

Incapacity Benefit and employment –

the experiences of
people with MS or arthritis

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The MS Society is the UK's leading charity for people affected by multiple sclerosis (MS), the most common disabling neurological condition affecting young people in this country. With more than 44,000 members – including more than one-third of all people with MS in the UK - we provide support and information, invest in research, campaign for better health and social care services, and do what we can to ensure that life doesn't stop when MS starts.

The average age of diagnosis for people with MS is between 20 and 45, a time when people are at a key stage of their working life. This diagnosis can have a devastating impact on people's lives, forcing people to face an uncertain future with an unpredictable condition.

Yet many of the initiatives designed to help disabled people and people with long-term conditions frequently fail to do enough for fluctuating and hidden conditions. All too often, people with MS do not have the support they need to help them remain in or gain employment.

We're pleased to have worked alongside Arthritis Care to explore the experiences of people with fluctuating and progressive conditions with employment and incapacity benefit. This report complements our recent publication *Working and MS*, and we hope that both will provide useful resources to further the understanding and sensitivity needed when considering the barriers to employment faced by people with MS.

Ken Walker
Deputy Chief Executive, MS Society

Arthritis Care is the largest UK-wide charity working with and for people who have arthritis. We aim to make a positive difference to their lives. For people with arthritis of working age our message to the Government is clear: practical support for those who can work; proper financial support for those who cannot; and fair and flexible arrangements for those with a fluctuating condition who may not fit neatly into either category.

People with arthritis form the second largest group of Incapacity Benefit recipients, yet we know that many would like to work. They face a number of barriers to doing so, including employers who misunderstand changing and hidden impairments – which can cause problems with benefits too.

While changing and hidden impairments are characteristic of arthritis they apply to people with other conditions. For this innovative piece of work Arthritis Care is pleased to have worked with the MS Society to broaden our joint understanding of the experiences of people with arthritis or MS who have changing or hidden impairments.

I hope that this work will be a useful contribution to the debate about the future of Incapacity Benefit.

Neil Betteridge
Chief Executive, Arthritis Care

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1. Introduction

1.1 The Department of Work and Pensions is planning to change Incapacity Benefit from 2008. The Government is currently carrying out a consultation to ask people to comment on the proposed changes. Arthritis Care and The MS Society will be responding to this consultation. They have jointly commissioned a small research project to help them draft their responses.

1.2 The aims of this project were to:

- Listen to people's experiences of applying for incapacity benefit, living on incapacity benefit and/or being in work
- Explore the particular issues faced by people with fluctuating conditions and hidden disabilities
- Find out what helps people with MS and people with arthritis to find employment and stay in work

1.3 The project involved interviewing 23 people by telephone: 10 people with arthritis and 13 people with MS. This group included 9 men and 14 women from across England, Scotland and Wales. The interviewees were selected on the basis that they had made use of employment-related services, training or advice provided by Arthritis Care or The MS Society.

1.4 This report summarises the findings from the telephone interviews which were held in March and April 2006. The findings are described in detail in Section 2 under the following headings:

- Applying for incapacity benefit
- Living on incapacity benefit
- Finding employment
- Support to stay in work
- Views on the proposed changes to incapacity benefit and employment

1.5 The main themes from the interviews are summarised in Section 3.

2. Findings from the interviews

2.1 Applying for incapacity benefit

Deciding to apply for incapacity benefit

The decision about whether to apply for incapacity benefit for most people is really secondary to a far bigger and more difficult decision about whether to stop working.

Many people reported 'struggling on' in their jobs because of the many benefits of working (see section 2.2). However, for some people there came a point where they realised that continuing to work was having too great an impact on their health or came at too great a cost to the rest of their lives to be able to carry on:

"At home when I start to do something more physical, I can only do it for a short period of time. Then I go and sit down for an hour, but you can't do that at work. So know I just couldn't do it – though I still think about it from time to time."

(person with MS, South East England)

"We moved to different premises a year ago...and it was a lot bigger, so I was having problems doing the hours. I'd cut my hours over the last 5 years but it got to the stage where I had to give up."

(person with MS, North West England)

"I couldn't lead a social life because I was so shattered from work that I didn't want to go out in the evenings or at weekends because it would mess me up too much for work. Now I'm on incapacity benefit I have more of a social life than I had before. I go out with my wife a lot more."

