be about looking at what the symptoms are and how they can best be managed. An employment tribunal will always start with were reasonable adjustments offered, not is the person disabled

**Brian - Working Life Service:** OH can only make recommendations, but these are usually acted on by employers. However, this could mean that the company is in breach of the Disability Discrimination Act. You don't need a diagnosis to be covered by the act. Your employer needs to make 'reasonable adjustments' ie how can the workplace, the equipment and furniture you use and the way you do your job be adjusted to minimise the effects of your condition

**Linda:** Thank you. I thought you had to have a diagnosis.

**Gail - occupational therapist:** Linda you mention both OH and your GP, but have you seen a neurologist?

**Linda:** Yes. My MRI tests were inconclusive and I'm going to have a lumbar puncture and see the neuropsychologist for a cognitive assessment soon.

That's the other thing about going full time - I'm still back at hospital on and off. But I think my confidence is going as I am largely better but still moping at home. The job I do really can't be part time though.

**Jo - occupational therapist:** Not working and 'moping at home' as you put it can lead to loss of confidence and make a return to work more difficult. I would aim to keep your 'working days' as structured as you can - get up the same time, plan your day, get out of the house etc can be really important.

**Gail - occupational therapist:** If you want to go part time, have you thought about a job share, that is another alternative and the work is still covered full time. You might need to be proactive in finding a job sharer if your employer agrees, but it is an option to consider

**Linda:** True Jo. I have been really disciplined since I wasn't allowed to go back a few months ago and it has really helped. I get up and do a virtual trip to work then typing/thinking practice in the morning. Then rest for a couple of hours then walk or housework.

I think I've been worrying about the bits of work I might struggle with so really want to get back in the thick of it to prove to myself I can do it. I know OH need to look out for the employer, but I wish I could persuade them no one is winning with me at home.

**Jo - occupational therapist:** Occupational Health should be representing you and the employer. They should be making recommendations as to what reasonable adjustments can be made to get you back to work. I agree you are a loss to them sitting at home when you could be using your skills at work

**Brian - Working Life Service:** Yes, OH is supposed to look out for you as well but this does not always happen. As I said before, try and approach your employer with solutions rather than problems. You know what works for you better than anyone else.

**Linda:** Thank you all. Coming in here has given me a boost to approach OH more assertively. Brian I like your suggestion for approaching it as 'why will my (condition) make be a better employee'

**Jo - occupational therapist:** Good Luck Linda!

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**Leonie:** Until five years ago I was a working mum with a family and a career. I had already upset a few dinosaurs at work just by being a successful, modern woman and when I was diagnosed with MS seven years ago there was an immediate assumption that my illness was the result of 'having it all.' There was an expectation that I would resign and just creep away quietly.

When I tried to carry on and negotiated flexible hours with senior management, my staff dug their heels in, even to the point of using my desk for someone else to sit at so that on the days I felt well enough to come in there was nowhere for me to sit.

The situation was managed terribly and I ended up being medically retired, with three flare ups in my last year along with severe anxiety and depression it has taken me years to get a fraction of my self-esteem back.

I realise it is too late for me to turn the clocks back but would like to know if anything is being done nationally to increase the awareness with employers of not just the physical but the cognitive effects of MS so that people who work alongside those with MS can be a little more empathetic.

Also, do you come across many people with MS who successfully manage their condition while running a home and family as well as working?

**Gail - occupational therapist:** I think being a working mum even without MS can be tough. A lot depends on support at home either from a partner or, if you can afford to pay, someone to perhaps do things like the cleaning. One person who took part in my research said she found work a rest from her lovely but lively children!

**Jo - occupational therapist:** The Employers Forum on Disability ([www.employers-forum.co.uk](http://www.employers-forum.co.uk)) is an excellent charity that is working hard with companies to improve the working conditions of disabled people. They raise awareness for all conditions but have a factsheet (among many) on MS specifically. People applying for a new job should check out the website and see if their company is a member - they do some great work.

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**Glen:** Reading back through the chat, Gail mentioned research she'd done. What was this about?

**Gail - occupational therapist:** I wrote about my research in the last Open Door - which you can access on the MS Trust website if you haven't seen it. In 2005/6 I explored what people with MS were experiencing with regards to work. I also looked at what people like MS nurses, occupational therapists and Disability Employment Advisors did to support people with MS. I am writing something more for Way Ahead (another MS Trust newsletter) which will come out at the end of the year / beginning of next year (Simon, I'm sure you can tell us).

People who took part in that study gave advice about their experience that could be used in a book, the result of that is the book *At Work With MS*

**Simon - MS Trust:** You can see articles from back issues of *Open Door* at [www.mstrust.org.uk/opendoor](http://www.mstrust.org.uk/opendoor) and of *Way Ahead* at [www.mstrust.org.uk/wayahead](http://www.mstrust.org.uk/wayahead). The next issue of *Way Ahead* will be out at the start of the new year.

The new book, *At Work With MS*, is published today. You can order copies on the publications pages.

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**Helena:** How tricky is it really to get a new job if you are quite open about your MS? I have told my employer but I was diagnosed whilst working here. I am now looking for new employment and I wonder how open I should be. One of my friends tells me it could really hold you back from getting interviews. I get that it is very different from job to job but what is the general opinion?

**Jo - occupational therapist:** Legally firms can not discriminate against you as that is against the law. However it is a difficult one as I have clients who have said they disclosed in interview and then found they did not get the job. It is hard to prove it is due to their MS. They cannot ask you directly in an interview if you are disabled, unless there would be an issue with health and safety. You may however be asked by occupational health (if you were to see them). It is your choice whether you disclose or not. I have clients who wait until their probation period is over then choose to disclose at that point

**Gail - occupational therapist:** Application forms can ask if you have a disability, or you may have to complete an occupational health questionnaire. It is important that you are truthful as you may have disciplinary action taken if it is found that you have withheld information. If they have 'two ticks' they should offer you an interview provided that you meet the requirements. Two ticks is a scheme that shows the organisation is positive towards disabled people



**Helena:** Thanks. I guess in my case I prefer to be honest about it. My friend has worked for years in places without ever telling, and I don't think I could do that. But then again my employer has been very supportive, so I guess it is different.

**Jo - occupational therapist:** I think I would want to be honest as well. I think long-term that is the best option. However there are some unsupportive employers out there who do discriminate so beware!

**Helena:** And I guess I don't really want to work for someone who discriminates against anyone so I guess it will be their loss

**Brian - Working Life Service:** It depends on how you disclose. Many people will say 'I have MS, which means I can't do this and I can't do that'. I'm not surprised they don't get the job.

Try turning this on its head and think why will my MS make me a better employee? Some ideas: You have something to prove - to yourself, your family, your doctor - and so have a determination to succeed - unlike those who only want a pay check at the end of the month. Also, if you are working with the public you are more likely to have empathy with customers who have any sort of difficulty and so attract more business for you employer.

This may sound strange at first but think about it. Always ask the question 'How does my MS make me a better employee'

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**Dave:** I was diagnosed in March 2007 at the age of 51. I am still working full time as a sales manager, mainly from home. Before MS I was doing over 30k miles a year. I came out about MS to my employer and clients as soon as I returned after my first big relapse. I now do most of my meetings on the telephone or via the web. The use of the internet and understanding of my employer and clients means a reduction of about half my old annual mileage. Whilst MS has slowed me down, given me fatigue, a dicky hip, walking stick and more, I still function in the workplace but in a different way than I use to. Informing people I had MS has, I believe, worked in my favour in that I am still doing the job I love with the ability to work at my pace and from home. I hope this helps others make the decision to tell or not to tell. It worked for me, but may not be right for everyone.