(person with MS, South East England)

One person also said he thought it was time to stop working because he felt he was letting down his staff:

"I was having trouble with mobility and we decided it was the right time to leave...The only problem was there was only one lift there, and if it was out of order, I had to go up and down the stairs, well you try and do that a few times...I did think I was letting them down. Because I was in management. Every time I had to reduce my hours I had to alter the way that I was working and I felt that it was putting pressure on the other people in the team."

(person with MS, North West England)

For others, having to give up work is not a choice but a necessity, in which case incapacity benefit seems to offer some form of compensation:

"It's not the difference between being on incapacity benefits versus working, it's working versus not working...I didn't consider it in any sense to be a choice."

(person with arthritis, London)

The application process

For many of the interviewees applying for incapacity benefit was simple and straightforward and seemed to automatically follow a period on sick leave or a relapse in hospital:

"I was on incapacity benefit for two years. I wasn't assessed, it was automatically arranged by my GP and the hospital."

(person with MS, Wales)

“It’s just I had time off sick from work and gradually after a time it became clear that I wasn’t going to be able to go back and it carried on into incapacity benefit after that time.”

(person with arthritis, North West England)

“I went straight from sick pay onto incapacity benefit. Because of the nature of the disease and how severe it was at the time they didn’t need to assess me because I was already on higher level Disability Living Allowance... Nobody ever contacted me.”

(person with arthritis, South West England)

For some people the process was more challenging. The sheer volume of forms seemed overwhelming and they expressed a need for help with navigating through the system.

“That’s one of the difficulties, the lack of information about benefits, it’s a minefield, especially when you’re like me, I’ve never been through it.”

(person with MS, North West England)

Others experienced administrative errors causing lengthy delays in processing their application:

“I went on benefits...it was a bloody nightmare. The amount of forms...I got the wrong advice about which scheme to go on. I had to spend the whole day at the job centre to sort it all out.”

(person with arthritis, East of England)

“It took a long time before I got going in the system...it took some time to even get the forms out to me...but once the forms were filled in and sent off then everything else went very quickly.”

(person with MS, South East England)

The assessment process

Some people had no problems with the assessment process. They felt that the questions were relevant, there was room to add their own comments and it had been easy to prove their eligibility for benefit. Other people had experienced serious difficulties. It seems to be the luck of the draw as to whether the person carrying out the assessment has any knowledge or understanding of different conditions. As one person with MS describes:

“I explained that I’d got MS...They didn’t quite grasp fully what it was...They said ‘Oh yes I’ve heard about that’, but then as the interview went on and they said ‘Really we don’t understand how it affects you’...So I was having to go along and give them information...They couldn’t really understand it.”

(person with MS, Yorkshire and The Humber)

Two people with arthritis felt that the assessment process had been inappropriate and had not asked questions relevant to their condition. However, both of these experiences took place over 10 years ago. As one person describes:

“The doctor came to my house and asked me a few questions and asked me to do a few physical things and wrote a report and I was turned down...but at the time I couldn’t drive, wash my own hair, cook a meal, I couldn’t pick my children up or change a nappy. But because I could walk a mile I was turned down.

They focused on whether I could go to the toilet on my own. The thing was I could, but it was very tricky with only one hand, but there was no way I was going to ask anyone else to help me when I was in my twenties.

They didn’t ask any relevant questions. They asked me ‘Can you lift a saucepan?’ Well I can with my left hand but I can’t drain it, and I had dropped a fair few using my left hand when I was used to doing everything right-handed. All they wanted to know was whether I could lift that saucepan, not whether I could empty it, serve the things or chop the veg in the first place.”

(person with arthritis, East Midlands)

Another person recalls:

“I do remember having to fill in the questionnaire about whether you could put a hat on your head and carry a bag of potatoes...That wasn’t very relevant, because it was asking can you do this activity once, it wasn’t saying could you do this 5 days a week, 52 weeks a year. So yes you may be able to do that activity once, but it wasn’t appropriate because it wasn’t asking if you can do it over and over again.”

(person with arthritis, North West England)

Similarly a person with MS felt that the questions asked during the assessment are not relevant to people with MS, because they don’t take into account the fluctuation in symptoms.