**Gail - occupational therapist:** Thanks for sharing your experience. It's really important to know that it's not all doom and gloom

**Jo - occupational therapist:** I echo Gail's comment - thank you for sharing. The issue of disclosure is always a tough one. Legally you do not have to disclose but there are definite benefits of taking the steps and disclosing...

**Brian - Working Life Service:** Disclosure is a huge issue. I'm glad it worked for you but, unfortunately, it doesn't work so well for everybody.

My usual advice is that you don't need to disclose if it is not having an impact on the way you do the work. When it does start to have an impact, then do talk to your manager. But approach her/him with a solution rather than a problem eg because of my MS I have difficulty getting going in the morning - would it be possible to come in an hour later and work for an extra hour at the end of the day?

**Teresa:** I found disclosing MS to my closest colleagues has worked in my favour as they now recognise when I am feeling unwell even though sometimes I don't want to recognise it myself as I feel I am letting them down. Although, deep down I know I do a good job. I have always found with my job, if they are flexible with me (which they are) I am more than flexible back and they appreciate that. I must admit I am quite choosy whom I disclose my MS to.

**Gail - occupational therapist:** Teresa, when you feel you are letting people down, even though as you say deep down you know you are doing a good job, if the thought 'I'm letting people down' pops into your head, immediately tell yourself 'I do a good job' don't let the negative thought linger

**Jo - occupational therapist:** I agree being choosy about who you disclose to is a good thing. Some people get diagnoses, head back to work and tell everyone, then regret it later. You need to think 'who needs to know?' and why?

**Dave:** It seems that 'to tell or not to tell' is quite a big issue. Here's how I did it. I started at the top with the MD, gave him a copy of Just Diagnosed [MS Society publication] to read then asked him if he had any questions. Next, my four close colleagues got a chance to read it, then we had a group discussion on how to go forward. From there it filtered through to the guys in the factory from my peers who knew what they were talking about. My point is they read the booklet and knew what MS was and how it may affect me. The rest is history.

**Gail - occupational therapist:** It seems to me that you are quite a confident guy, as it must have taken guts, and perhaps feeling secure in your working relationships to be that open. I think what seems to be emerging is that there are no hard and fast 'rules'. You have to do what is right for you at that time

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**Kaye:** Unlike most people here, I am a few years short of retirement and would like to stop work. My company doesn't offer retirement on health grounds but operates a long-term disability scheme. How would they assess MS in terms of ability to work? I have very limited mobility and am easily fatigued but I can still sit at a laptop and type. My GP will sign me off long-term sick but what criteria will the insurance scheme operate?

**Jo - occupational therapist:** Different insurance schemes have different rules and often the process can take a long time. You need to get a copy of your insurance policy and read the small print.

**Gail - occupational therapist:** It's hard to answer your question about the company insurance. However, you say you can still sit and type - does your speed change as you get more tired? Do you make mistakes when you are tired that you don't when you are fresher?

**Kaye:** Yes my hands get tired, my typing slows and I have difficulty writing

**Gail - occupational therapist:** I think that shows that MS is affecting you, and may help you build up the evidence required for proof of disability. However, as Jo said, you need to know what the policy says

**Brian - Working Life Service:** Disability is different to diagnosis. After all, some people with MS will show very few symptoms that do not get in the way of their life whilst others will be disabled very quickly.

Disability is about how you interact with the world. Sometimes the world makes it difficult for you (such as trying to get up stairs in a wheelchair or in the 'does he take sugar' syndrome). If your MS makes it impossible for you to do your job despite making adjustments, then the insurance company should see you as disabled.

One other issue the insurers will look at is is there a chance you will get better? This can sometimes prove a stumbling block and will, need letters from your GP and neurologist

**Jo - occupational therapist:** An occupational therapist assessment would also support your case. I often go with my clients to meet the OH

**Kaye:** The issue as I see it is I can still do a job, up to a point, but it then knocks me out in my personal life. Does that count ?

**Jo - occupational therapist:** Yes this is relevant and should be taken into account

**Gail - occupational therapist:** I also think your comment of being able to do a job up to point is relevant. Part of the process will be about how much you are able to do. As Jo says and occupational therapist assessment may be really helpful

**Brian - Working Life Service:** There's always a tricky balance between work and personal life. If you were to lead your personal life to the full then you would be unable to do your job.

You need to think what you want out of life. It sounds like you could manage your job at the expense of your personal life. If that's what you want then go for it. But if you want to spend more time with your family (as the politicians say) then you need to reconsider your work/life balance.

If you need to convince the insurers, then play hard and do your work with great difficulty

**Kaye:** OK will do. Thanks

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**Jill:** I was diagnosed with MS in December 2005 and informed my employer right away. I work in the office of an ambulance trust. My employer has been very supportive but a year ago the trust merged with two other ambulance trusts and it seems very likely that the office I work from will close.

I chose this job three years ago because the office is only seven miles away from home. The relocation is likely to be an hour to an hour and half away from home and I know from experience that I will be unable to do this journey, work an eight hour day then drive home. Under the Disability Discrimination Act's requirement of reasonable adjustment, will I be able to still work locally? I would suggest from the ambulance station in my home town. Most of my work is on the computer and I feel I could carry this out anywhere.

**Brian - Working Life Service:** The law talks about reasonable adjustments. I don't know if working from your local station would be reasonable or not. But it is up to the trust to prove that it is not reasonable. It may be that your job will not exist in your local station. Put your ideas to your manager. If the response does not seem reasonable to you, then put in a grievance.

**Jo - occupational therapist:** Legally your employer has to make reasonable adjustments - however from what you are saying, if the ambulance unit is to move location it would not be seen as reasonable that they keep open the unit locally for you. However, they could consider you working from home if you feel this is viable for the work you do. Or perhaps setting you up in another service-linked centre locally or maybe consider offering you another role within the trust. It is important to discuss option with your employer and I would hope a solution could be reached in a sensible manner

**Gail - occupational therapist:** As has been said earlier, going in with some possible solutions to the problem help make your case, plus, as we have said to others, reinforce your value to the organisation, your skills and knowledge, and

that it might be more economical to keep you than go to the expense of finding and training someone else

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**Margaret:** I am an occupational therapist working with MS clients in an in-patient assessment unit where the majority of my clients are no longer working. However, what agencies/services do you recommend I refer to/utilise if a client is experiencing difficulties at work or wishes to return to employment?

**Gail - occupational therapist:** In some ways it depends on the individual's problems and work set up. However, the Disability Employment Advisor (DEA) would be a useful contact. Also, if it is a return from sick leave, then they may have occupational health department. As has been discussed earlier OH experiences can vary and the person with MS may need to be assertive.

Sometimes just by discussing their problems and finding alternative ways of managing symptoms is helpful. This can be done by the occupational therapist or their MS nurse, or another member of the multidisciplinary team they are in touch with. I think occupational therapist is a bit of an underused resource when it comes to supporting people with MS in work. We hide our light under a bushel I think. Or see people too late to influence their work situation

**Brian - Working Life Service:** The Disability Employment Adviser at Jobcentre Plus is always a good start. However, they are not experts in any particular condition. There often more specialist organisations but it depends on what part of the country you are.

**Jo - occupational therapist:** I imagine with the client group you are working with that if they have a job and are in your unit then are likely to be experiencing issues at work. What is your capacity for working with them in this area? I would argue an occupational therapist is often the most skilled in supporting a client in work issues. You can work with them as an advocate, an educator and facilitator. Access to Work offer good support (again you can be involved in this) as can a DEA. As I said earlier I would go with your client to meet the DEA as you cannot assume they experts in MS - they are not medically trained but can have good links to the work place

I agree with Gail that the role of the occupational therapist is frequently misunderstood in this country. In Australia for example an occupational therapist would often be the first point of contact in disability related work issues. I think change is coming here but as occupational therapists we need to be better advocates for ourselves

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**Margaret:** Thanks for all your comments. It is an area that I wish to further develop. In addition to functional, motor, cognitive assessments etc, completed, do you have any opinion on the suitability of VALPAR with MS clients? [Valpar is a company providing specialized test instruments and software that measure work-related skills].

**Gail - occupational therapist:** VALPAR (as I understand it) requires you to go on an assessment course etc, and so requires investment that you might not have available. Jo might have some advice but the two work scales for MS that I know of are American, and have some good and bad points. There is also the MOHO (model of human occupation) worker role interview and work environment

assessment (on the COT website). Depends on your familiarity with using MOHO stuff.

**Jo - occupational therapist:** I personally do not use the VALPAR with my clients. I tend to complete a verbal initial interview, identify problems and establish goals. I often complete fatigue management (COT just launched their new fatigue management pack), complete work site visits and meet employers, support with disclosure, refer to places such as Access to Work, educate and work towards goals. I have used AMPS [Assessment of Motor and Process Skills - an assessment tool that is used to measure the quality of a person's activities of daily living] to identify specific issues with process skills and will refer to neuropsychology. However my understanding of VALPAR is that it is external to the work situation the client is in and I believe the environment and the specific job is the most important things to be considering. There is a good debate going on through the MOHO chatroom about work assessments - worth a look... hope this helps!

**Gail - occupational therapist:** The occupational therapist in our local brain injury vocational rehabilitation (VR) service learned to do the VALPAR (I think), but has never used it. While it is a different client group, using 'normal' occupational therapist assessments and doing the kind of things that Jo has written about seem to be the best things. We mustn't undervalue our own assessment skills.

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**Bill:** Do you have any advice about telling people about my MS. I've been diagnosed five years and never had any problems in my current job. I'm beginning to find I need to go to the loo more often and get tired very quickly. I'm happy to raise this with managers, but my colleagues are a more daunting idea.

**Gail - occupational therapist:** Why is telling your colleagues is more daunting for you?

**Bill:** As these are 'invisible' symptoms I'm worried they'll not believe me and think me slacking

**Gail - occupational therapist:** They must have seen you disappearing to the loo, which is slightly more visible than fatigue.

**Jo - occupational therapist:** I would practice what you want to say with a friend or family member as this can help a little. The MS Society and the MS Trust both produce booklets that you could give your colleagues. Also work out who you want to tell and why, rather than making a huge announcement. Be ready for sympathy (which can be unhelpful) and also 'my aunt had MS and was x,y,z' responses. MS is unique for each person, you may need to be willing to educate and inform people of how it is for you.

**Gail - occupational therapist:** Thinking about what might happen when you tell people can sometimes be worse than the actual experience. I agree with Jo, the MS Trust has a factsheet on talking to family friends and colleagues about MS that might be useful to look at. Your colleagues might also be worried about your health, but too nervous to ask.

**Brian - Working Life Service:** As I said earlier, disclosure is always a problem. If your MS is not affecting your work there is no need to disclose it. It sounds like

your work is starting to be affected so now is the time to talk to your employer. Frequent loo visits are often seen as shirking so you need to discuss this. The MS Trust has a good booklet that you can show to your employer explaining some of the difficulties people with MS may have with work. You can also offer something in return for all your loo visits such as a shorter lunch hour or adding a bit to the end of the day.

Colleagues may wonder why you are getting preferential treatment and this may cause resentment. Think carefully why you do not want to tell them. Colleagues can often be a good source of support when things get difficult for you but you do need them on side.

**Gail - occupational therapist:** Have you had any advice about your increased trips to the loo and how to manage this? Also how does your fatigue affect you, and do you use any strategies?

**Bill:** I tend to grin and bear it with the loo breaks. And maybe it's just me worrying what people think rather than keeping a tally of how often I'm away from my desk.

As for fatigue, I try and pace myself, but work doesn't really allow for that. You do it or you don't - though I do seem to end up working quite slowly as the afternoon goes on. I seem to end up losing out on evenings and weekends.

**Brian - Working Life Service:** Contenance advisers can offer loads of help around these issues. Your GP should be able to refer you or there may be one that your neurologist uses.

**Gail - occupational therapist:** I know it can be difficult but sometimes taking a break can increase your productivity, particularly if as you say you work slower in the afternoons. Eating lunch at your desk (or not even having lunch!) can worsen your fatigue. Sometimes people with MS can overcompensate and end up taking fewer breaks than their colleagues.

**Brian - Working Life Service:** Fatigue can be a serious issue and it may mean that you lose out on your personal life. Talk to your neurologist or MS team about fatigue management. It may also be possible to look at your work practices to see if there is any way you can adjust them so that you do not get so fatigued. If this does not work for you, you will have to look seriously at your work/life balance and make adjustments accordingly

**Gail - occupational therapist:** I know I've mentioned this before and don't want to sound obsessed but men can have bladder problems that are not MS related, but are usually age related. Also if you have to go to the loo often it can be tempting to restrict what you drink. Unfortunately this can irritate your bladder and end up making you go to the loo more. Seeing either a continence nurse or an MS nurse may help. I know you've said you're just starting to have problems, but actually it is easier to tackle them while they are small problems than let them get bigger before doing something

**Bill:** Thanks for the advice. The difficulty is making myself follow it! I have read about pacing oneself and managing fatigue, but so often the easiest part of life to give is the home life. Despite good intentions, this is the area that suffers most from running myself into the ground.

**Gail - occupational therapist:** At the end of the day only you can change things! In the short-term it might seem easier to neglect your home life, but it

can have long-term consequences that are just as difficult as dealing with work issues

**Bill:** To be frank, part of the problem is admitting to myself that these problems are impinging on my life. Ignoring them is no way to cope, but facing up to the fact that they are causing me problems is not an easy step to take. It feels like giving part of myself away

**Brian - Working Life Service:** It is often worth thinking about why you go to work. Money is just one reason. Others might be to meet people, develop skills, have an improved social life, build self-esteem etc. Some of us work so hard or long (this is just not MS related) that we lose out on a lot of the pleasures of life. Could you afford to reduce the hours you work?

**Gail - occupational therapist:** I think that is a very understandable feeling. I think one way of looking at it might be to look at from the point of view that by ignoring these problems they are in fact dominating what you do with your life - in that you are sacrificing one part for another. By biting the bullet you are starting to assert yourself against the MS. You may not be able to control the MS, but you can influence how much you let it affect your life and what is important to you. But it is hard. No getting away from that

Also by coming here, you are starting to acknowledge that these problems exist, you have taken the first step

**Bill:** I suspect, like many, I define myself by my job - it's not what I do, but who I am. It's hardly a vocation, but it is somewhat central to my life. It's not easy to let this go - though I recognise how this attitude isn't helping me

**Gail - occupational therapist:** As work is so important to how you feel about yourself, think about how making positive steps by addressing the fatigue and bladder problems can actually prolong your working life rather than cut it short. In the longer term you could start to think about other parts of your life that are meaningful to you, but have been too busy with work to pursue

**Brian - Working Life Service:** It may be worth talking through with somebody about why you define yourself by your job. There are many other aspects to our lives that define who we are - friend, father, son, member of the football team etc. What do you get from work that you can't get anywhere else? I am not suggesting that you give up work, rather than you give it a more balance place in your life

**Bill:** Thanks for your help today - it has been very useful

**Gail - occupational therapist:** Good luck, Bill

**Brian - Working Life Service:** Good luck

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**Jo - occupational therapist:** I am signing off now. Thank you, I have enjoyed the opportunity to be part of this discussion. It highlights the fact that working with MS presents many challenges and that the attitudes and understanding of employers still needs to be changed. Thank goodness there are some good employers out there!