“Some questions are not relevant. E.g. How far can you walk today? How long would it take you to walk x distance? When do you think you will be able to walk x distance again?

He asked me if I could go upstairs and I can do...but only on my bottom and with great difficulty. I didn’t think I met the criteria, but the assessor ticked the box that I can use the stairs – and my benefits were dropped.”

(person with MS, East of England)

This person subsequently appealed and was successful in getting their benefits reinstated. However, others felt they hadn’t the strength to take on a battle because of their poor health:

“I was already upset and in pain and distressed...but I thought right I’m not entitled to it [incapacity benefit] so that’s it, so I continued to work to the point where it just about killed me.”

(person with arthritis, East Midlands)

Improving the assessment process

There were several suggestions as to how the assessment process could be improved including:

⇒ Training the assessor so that they are more knowledgeable about different conditions, especially fluctuating conditions and hidden disability

“It’s not just how people feel at the time, and I did try to get that over, I look perfectly normal...but it’s how differently MS affects different people. I do think that in a lot of cases they’re not specialist in any one field and it’s a shame really, because with a changing condition like MS, you do need a specialist.”

(person with MS, North West England)

⇒ Asking more in-depth questions in interviews

“You have to have more of an interview, so that you can ask more probing questions, so that you can ask how would this affect you or what would happen if...Rather than just saying ‘Can you do this yes or no?’.”

(person with arthritis, North West England)

⇒ Relying on the opinion of health professionals who know the individual concerned

“However much your GP says... you’re not going to be able to work, you still never know because you then get referred to a Department of Health doctor who doesn’t know you. I think they should take more notice of what an individual’s GP says because they know the person better.”

(person with arthritis, North West England)

⇒ Relying on people’s self reporting of hidden symptoms such as pain

“The one difficulty with the assessment is measuring pain - it’s totally subjective – people vary in what they can tolerate – and work helps by providing a distraction. So a process of assessing people relies on people being honest about their pain – no one else can really measure that. Will the system be flexible enough to allow people to make their own assessment?”

(person with arthritis, East of England)

⇒ Providing permanent certificates of incapacity to work

“I think if it’s obvious from a medical person that you’re not going to be able to do any kind of work, then you should really have a permanent certification of some kind. So that you know you are going to be entitled to benefits unless you improve.”

(person with arthritis, North West England)

2.2 Living on incapacity benefit

Some people do not feel at all comfortable receiving incapacity benefit and would really prefer to be working:

“I was...feeling like a second class citizen because I was on IB...And I still feel very emotional about that. It upsets me that for 10 years I felt like I have been sponging off the state and that I didn't deserve it somehow. I've never felt comfortable with it...It's a horrible name for a benefit. You're incapacitated... In my heart of hearts I felt I should be working. I'm of that generation where you always pay your way...It's never felt comfortable to be unemployed.”

(person with arthritis, South West England)

Some also have a concern that because their disability is hidden, others might think they are not eligible to claim:

“I do feel under-valued by society...the first question whenever you meet somebody is ‘Oh what do you do?’ That's definitely a down side of it...I think the bad press does us no favours. There's always people who play the system and who are claiming benefits they're not really entitled to, but that's puts a slur to everybody else, we're all viewed the same way. Particularly when it's a hidden impairment.”

(person with arthritis, North West England)

Some people see incapacity benefit as a form of compensation for not working, whereas for others it's just an income:

“It's [stopping work] changed absolutely every aspect of my life, really...loss of self-esteem, loss of status, loss of ready money...Having a job is terribly important psychologically, and if it's a good job, and a job that you enjoy, then I think being on incapacity benefit, it's a compensation from something that you're excluded from by a condition that you haven't chosen.”

(person with arthritis, London)

“I suppose it is an income of sorts. But really that's all.”

(person with arthritis, North West England)

The financial gains are small and may not be sufficient for everyone, but they do make a difference:

“It isn't a sufficient amount of money. I get by, but it prevents me from doing a lot of things I'd like to do.”

(person with arthritis, North West England)

“It's the difference between living in a place where you want to live in and you can afford to live in and being forced to move... And having to move just to be able to afford to live... It's made us feel comfortable, not pressured to have to do anything drastic...We haven't got loads of money, and we're not well off, we never will be, we just take it as it comes, but we've got enough to manage.”