**Simon - MS Trust:** Thanks for your contribution this morning

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**C:** Working for yourself would seem, on the face of it, a good option, as it would allow you to work flexibly. But there seems to be a lot on the downside too:

1. Difficulty in finding or affording an insurance policy to cover the bills if you're too ill to work because of a flare up of MS symptoms.
2. Not the right National Insurance contributions, so ineligible for Incapacity Benefit if you can no longer work at some later stage.
3. No holiday pay, sick pay or maternity pay so pressure to keep on working when you should be taking time off to manage your condition.
4. If you can only work part time, would you be eligible for any other financial assistance because of your low income?

Any ideas on how you could make working for yourself work (apart from winning the Lottery or finding yourself a millionaire partner?)

**Gail - occupational therapist:** Self-employment without MS can be risky, as you've so eloquently put it. People who I know work for themselves successfully have managed it either by continuing what they did as a paid job, but on a consultancy basis, however the anxiety over agreeing to do something when you don't know how you will be in advance is quite a pressure. Others have a family business where it doesn't all rest on them, it is shared, and they work flexibly to do what is necessary to contribute to the business. Jo wrote earlier that a client she worked with had been able to get help through Access to Work for equipment, but that doesn't really answer the ongoing issue of money coming in that is sufficient for your needs

**Brian - Working Life Service:** Some very difficult questions

1. Insurance is difficult to find but so would it be if you were in someone else's employment and they didn't have a good sick pay scheme
2. National Insurance. You don't have to pay the minimum stamp. You can make voluntary contributions so that your entitlements are protected. Speak to Jobcentre Plus or a welfare rights adviser
3. I can offer no solution to this except, like all self-employed people, to take account of this in how you manage you earnings.
4. You may be eligible for tax credits, especially if you have children or can show you have a disability - speak to a welfare rights adviser to see if you qualify

You can get advice on setting yourself up in business by speaking to the Small Business Service is sometimes called Business Link. They are usually based with Chambers of Commerce but check your telephone directory

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**Patrick - occupational therapist:** Hi, just logging-on for the afternoon/evening session.

**Simon - MS Trust:** Hello Patrick

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**Rachel:** I would like to start working from home, part time. What can I do from a wheelchair and MS? How do I go about it? And will it effect my benefits?

By the way, I was a food technologist before diagnosed with MS at the age of 30. I am 33 now. I have a degree in home economics. I fancy running my own business, possible in cake decorating?

**Gail - occupational therapist:** From the point of view of the type of business, using your existing skills and knowledge is a good idea. A kitchen could be adapted so you can access what you need to do. The main issues would be about how do you ensure you don't let clients down as cakes tend to be ordered for a specific date. You would need to build in a contingency plan so that you could still meet your orders. I have no idea bout how much you could earn, but what about teaching cake decorating? It might be an idea to brainstorm what skills you have, what you enjoy doing, and food related jobs that exist and see what options you might have.

**Brian - Working Life Service:** Unless you are on a very low income (less than £20 per week) your Income Support and Incapacity Benefit will be affected. It is possible to do Permitted Work whereby you can still get your Incapacity Benefit and earn up to £86 per week and work fewer than 16 hours a week. However, this will affects your Income Support. You will need permission from Jobcentre Plus to do this. Your Disability Living Allowance should not be affected.

It may be that you can claim tax credits if you are not earning much (highly likely if you are just starting up in business). You must be working at least 16 hours a week for this.

I suggest taking advice from a welfare rights adviser to see how much you need to earn in order to be better off. Business Link/Small Business Service can offer advice on setting yourself up in business

**Gail - occupational therapist:** I think, as has already been said, money is only one reason for working. If you want to do this in order to have something constructive to do with your day, you could try doing something on a voluntary basis. This might give you a feel for how you can manage if you have not worked for a while. You would have to limit the number of hours you do as I think it can affect your benefits if you are seen to be 'working' albeit for free. Is that correct Brian?

**Brian - Working Life Service:** Yes you can do voluntary work up to 16 hours per week

**Patrick - occupational therapist:** I don't see any reason why you couldn't 'test' the market by doing the cake decorating on a rather informal basis for a period of time to see if it is viable and compatible with any of your limitations.

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**Glen:** Brian, can you explain what the Working Life Service is - I'm afraid I haven't come across this before

**Brian - Working Life Service:** The Working Life Service is part of a voluntary organisation called Neurosupport based in Liverpool. The organisation was set up to look at all the non-medical aspects of neurological conditions and brain injuries. The Working Life Service offers one-to-one advice and guidance on

employment issues and meaningful alternatives to working. You can find more information on [www.neurosupport.org.uk](http://www.neurosupport.org.uk)

**Glen:** Is that just a Liverpool thing or is it national?

**Brian - Working Life Service:** It's a national thing. Obviously the amount of direct support we can offer reduces the further from Liverpool you are, but the advice and guidance remains the same

**Gail - occupational therapist:** Brian, do you get a lot of people asking about self employment, as that seems to have been something that people want to know about today?

**Brian - Working Life Service:** Not a lot, but there is a significant minority of people who see self employment as a way around the issues that their condition causes in their employment.

Like anybody who chooses this type of working, you have to ask yourself a lot of hard questions before you start. And many small businesses go under in their first year. Self-employment is not an easy option but can be very worthwhile if you can make it work.

Maybe this is a future area of research?

**Gail - occupational therapist:** Not for me - I have enough to be getting on with! Seriously I think self employment for people with disabilities as a larger group would probably be an interesting area of research.

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**Glen:** Reading about today's topic it says that people with MS who leave the workforce usually do so for reasons other than disability. Can you explain what this means?

**Gail - occupational therapist:** As a lot of people with MS are women they may leave work to look after children / elderly parents, or not return after having a baby. Also redundancy happens, or being sacked - MS isn't the only reason given. Although men are more likely to give MS as the reason they left work compared to women (this is based on US research). In the general population men are less likely to work part time than women, so it may be that that men with MS choose to retire rather than work part time - just a possibility

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**Anne:** Who do I turn to if I'm having a problem with my employer? I feel they aren't treating me well and would prefer me to leave.

**Gail - occupational therapist:** Can you explain a bit more about your situation?

**Brian - Working Life Service:** The Disability Employment adviser at you local Jobcentre Plus is a good place to start. Part of their role is to work with employers and employees to help maintain jobs.

However, they are not experts on MS and it would be useful to talk to you MS nurse or occupational therapist who may be able to offer practical ways forward.

I could talk to you outside the chatroom if you like. Simon can give you my email address

**Anne:** I find I'm slowing down, and can't work so long. I have days when the pain in my legs either makes it hard to concentrate or hard to even get to work. At first they were fine, but I think because I don't have my leg in plaster or use a wheelchair or actually look ill, they think I'm trying it on. I seem to be ignored for interesting jobs and rather put up with. I get the feeling they would like me to leave. Not actually said as much, but it's the feeling I get.

**Patrick - occupational therapist:** Unfortunately this is very common with all 'hidden' conditions. Try a bit of education with colleagues you know well or put some of the MS Society or MS Trust leaflets around.

**Gail - occupational therapist:** Do you have an MS nurse or occupational therapist who you could discuss things with? Perhaps there's something that could be done to improve the pain you are experiencing? As Brian says the DEA is a good option to help with talking to employers, but involving an MS nurse or occupational therapist would help as DEAs are not medical specialists. Also do you have an occupational health department, as they may be able to help?