(person with MS, North West England)

“It has enabled me to do things that I wouldn’t otherwise have been able to do... That makes it sound like I’m having a whoopee time, and I’m not, but you have to make a life when your life has been completely focused around work... You have to look for the positives.”

(person with arthritis, London)

2.3 Finding employment

The desire to work

For the people with MS or arthritis who are able to work, even if only part-time, staying in work is essential not only for financial reasons, but also for people’s health, self-esteem and sense of well-being.

“I know that if I didn’t work I would become so stiff, the bowels would be worse and mentally I would shut down – so it does help to keep as flexible as you can.”

(person with MS, West Midlands)

“I want to be at work for my sanity’s sake.”

(person with arthritis, East Midlands)

“It forces me to get, up, get dressed and go out... It gives me a purpose... And meeting other people and keeping your brain working, and just knowing that you can actually give something, instead of just taking all the time... and of course to earn something for yourself.”

(person with MS, South East England)

“People think if you’re disabled and you’re in a wheelchair that you don’t work and I think it’s very important to have some another identity, not just a disabled person.”

(person with MS, South East England)

“[Going back to work] has made an enormous difference. Absolutely enormous. My daughter’s got a working mother role model, that’s really important. Secondly I’ve got my independence back and my sense of self-worth is returning ten fold. And our standard of living has gone up. Well it’s doubled. We’ve never had a family holiday since my daughter was born, she’s 12, so this is the first year we’ll be able to afford to have a family holiday.”

(person with arthritis, South West England)

Disabled people are also prepared to work extra hard once in they are in a job to ensure their value and contribution is recognised:

“I don’t want to give up work, it’s important to me to keep working... I do work hard when I go in there. Just because I’ve got a disability, I’m still giving something... I do pull my weight when I am in there. I daren’t not, actually.”

(person with MS, South East England)

For people with a progressive condition, changes or fluctuations in their health are very worrying and it’s at this time that they need extra support to help stay in work or

access benefits(see also section 2.3). For example one woman who has arthritis and is a single parent explained:

“The changes are frightening me a bit because I’m getting worse and having all these problems with my job. I was working 30 hrs, but that has been cut down to 15 hrs and now I’m struggling with that. I really, really want to stay at work but I don’t feel like I get any support – but if I don’t work who will pay the mortgage?”
(person with arthritis, East Midlands)

Incentives to work

The financial incentives for work are obviously important to people and it is essential that any Government scheme that wants to help people back into work makes employment financially viable. The Return to Work Credit (RWC) does help in this regard. As one person described, the RWC was crucial to her return to work:

“At the time the Return to Work Credit gave me extra income...I started to work 16 hrs - which was less income than what I got on incapacity benefit, so [the credit] topped it up and helped with extra expenses of travelling to work...[otherwise] I would have had to take a job with more hours to make up the money, so it was quite important to me.”
(person with arthritis, Scotland)

However, there is a danger that people might be encouraged to take on more work than they can cope with. Another person was encouraged to increase her hours to 16 hours per week, in a job that was only advertised at 9 hours, so that she would be eligible for the extra money. But working the additional hours put too much strain on her health.

Some people fear that if they go back to work they will lose all their benefits and be far worse off:

“I get housing benefit, council tax rebate, DLA and incapacity benefit – if they all went if I got a job, I would have to earn over £22k to stay at same level...It’s simply not possible for me to get a job paying that much. I’d prefer it if the Government topped up your earnings to keep you at same level of income. It would cost them less money to do this than for you not to work at all”.
(person with MS, East of England)

Being able to go straight back onto incapacity benefit is also a vital fall-back for people contemplating going back to work after a period of illness:

“If you were on DLA for life they didn’t question your Incapacity Benefit... Which was why it was so scary to think of coming off it.... They hold it for me for 12 months anyway, and if I couldn’t cope with the job I could go straight back onto IB without any questions being asked.”
(person with arthritis, South West England)

“[The best thing was] knowing there was a fall back that I could go back onto benefits without having to worry about that.”

(person with arthritis, Scotland)

Recognising new limits on your capacity to work

One of the common problems that a number of people reported is that they didn't have a realistic idea of their capacity for work when they started to look for a new job. This is understandable given the extremely difficult and emotional challenge of coming to terms with 'not being able to do what you used to do' and having to accept new limits and restrictions imposed by your health condition.