**Anne:** No, we don't have an occupational health person.

**Gail - occupational therapist:** Have you had any help with managing your pain, or discussed with your doctor what pain relief you might try? As that seems to be having such a huge impact on your life

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**Joanna:** I have been diagnosed about five years and am on beta interferon (recently suffered a relapse) and work for the NHS. They have been brilliant with me and via my HR department I have now reduced my hours for a period of 18 months with full protected pay. I still have numerous problems related to my MS, the main one being the tiredness/frustration and bad moods - if you have any suggestions re this please let me know.

The other thing I forgot was if I decided to reduce my hours after this time or if in the future I couldn't cope with my job what sort of financial help would there be for me?

**Brian - Working Life Service:** It may be possible to get tax credits but this depends on a number of factors like is there any other income in the household, how many children you have, whether you are any higher rate DLA. You will need to talk to a welfare rights adviser to assess your exact situation. Also you need to be working at least 16 hours a week.

**Patrick - occupational therapist:** If you reduce your hours on a permanent basis then you'll probably have to take a reduction in pay.

**Joanna:** Well I live alone with no children and my hours currently are 37. I would find it hard paying bills etc if I reduced my hours permanently. That's why I will have to keep going until I find that I just can't anymore

**Gail - occupational therapist:** Have you talked to anyone about your tiredness and how to manage it? It may be that your bad moods and frustration are linked to that?

**Joanna:** I have talked numerous times to my MS nurse who have given me loads of literature about my tiredness and some of the exercises do help a little but I get so short tempered so quickly that thank God I live alone! I get frustrated that I plan my life around being able to get to bed early, mind you I have to be up at 5.30am so thankfully as they have reduced my hours for a while I can now leave at 2pm and get home for a cat nap. Have tried two drugs but they didn't work and they tell me there is nothing else - have you heard of anything?

**Gail - occupational therapist:** Do you find you get quite stressed? Are there any particular things that set off your temper?

**Joanna:** Well things came to a head for me as I was diagnosed two months after my dad died. I have my mum down here but my brother and his family live away, so I sometimes feel a bit isolated and then get stressed and angry with myself when I cant sometimes do the simplest of things. I used to read quite a lot but now struggle with my vision and more so when I am tired.

**Brian - Working Life Service:** It might be worth looking at some alternative ways of coping with your short temperedness and frustration. Counselling can help but it is important that the counsellor knows something about MS and the changes it can make. Other ways could be yoga, tai chi, meditation or looking for a coping with stress class. Yoga and tai chi are good for both physical and mental relaxation

**Patrick - occupational therapist:** What sort of reduction in hours are you working at the moment? Sometimes changes don't work first time and they need to be revisited to see if they need to be altered more particularly if you're working shifts for instance. The other thing is that the NHS is a very large employer and you may be able to use your skills in a different role that lends itself to more flexible hours.

**Joanna:** I have spoken to my MS psychologist - she was very good and made a lot of sense. I might try some of your suggestions, as I really need to calm myself down when I find myself in stressful situations

**Gail - occupational therapist:** You seem to have had a lot happen at once. If you get so tired, do you have much of a social life or see friends? It might be worth trying to listen to a relaxation tape or regularly do some controlled deep breathing to try and calm things down for yourself. Have you thought about audio books? I know it's not the same, but you might find it helps you to relax and gives you something else to focus on?

**Brian - Working Life Service:** As regards reading have you thought about talking books? You don't need your vision and sitting down with the headphones on and listening to a good story is a wonderful way of shutting out the world and relaxing. Your local library should have a stock of talking books. The RNIB also has a large collection

**Joanna:** At the moment I work 8am to 2pm but I work in a very stressful environment for someone who is very demanding and although he is very supportive of me he does have his moments. If at the end of my reduced hours I am still struggling I will have to seriously think about another post in the hospital.

**Gail - occupational therapist:** You might find it helpful to go on an expert patient's course; they cover things like managing stress and frustration. You can find out about your local course through [www.expertpatients.co.uk](http://www.expertpatients.co.uk) I know this

course has really helped people get through a difficult time, so it may be worth checking out.

**Joanna:** I hadn't thought of those books. I will give them a try as I sometimes find it hard, even though I am exhausted, to drop off to sleep, whereas if I listened to one of those when first getting into bed I will probably drop off easier

**Patrick - occupational therapist:** I did some work with a Respiratory Specialist Nurse and one problem we had to solve was the enduring staff shortage on the ward. Eventually by highlighting to personnel their responsibility to comply with the DDA, they agreed to change the minimum level so that my client could actually have the rostered breaks off the ward. It actually made the whole team happier and more productive with less sickness so it ended up paying for itself!

**Joanna:** I think that's what our Trust is aiming for with the protected pay scheme they are running. My MS team didn't know about that until I told them last week because they are always trying to look at and resolve staff problems like this

**Brian - Working Life Service:** I want to endorse what Patrick just said. There have been many occasions when I have looked at ways of adapting the workplace for a disable person and the rest of the staff have taken it up. Sometimes employers just don't think in the right way.

**Joanna:** I don't have much of a social life. I split up with my partner just before being diagnosed and have been on my own since then. Mind you have now joined an internet site and have actually met up with several people and one person in particular. Mind you how I am going to tell him about the MS is another major concern of mine

**Gail - occupational therapist:** It's important to remember that no one is perfect. The MS Trust has a fact sheet about talking to friends and family about MS, perhaps that will be helpful to look at?

**Joanna:** I think I will get that leaflet. I haven't told him yet as I wanted him to see me as me and not somebody with a disability. A lot of people, as I have found to my disadvantage, are ignorant of MS

**Simon - MS Trust:** You can either download or order the factsheet from the Publications pages ([www.mstrust.org.uk/publications](http://www.mstrust.org.uk/publications)) or ring us on 01462 476700 and we'll get a copy to you.

**Patrick - occupational therapist:** That sounds promising. Do you think there is any mileage in trying to un-pick the stressors, i.e. what comes from where? Job (probably normal in the NHS!), home, family, MS? Are there any daily/weekly patterns to the feelings and frequency as well?

**Joanna:** I was chatting last wk to my MS nurse about my hours and really feel strongly about taking the NHS blinkers off completely to disabilities. So much so I have now volunteered to having my picture taken for one of their posters for a conference they are attending soon

My biggest stress factor is my job. As I have worked there for 22 years and I guess because no matter how much I try and explain because I don't look ill, they still bring all the problems to me.

I also feel I wish my family lived closer as my mum is not well herself and I try not to burden her with my problems

**Patrick - occupational therapist:** Sometimes employers aren't being obstructive, they just don't know and have the laypersons perspective on the condition. I have a client who works for a large private company and they change the area manager every 2-3 years. We have to go in and educate someone all over again so the carefully balanced system of hours and working pattern don't get challenged.

**Gail - occupational therapist:** Joanna, do you find it hard to say no when these people come to you?

**Joanna:** I do find it hard to say no as it's not usually in my nature to do that and I feel that by saying no to them I am admitting to myself I am unable to do something and that's when the frustration would start

**Patrick - occupational therapist:** I think being 'open' is the key to your situation. However, that is also a very difficult thing to do. If you have long standing colleagues then I'd start with them trying to explain how your MS affects you. I did do some work in someone's home where she felt there were very 'snappy' periods with the children. Eventually we settled on a 'jokey' mood thermometer in the kitchen so everyone knew when Mum was only to be bothered with really important stuff. Any mileage in trying that system at work? Or have set periods with gaps when people can bring their problems to you?

**Joanna:** I have taken so much literature into work for people to read and although they are enthusiastic to my face they tend to still be ignorant of my situation. I did talk at an MS conference three years ago to newly diagnosed people and did invite colleagues to come and listen and needless to say nobody did!