“Initially I wanted to go back to work for financial reasons and was feeling at that point that maybe I could manage going back to work part-time. When I look back I think I over-estimated what I could manage.”

(person with arthritis, Scotland)

“It took a while to accept that I can't do what I used to do.”

(person with MS, South West England)

“I've got a bit of denial... I've taken a full-time job and pretended I'm not sick. I think the advice I'd give would be to try to limit yourself, not to get a very demanding job, just get something you can tackle. I'd work 12 hours and I'd spend the next 2 days lying in bed just to get over it, then I'd get up and go back to work again. It's very devastating because you never expect that you're not going to be able to keep on working.”

(person with arthritis, East of England)

“It's knowing what you can do – so you can enjoy your work without putting too much strain on your health.” (person with arthritis, Scotland) *“I was struggling at work...because I had heart attack 3 years ago and had a triple bypass. After I recuperated I went back full time and it absolutely killed me. The doctors then said I should have gone back part-time and slowly built up my hours. So I went down to 20 hrs and worked up to 30 – but since then my MS has got so bad that even the effort of going into work is too much.”*

(person with MS, South East England)

In particular, people who are newly diagnosed may not immediately acknowledge, or may not even be certain of, their future limitations. Even if a person is currently feeling well, they may have to anticipate being unwell again in the future and choose their employment options accordingly. This is not an easy thing to do.

Nor is it a simple matter to adjust to changes as a condition worsens over time. The uncertainty and unpredictability of health conditions like MS and arthritis makes this even more of a challenge. People may suddenly have to make major adjustments to their work and home life, due to unexpected and frightening changes in their health. Nor can they be certain of how long it will take, or even whether they will fully recover from a relapse or a flare-up. Many people feel they don't want to give in when this happens:

“Initially, when it first happened, I’d lost the use of my legs, it was very scary.”
(person with MS, Yorkshire and The Humber)

“I’m really beginning to find it too much. The trouble is I won’t give in to it – I do too much and over do it and end up down on the floor. A job keeps you going – gets you out and doing something... but it’s all getting too much.”
(person with MS, South East England)

“I think it’s the not knowing where you’re going to end up, it’s when you’re not used to having to ask for help... Sometimes you feel like a fraud, but people don’t see me when I’m really ill, and sometimes I tend to forget that I am ill, you do push yourself. I think it’s a case of not giving in, you don’t want to give in.”
(person with MS, North West England)

Finding the right job

A number of people had ended up in jobs that were unsuitable and placed too many demands on them. This may have happened because some people had unrealistic expectations of how much work they could take on. However, others may simply not have known what their new job really involved, because they were forced to change their career on account of their health condition. Nor do job descriptions always provide an accurate picture.

“I got a job in a hospital pharmacy which is completely different to anything I’d done before so I didn’t have much idea about what the job would entail... my health got worse and worse because the amount of lifting I was doing. I was lifting boxes that weighed up to 25 kg. And I had to go into drug cupboards that were high up so I had to climb up on things and reach above my head, which I’m not supposed to do. It caused more and more problems until in the end I had to have my shoulder operated on and then I was off for 10 weeks. When I went back I was in so much pain I was being sick all the time. So they ended up redeploying me.”
(person with arthritis, East Midlands)

“I was in a part-time job – admin – it was advertised at 9 hours per week, but it changed. I ended up working on average 25 hrs a week. My health ended up getting worse... It was more the hours than the job... I thought I could manage – so I didn’t ask for support. It was my own expectations of what I can do... But it got to point where my health was really suffering so I stopped.”
(person with arthritis, Scotland)

It is of great concern that some people end up in unsuitable jobs, not only because of the effects on their health, but also because of the effects on their self-esteem. If people end up feeling a ‘failure’ for not being able to cope, this can have a major impact on their confidence and their subsequent willingness to find further employment.

Support with finding work

Like any other jobseeker, people with MS or arthritis benefit from the practical support (e.g. resource centres) and training (e.g. in interview skills) provided by Job Centres to help find employment.

“My job-broker helped me draw up a CV, look for jobs, and provided facilities to help find jobs, help with form filling, and interview tips to build up my confidence. Practice interviews really helped – I hadn’t worked for many years so it was daunting going for interview. Everything was there for easy access - lots of newspapers and somebody to help with queries.”

(person with arthritis, Scotland)

“Another positive thing was she revamped my CV... she told me most people who look at CVs only look at them for 30 seconds, so you need to make sure that they’re going to get to like you in 3 sentences. She was really good at getting me to look at that. She did it all for me on the computer...And she was also there if I wanted somebody to help me fill out application forms, so she was very good from that perspective.”

(person with arthritis, South West England)

However, unlike other jobseekers, people with MS or arthritis have additional support needs – they need extra help in coming to terms with and managing their condition, as well as support to overcome the fear, lack of confidence and depression caused by the unwelcome and uncontrollable changes in their lives. People often say they find it very difficult to talk about their disability and need support to do this. This kind of emotional support does not seem to be as readily available, although it seems to be of equal importance in helping people to find work.

“I have a problem accepting my health. Because I used to be sporty and independent I find it really frustrating. I’m really upset and angry. It’s really difficult to explain to people. It’s not just one word. It’s a whole list of things most people have never heard of and I don’t want to have to explain it all.

It [Support to Work] gave me some of my confidence back and gave me the encouragement and support that I needed. I was feeling low and thinking why would anyone want to employ me when I’ve got all these problems.”

(person with arthritis, East Midlands)

“I went to see my Disabilities Officer, who was really helpful...And he was also very honest about the fact that ‘Look at the end of all this you might actually find you can’t manage to work and that’s OK too’...I went in and said ‘I really want a job, I really, really want a job and I’m quite stable at the moment. What can we do and how can we do it? And what happens if I can’t cope?’ I just asked him masses of questions. You know like ‘What happens if I do a few days and then it kills me and I can’t manage any more?’ And you know ‘I haven’t worked for 10 years and I’m quite anxious’. I really laid bare my soul really. Because I wasn’t going to do this lightly.”

(person with arthritis, South West England)

Another person who had been a participant in the Government Pathways to Work Scheme reported the following benefits of taking part in a Condition Management Programme:

“It helped me to know better where my limits are...I saw a team of health professionals, who looked at your condition and how best manage it to get back into work. I saw a psychologist because I have had problems with depression as well, and a cognitive behavioural therapist. I went once a week for six weeks to look at where I thought had problems with working and to find ways to solve that...It built up my confidence again. And helped me look at what went wrong with the previous job and how I can make sure in future that doesn't happen.”

(person with arthritis, Scotland)

Another person said that what they wanted from the Job Centre support was:

“More emotional and moral support – to find a job that does suit me – help me find a job that's suitable and to deal with the employers, to tell them my needs. I find it hard to discuss with people.”

(person with arthritis, East Midlands)

The role of Disability Employment Advisers (DEAs)

Given the challenges faced by people with MS and arthritis seeking employment, it seems that a crucial role for DEAs is to help people to develop a realistic assessment of their capacity for work and provide the emotional support they may need to come to terms with their limitations. DEAs that have direct experience of a disability or health condition are more likely to be effective in this role. They will be able to empathise with what the person is going through and so will be in a better position to provide the advice and support that person may need.

“I think the disability adviser did help, definitely, because I was having a lot of trouble, and I was quite exhausted...I did not consider myself to be disabled at that point... I was in a huge amount of pain...The impression I got was that they were doing their best.”

(person with arthritis, London)

“I think you need to build a good relationship with your disabilities officer at the job centre, and be really honest and sharing your anxieties and concerns about it, because if you're not honest they can't do anything for you. I mean one day I said I really want to give this a go but I'm frightened, what happens if I fail, and it's like nobody's ever said that before...”

(person with arthritis, South West England)

A disabled person working as an adviser for New Deal for Disabled People thought that their knowledge and experience of life with a disability would ensure they provided a better service for their disabled clients:

“If you're an adviser like that, it's better to be realistic and tell it how it is. People have too high goals for themselves – it's human nature – you have to look at and ask the question 'Is this realistic for you to do?'

You need to be asking the right questions to test whether your assumptions are correct. It has to be said. 'Do you really think you are going to be able to do this job? Think about it before you apply'...It's no good people applying for jobs they can't do. They get knocked back. They get despondent, not getting interviews.