**Gail - occupational therapist:** I think you might have identified something that is contributing to your stress. As you have reduced your hours, it would be perfectly reasonable to say (nicely) I'd really like to help you but I really don't have the time. Don't look at it as you're not able to do something - you only have so many hours and you have to prioritise your boss' work first.

**Joanna:** I did chat to some of my close colleagues and told them that sometimes when I am really stressed and become irritable not to take too much notice if I start ranting (although I have never ranted at anyone I work with) as I don't mean things. I have never been a person to be like that and find it quite strange sometimes

**Gail - occupational therapist:** It sounds as though you bottle things up, until they burst out?

**Joanna:** I intended to talk to one of my admin bosses shortly anyway as they always seem to appoint the juniors to shadow me. That was fine a while ago, but now I can't handle it as I need to get on and have no time or energy to be teaching someone else

**Patrick - occupational therapist:** I also have difficulty saying 'no', especially at work. A mentor once said to me "If you never say no, people won't value your yes." I try to remember this when I get asked to do something extra.

**Joanna:** That's a really good comment Patrick - I will have to remember that one. Mind you, I will probably have to write it down as my memory is another thing that has suffered!

I am and always have been a really private person - so much so that when I am not feeling well I hibernate at home and don't get in contact with anyone (except mum). I have always been like that, even when I was ill when I was a kid

**Gail - occupational therapist:** I'm not sure that hiding away is a useful strategy for you anymore, it may be making things worse rather than better. Unfortunately as we get older, the capacity to stew on things seems to grow, and stress like this affects both our physical and mental well being.

**Joanna:** I know I shouldn't hide away but my self esteem hit rock bottom big time recently and it's only now climbing back up again. I just seem to face quite a few hurdles in my life

**Patrick - occupational therapist:** One thing you need to get the powers that be to understand is that job changes for people with MS are not 'fire and forget'. Since the condition varies over time, and depending on external factors that generate stress, you'll all need to revisit the adjustments on a yearly basis to review what is/isn't working. It's the nature of the beast really.

**Joanna:** I know when I first started the beta interferon I was much better for ages. Then, towards the end of last year, I began to feel ill again. So much so that it ended up with me having a relapse and having IV steroids for a few days. Mind you I had to be desperate for that as on the other two occasions I had them I hated it as you do tend to hit rock bottom for a few days before climbing back up to feel well again

**Gail - occupational therapist:** Jo, an occupational therapist who was with us earlier, suggested doing a SWOT analysis - strengths weaknesses and opportunities and threats. You might find it useful to have a good look at all your strengths. You are obviously good at your job, otherwise they wouldn't want you training junior staff, and they value you enough in the organisation to look at your hours etc. By going through all your strengths you can use this to remind yourself when you're feeling a bit down, and to challenge negative thoughts.

Also you might consider the expert patient programme as a way of finding out how other people face the horrible things life can throw at us, while also living with a condition like MS.

**Joanna:** I think I will look at the expert patient programme to see if I can pick any pointers up from that. The only other thing with regards to work is to win the lottery!! Mind you I enjoy being in work and very rarely take any time off through the MS. I will be working for many years yet (I hope)!

I think things might get a bit better anyway now my personal life is getting better and I might even start to feel better about myself

**Gail - occupational therapist:** Well, the transcript of these chatrooms is kept on the website for a while, so you can always come back and refresh your mind about anything we have suggested. Good luck Joanna

**Joanna:** Thanks for everyone's comments - they have been really helpful. I will keep an eye out for the next one....

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**Brian - Working Life Service:** I'm going to sign off now but I will keep an eye on what's going on so I might keep popping up at odd intervals. Good luck to all who have been asking questions

**Simon - MS Trust:** Thanks for your excellent comments throughout the day.

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**Janet - occupational psychologist:** Hi, I am an occupational psychologist with a job role that supports people with disabilities to find and keep jobs.

**Simon - MS Trust:** Welcome Janet

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**Alex:** I have been out of employment for some time now, due to family and the effects of MS. I am now wanting to start to look for work, but am a little apprehensive about being someone with limited stamina and a walking stick competing for jobs.

**Gail - occupational therapist:** What did you used to do before you stopped work?

**Alex:** Admin, secretarial work, then some shop work too

**Gail - occupational therapist:** Have you kept your admin skills up to date, as an admin job might be easier than shop work, which involves standing? Have you talked to anyone about going back to work?

**Alex:** I haven't really kept up my skills. And I've not really spoken to anyone about going back to work. Is there someone you'd think I should see?

**Gail - occupational therapist:** Well you could talk to the Disability Employment Advisor at your local Jobcentre Plus. Alongside that you might want to talk to an occupational therapist about work, as they might be able to help you think through what you might want to do, considering your MS

**Patrick - occupational therapist:** Sorry more questions! How long has it been since you were working, are you thinking about returning on a part-time basis?

**Alex:** It's been five years. I've split up with my partner, so I'm really looking for a way of making ends meet

**Gail - occupational therapist:** Brian from the Working Life Service had some really good advice earlier. He suggested that it was a good idea to see a welfare rights person so you could make sure that working wouldn't make you worse off financially, particularly if you work reduced hours

**Patrick - occupational therapist:** Gail's right about Jobcentre Plus being a good starting point. You might want to think about retraining related to things that interest you? Local colleges have lots of opportunities for vocational training.

Try listing things you can do and what the functional impact of your MS is so you have a starting point.

**Janet - occupational psychologist:** From my perspective, a chat with the DEA in the jobcentre would be a good starting point. They can clarify with you the benefit implications of any choices and check that you are getting what you might be entitled to. The Jobcentre has a range of programmes designed to support people and help them to get back into work. Nothing is forced on you! They can even do something called 'Better of calculations' that can give you an idea of the implications of working different amounts of time.

Following on from Gail's comment, with the range of benefits and tax credits for some people generally on lower incomes, reducing the hours can actually make much less difference to take home money than is often thought

**Alex:** Thanks Janet. That sounds good. It feels really scary to be starting to look for work again and knowing that there is help out there is very reassuring

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**C:** I have spent a lot of time and effort managing a range of symptoms and have got to know my MS pretty well. Having finally got to a stage where I'm reasonably stable, I'd like to explore the possibility of trying to work again but in a sustainable way without undoing all my hard work.

What worries me is that if I get into a position at work where I know I'm pushing it too much can I pull back before an exacerbation happens? Each exacerbation leaves residual damage that never clears and I'd like to avoid that if I can.

Or, in the words of a so-called disability support professional I spoke to: 'I don't know what you're worried about, if you get ill again you can always just go back on benefits'. It's not all about money. Sometimes it's about losing brain function or the use of a limb or being able to live independently and in not too much pain. Who decides? Do you really have to work till you drop? Is it all or nothing?

**Patrick - occupational therapist:** I think that there is great potential for proactively managing exacerbations but it depends on having good communication structures within whatever employment you get. Most people with MS who I've supported in work have set up such systems. So, for example, if they are coming down with a cold, they take sick leave early and judge when they are fit enough to return. Sometimes they have an agreement that their GP will certificate them 'on request'. The trick is making sure the job isn't generating too much stress and educating any manager to understand the subtleties of MS self-management

**Gail - occupational therapist:** It may be that permitted work might be one possible way of trying work out. See earlier response by Brian

**Janet - occupational psychologist:** Life is, to my mind, about balance and it can be hard to know whether one has 'done too much' until one has! Certainly permitted work might be worth thinking about. Voluntary work too can provide a bridge. While we know employers vary, a good dialogue with an employer may be fruitful. Certain jobs lend themselves to greater flexibility but specialized skills/knowledge can also be valuable to an employer, so looking for a correct 'match' in the job search may help with your concerns.

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**Alex:** Looking through earlier comments, it seems lack of self esteem and confidence are a big hurdle for people. It's certainly the case for me

**Patrick - occupational therapist:** I think this is a commonality for people with enduring conditions. The 'invisibility' and variability of MS often make it particularly difficult for lay people to understand. It's hard to maintain self esteem when people can't grasp that something that was OK last week isn't this but probably will be next week.

**Geoff:** Alex, I quite agree. When I started using a wheelchair my self image went through the floor. It took a while for me to accept I was just the same person, just sitting down. It takes a while to be able to see one's strengths, not just to dwell on any disabilities.

**Janet - occupational psychologist:** It's scary all right, and that is why sometimes I suggest considering voluntary work as a first step. There is a vast range of work available including admin work. The value is that it seems to provide the chance to test the water in a less threatening way and can enhance skills as well as providing recent experience that employers seem to like! I am thinking of one person who worked as volunteer with the NHS, learnt their IT system and then found herself well equipped to apply for (and secure) a part time job with them!

**Geoff:** The word 'disability' is commonly used as a blanket term, and just because there's something you can't do, there is the assumption that you can do nothing. I quite happily applied this to myself in my dark days until I realised how stupid and limiting it is.

**Patrick - occupational therapist:** I'd agree, Geoff, and the next sea-change for us is convincing employers to see people with disabilities as being potential assets.

**Geoff:** Quite. I work at a desk, so it hardly matters that the casters on my chair are bigger than those on everybody else's :-). They haven't employed me for my fancy footwork

**Gail - occupational therapist:** It's good that you have such a positive attitude. I take it from your earlier post that this hasn't always been so, what helped you turn things around?

**Geoff:** It wasn't easy for a long time. I had very black moods when I started to need a stick to get around and tried to resist using a wheelchair. But once I'd grudgingly accepted the wheelchair, I found that it freed me up no end. I could get about much more easily and didn't tire myself out walking with a stick. This meant I could achieve more and helped me see life in a more positive way. Not saying this is the answer for everyone, but it worked for me.

**Patrick - occupational therapist:** Very good! I think that anyone working who has MS is stuck being a pathfinder for the employment of anyone with a disability as companies are, of course, full of people who would classify themselves as 'normal'. I think the biggest frustration for people is employers want the kudos of being 'compliant' with the DDA but get all coy when asked to actually adjust a job or its environment. Best laugh I had was with one client who was allocated a 'close' parking space slap in the middle of the Directors zone Tee hee!

**Gail - occupational therapist:** Bill who was in earlier on was having difficulty coming to terms with his MS symptoms being more noticeable at work. Would you have any advice for someone like him?

**Geoff:** I've found it best to be very upfront about my MS and wheelchair. If I present myself as this is how I am, people have been happy to accept that and let me get on with my job. When I was more apologetic about myself, people were more patronising and actually, unintentionally, reinforced my low opinion of my own abilities.

I'm fortunate that I'm able to accommodate fatigue by managing my time, and also that I'm able to think straight. I know these can be problems for some people with MS. It took a while, but I'm now secure in what I can do and a much happier person for it.

I don't mean 'think straight' to sound as dismissive as it looks written down. I'm just comparing myself to a friend with MS who has problems concentrating for very long and also has a dodgy short term memory. I don't have these symptoms. Mind you, his legs that work better than mine

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**C:** I had to give up my job a few years ago. If I try to get another job now, what are the realistic chances of getting a permanent post? If my previous employer wouldn't keep my job open indefinitely when I was ill for an extended period, what are the chances of a new one doing so?

I have this fear of the Job Centre pushing me into some awful call centre job on one of those long-term temporary contracts and as soon as I'm off sick the company will just not renew the contract – gets the Jobcentre targets down and me off their books for a while, but in the long-term where will I be?

If I were only working part time would I have enough NI contributions to qualify for Incapacity Benefit again? I know there's something about being able to go back to the benefits you're on if you get ill within 52 weeks of starting a job, but what if it happens in week 53 or 54? It's going to happen at some point, it's not as if there's going to be a miracle cure for MS within the next couple of years.

**Janet - occupational psychologist:** To my mind the question that first needs consideration is what would you like to do work wise? Spending time considering your skills, interests, motivators, strengths and previous work history are very important in securing a suitable long-term sustainable job. What you may also find helpful is think about the job market and your needs in terms of location, transport and so forth.

The Jobcentre are keen to find people work, it is their job after all! But they do ask what your work goal is and if you are on Incapacity Benefit then there are programmes there to help you move back to work, permitted work has been mentioned and permanent jobs can be part-time if that suits you.

If the worst happened and it did not work out in week 53, then you would make another claim for benefit having been signed off sick by your GP and if you did not qualify for IB then Income Support could be an option. I don't know the rules in detail but you might want to go in and discuss it with an Incapacity Benefit Personal Adviser and get them to do the sums for you in different situations

**Gail - occupational therapist:** Well it's stopped raining so I think I feel brave enough to walk home, so will say goodbye. I've found it stimulating to read and hopefully respond to people in the chatroom. Good luck to everyone

**Simon - MS Trust:** Gail, thanks for all your input to this chatroom and also the At Work With MS book (now available on the Publications page)

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**Geoff:** Janet, you are listed as a work psychologist. Could you explain what this means?

**Janet - occupational psychologist:** Well I can try! I am by training an occupational psychologist. My remit is to offer support to colleagues helping them to increase their understanding and skills when working with individuals with disabilities. I am also there as a listening post for them when they feel stuck. I do see individuals who are looking for work or in work and explore with them what it is that is making it harder for them to carry out their job or what needs they might have to help them sustain work. Sometimes this will involve undertaking psychometric assessments. Does that help?

**Geoff:** Thanks

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**Emma:** Geoff was mentioning problems concentrating. I get that. As the day goes by I can find my mind turning off and it's a real struggle to try and stay focussed on what I'm doing

**Patrick - occupational therapist:** It's common for concentration to drop, especially if fatigued. Does it always happen towards the end of the working day? If so, one strategy might be to build in a very specific rest period earlier in the day. This can be a 'reasonable adjustment' under the DDA as a way of managing the effects of MS.

**Emma:** It does seem to be the afternoons that are worst. Sometimes my brain seems to go a bit mushy, other times it's as if I'm getting too much information and have to go and find somewhere quiet to sit

**Janet - occupational psychologist:** Sustaining concentration over a long period is never easy. Have you tried anything? There are things different people find helpful. For example, actually taking a break away, looking at how you plan the day in terms of activities, finding a quiet location, introducing your own noise through headphones, motivators like rewards, fresh air, breaking the task into small chunks, deep breathing... Experimenting may be helpful and I am sure others will have other ideas

**Emma:** I work in a shopping centre, which is full of colour and movement and piped music. Sometimes it can seem so overpowering that I feel I need to get outside for a breather so that I don't faint.

**Janet - occupational psychologist:** Not sure how practical it might be but swapping tasks might help. If it is fatigue related then, as Patrick said, giving yourself a break may be more productive than struggling through it. We all have our own natural patterns of wakefulness that can impact as well

**Emma:** At work they are quite good with MS and I've redone my hours so that it's not so tiring and so on. But I'm worried by the bouts of slushy thinking and these panicky attacks.

**Janet - occupational psychologist:** Do you have anyone you could help you develop a relaxation technique? Just something you could do for three or four minutes maybe? I use a simple visualization exercise

**Patrick - occupational therapist:** I think a break is probably the best method. We know that people with MS can get overwhelmed in environments that stimulate lots of senses at once, so going into a quiet area - staff room or even a stock room - could help. If you can negotiate a specific time and period then people will know where you are and why rather than wondering if you've disappeared off. Having had the 'time out' from the noise and lights you may then find managing for the rest of the day easier?