If a DEA isn't disabled they won't ask the right questions. Mine didn't even ask me what condition I had – but asked what problems I had. They need to be knowledgeable about different conditions, to know what it's actually doing to this person.”

(person with arthritis, East of England)

Based on his awareness of how his clients might be feeling, this adviser also identified the important characteristics of a good quality service. These included:

⇒ Getting appointments quickly

“Waiting too long time for an appointment can make people despondent. Then they can't be bothered to turn up...With any condition people always have added depression on top. If they are waiting for long time, they get anxious and stewed up and then can't get out of the door to come for an interview.”

(person with arthritis, East of England)

⇒ Holding meetings in private

“People need privacy at the Job Centre. They need to be in enclosed office so they feel free to say about the problems they are having. If I'm talking to a client with colitis – how embarrassing is it to tell me about that – when someone is talking to another client at the desk next door...People can request a private office but may not know they are able to do that.”

(person with arthritis, East of England)

⇒ Being flexible, for example offering to meet people in their homes if they are currently too unwell to travel

People's experience of DEAs

A number of people said that their Disability Employment Adviser had actually done very little to provide any help. Many more people benefited from advice and support from independent, voluntary organisations (see also section 2.4).

Some people reported that their DEAs had very little understanding of their disability. For example some DEAs had been found to have offices on the second floor, or to sit at a desk behind large plants, making them impossible to access in a wheelchair.

Other people had been referred to employment advisers who couldn't provide the specific support they needed. For example, one woman with arthritis who was also a single parent was referred to the lone parent adviser. She felt that:

“They tried to be helpful but had limited experience of people with health problems – I did feel like I was banging my head against a brick wall.”

(person with arthritis, East Midlands)

She was also referred to a Support to Work Programme but found:

“It was suited to younger people not single parents. I got into an argument because I was off with my daughter with chicken pox...it was more geared to 17-18 year olds that needed a firm handling – not for an adult with children

(person with arthritis, East Midlands)

Job Centre staff in general were thought to not know enough about different kinds of conditions, for example the different types of arthritis. There were concerns that this would result in staff giving inappropriate advice to disabled people.

However, there were also people who had very positive experiences of DEAs.

“The DEA went through options and referred me onto the Job Broker...She was very helpful. She had a good idea of my condition and needs and a good overall manner and general knowledge of the subject.”

They gave me the confidence to go back out and try going back to work. The best thing was having someone going through the various options with you.”

(person with arthritis, Scotland)

Availability of jobs and discrimination in job interviews

Some people who had been forced to leave high powered jobs commented that it's impossible to find equivalent employment as a disabled person. They believe this is due to employers' misconceptions and fears of disability.

“There's no jobs for graduates at the job centres.”

(person with MS, East of England)

“I trained in marketing and got temporary voluntary work for local wildlife trust in their marketing and fundraising department. It was my dream job – but only voluntary.”

(person with arthritis, East Midlands)

A number of people thought they had been victims of disability discrimination at job interviews, but also thought it would be too difficult to prove this to be able to take legal action.

“I had applied for job as a disabled person, at the hospital, working as a receptionist and I got a really bad response...I went for a job working in the oncology clinic. Because I have quite a bit of experience as a nurse I knew all the drugs, all the treatments, that's why they interviewed me...But one of the things they sprung at me was that I'd be making frequent trips to the pharmacy to pick up chemotherapy and drugs and that wasn't in the job description... but I said well I could have a

wheelchair to go down to the pharmacy and back...But the minute I mentioned wheelchair they both started talking at once, going on how there wasn't any space for a wheelchair, and it wasn't really an office, more of a cupboard without a window and that a wheelchair was completely out of the question...I actually got a bit assertive, and I said you're really discriminating against me, you're really not allowed to talk like this. Well I didn't get the job... They even said to me it's really good you told us you were disabled, and I thought, well I came in here and I could hardly walk."

(person with arthritis, East of England)

"I have applied for other jobs and it's not so easy in the big bad world. I wanted to work for CRUISE and they weren't happy about it, because you have to go to people's homes. I also wanted to work for a relationship counselling service as I'd done a counselling course and a degree – but they weren't happy either... They said it was not a successful interview, but I thought the interview went well. I was more than well qualified for it...it was a voluntary job...they've not said why, so I can't get them for discrimination."