**Janet - occupational psychologist:** I agree with Patrick. Getting agreement and a good space with a suitable chair is important

**Emma:** I hadn't realise the overwhelmingness could be MS. I knew the concentration thing might be.

**Patrick - occupational therapist:** Do you have concentration problems in quiet environments, say at home? If not then it's probably the stimulation that is 'overloading' you and the more tired you are the more it's likely to happen, which is why a rest may help.

**Emma:** I seem to be OK at home. I can find the cinema a bit much at times, but don't go very often and it doesn't always happen.

**Janet - occupational psychologist:** Often feeling panicky is linked with feelings of not being on top of things or not being in control, which is scary. The chance to 'regroup' is important

**Patrick - occupational therapist:** You'll probably find that it's a combination of factors working together that trigger the 'overload'. You might want to try keeping a simple diary of things like fatigue and if the day was busy or stressful or you have cold coming? If you can find a correlation between factors you can start looking at controlling one or a number of them.

**Emma:** Thanks, I'll do that. I've learned to cope with (or at least accommodate) the mushy brain and the fatigue, so something that heads off the overloads would be good.

**Janet - occupational psychologist:** Hope you find something that works for you

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**James:** I'm having difficulty settling back into work after a few months off with a relapse. I seem to be Ok for a few days, but then get headaches and find I need another day off to recover. I'm beginning to wonder if I should face up to quitting my job.

**Patrick - occupational therapist:** Do you get the headaches at other times, are the regular or related to varying work stress?

**Janet - occupational psychologist:** How long have you been back in work? What kind of hours are you doing? Did you have a 'reintroduction' back after you had been off?

**Brian - Working Life Service:** It is often useful to have a phased return to work after you have been off for some time. Maybe going back for a few days a week or a few hours a day whilst you build up your stamina. You can gradually return to full time work.

This can be considered a reasonable adjustment under the Disability Discrimination Act

You need to negotiate this with your employer. The Disability Employment Adviser at the Jobcentre Plus or your MS nurse/occupational therapist should be able to help if you don't feel confident enough to do this on your own

**James:** I went back to work on a more part time basis. I haven't felt like this outside work, and think it could well be part of getting back into the daily cut and thrust of work. I thought I'd be OK, but maybe I've taken on too much

**Janet - occupational psychologist:** Going back to work after a break is stressful demanding and tiring in its own right, quite without the MS. So it might be worth having a chat with your employer about your job role and tasks. Start back very gently - an hour or two a day to start with clear goals that give you a sense of success.

**Brian - Working Life Service:** It sounds like you have tried to take on too much at once. You could consider a further phasing in of work (ie do less hours/days) or you need to look at the tasks you are doing. Are there any tasks that overwhelm you? A different way of phasing may be to leave out the onerous tasks until you feel up to them.

**James:** I suspect it's problem of my own pride - wanting to get back to where I was before, along with the feeling that my company is rather grudging about the changes they have to make for me

**Patrick - occupational therapist:** People in your situation often think that having asked for an adapted job it's a 'one shot deal' but you can't expect to get it right first and every time. A bit of renegotiation is probably needed, even if it's only temporary.

**James:** After so long off, it's very hard to accept I've got my return to work wrong. Maybe I'm putting too much pressure on myself

**Brian - Working Life Service:** Your company has business, legal and moral case to make it as easy as possible for you to get back to work.

The company has paid out to recruit you, train you and support you so that you are doing a good job. If they let you go, they have to go through the expense of having to train someone else and wait whilst they become efficient at the job.

It is also a legal duty under the Disability Discrimination Act to make 'reasonable adjustments' so that you can return to work effectively.

And, over the years, you have given a lot to the company - now it's time for them to give you some respect and support

**Janet - occupational psychologist:** From this distance, it seems to me that talking to them a bit more at this stage may help in the longer term. If by doing shorter hours you are delivering and attending regularly, they may feel more positively about the situation than perhaps feeling you are not as reliable as they would like. Over time the hours may well increase.

**James:** Thanks. It's easy to forget that and get frustrated about getting back to a regular routine. Yes, maybe I could stretch things out a bit and not keep having these crashes

**Janet - occupational psychologist:** I think maybe you are being a little hard on yourself! Starting any new job or going back to work after a gap is tough. Have they given you any induction as they will be things to 'catch up on'. This can help

As Brian says they do have a duty to you under the DDA and your manager may need that pointed out to them. While senior HR professionals are aware, line managers may not always be as fully aware as they should be and have pressure on them in terms of delivery.

**James:** I'm sure I'm being tough on myself. I was always pushing myself at work and so being laid up was extremely frustrating. I'm finding it difficult not to be up to speed straight away now.

**Janet - occupational psychologist:** Most of us cannot run a marathon without building up to it, so why should work be any different?

**Patrick - occupational therapist:** When I'm working with employers, I go right back to basic explanations about how even the person with MS is having to guess to some extent what adjustments they'll need. I tend to explain everything fairly regularly to the laypeople involved so they grasp that there is an unpredictability to symptoms and that they can be transitory. Even if they say they understand the condition, I say I don't know that much and I'm meant to be an expert - every person with MS is utterly unique. The challenge is establishing the dialogue with the 'right' people in a company or structure.

**James:** I get the feeling that their obligation under the DDA is just that - an obligation. There's no great concern about me as an individual.

**Brian - Working Life Service:** That is sadly too often the case. However, there is legal redress if they don't follow their obligations. Some companies need a kick up the a\*\*e. There, that's got a bit of my anger out!

**James:** Thanks Brian - good to know it's not just me :)

**Patrick - occupational therapist:** It may just be the obligation driving the company, and managers often only want a quiet life, but the legislation is very powerful. If you can present a 'solution' to them, saying it means they'll be meeting their obligation, they may well comply quite easily. Since work sounds difficult at present, what have you to lose by making the request for further changes?

**Janet - occupational psychologist:** Employers do struggle to understand many disabilities, MS in particular. If the initial dialogue can include how it is variable and set up the open and frequent discussion that Patrick has mentioned, then in my experience the trust, understanding and willingness to be flexible increases

**James:** I'm sure this is right. It goes against the grain perhaps, but I suppose it's more hassle to get rid of me than to make it easier for me to stay

**Janet - occupational psychologist:** Going into a meeting with ideas and suggestions that have value to the others round the table is a win-win situation. You do have things to suggest that make it more manageable for them as well as you. It can be about presentation, even if they are starting from the point of obligation

**Patrick - occupational therapist:** I'd agree about the a\*\*e kicking. Some years ago I was working with someone who was employed by a household name and they went all the way up to a week before the court date until capitulating! The person involved is still working for them seven years later because we forced the reasonable adjustment issue. I'm afraid it is still trailblazing for many people working who have a disability.

**James:** Thanks to you all for your advice. You've pushed me towards what I probably knew I should be doing but was a bit reluctant to face up to.

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**Patricia:** When I hit 60 I was offered severe disablement allowance (SDA) or a pension. I took the SDA as this pays my stamp. Given that able bodied people can take their pension at 60 and then go back to work, how does this decision affect me? I know that SDA is being phased out but there will be other people in the same situation as myself.

**Brian - Working Life Service:** I understand the position to be this. SDA is given because the recipient can not work (they must be 80% disabled). So if you go to work you will lose your SDA. However, as you are now entitled to your pension, paying your stamp is no longer relevant. So if you gives up your SDA and claim your pension, you will be able to work as well.

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**Simon - MS Trust:** We're coming up for 7pm when this chatroom closes. Thanks to Janet, Brian and Patrick and to Gail and Jo earlier in the day.