(person with MS, South East England)

Another person was convinced she was discriminated against when she last applied for jobs. She was successful at getting interviews, but said,

"When they saw me, they made things up about why I couldn't have the job, which I later found out weren't true."

(person with arthritis, East of England)

2.4 Support to stay in work

Adapting the job

Many people reported that their employers had been extremely helpful in agreeing to adapt their job to better suit their needs. This included making changes to the number of hours, allowing more flexibility in work, changing jobs completely or making adaptations to the physical workspace.

"I work as a domestic for social services. There are jobs I can't do anymore, I can't Hoover. My job has changed so it's what I can do, dusting and cleaning. My employers have been very supportive – I've got no problems with them."

(person with MS, South West England)

"If I found that I couldn't do things – then they [my employers] said they would have to get someone else to do it. I was working on big machine – and I couldn't do it as I couldn't stand up. So they accepted that and understood there were certain things I couldn't do."

(person with MS, South East England)

"I work in a distribution centre. Since I became less able they gave us a lighter job. I was doing heavier work making up packages, moving pallets and driving forklifts – now I'm just on the mailing side – making up smaller packages."

My employers have been very flexible. They adapted my work station – they are very, very helpful if I need time off I can get it. I can't say anything bad about them.”
(person with MS, Scotland)

“I have this wee scooter as I can't walk at all now. So the security guard brings the scooter to my car – which is parked near the front door – I just have to do one step onto the scooter then I'm into work and then at night again they come for us and take us to the car.”

(person with MS, Scotland)

“Access to Work offered money to provide equipment – a laptop so I could travel between two different places. They kitted out the two offices with arm rests because I can't keep my arms up very well and a stand for the lap-top and they paid for voice activated software.”

(person with MS, Wales)

People who had a history of a good relationship with their employer found their employers a lot more accommodating:

“I worked for the council for 20 years and never took sick leave before I had MS. I think they picked up on that. I had a good response with my bosses – they were so sympathetic it shocked me.”

(person with MS, South West England)

“I worked in this job for two years then I was diagnosed with MS. My employers were great, really great, quite sorry – even my boss came to see me in hospital.

Every six months I'd have a relapse and have two weeks off – they were really good about it. Now I've got secondary progressive MS... there's no hiding it. But I can't complain – they've even turned a cleaner's cupboard into a little loo – I appreciate that toilet so much!

There is no lift – but I don't complain because I am still in the job and people appreciate me. I've got another technician that works with me – I couldn't do it on my own. I couldn't complain about my employers at all.

As regards the lift, we're talking serious money...The way I look at it – I've got my toilet which is the main thing for me – my bowels and bladder are my main problem – once I'm in the building and up those stairs I'm on the same floor until I leave. It's hard work it's painful but so is MS.”

(person with MS, West Midlands)

“I've worked for same company for 28 years. They have always been very good to me. They have helped me lot. I work as a receptionist though I used to do more. They allowed me to go part-time and do less work and less complicated things.

We have a very good relationship – they are friends as well as employers. When I first went into the wheelchair I was in hospital for five months and there was no question that they wouldn't take me back.

But I don't think all employers will be as good as mine – I wouldn't like to go out into the world to find a job."

(person with MS, South East England)

It makes an enormous difference to people if their employer is supportive:

"When I phoned up and said I've got crutches they said don't worry, we'll put bollards out the front so you can park there... They were just so helpful. And it does make a difference to your life when people are helpful like that, you feel a bit more willing to give...you do give more, because you feel happier in yourself."

(person with MS, South East England)

Getting employers to agree to making changes was not straightforward for everyone:

"My employers have been very good, but it's been a long slow process. I had to keep going back to Occupational Health. First they said I ought to retire on medical grounds – so I fought against that. They were also against me being full-time so I had another battle there. But my employers have been good. My team manager came to all the meetings and was very supportive."

(person with MS, Wales)

"I didn't have good experience at first, they weren't particularly helpful. I struggled and finally got a stair lift in, and did that with a lot of help from Shaw Trust and Access to Work... That helped me stay on and I cut my hours down.

It was their attitude really, because...they're not particularly nice if the stair lift's broken down. It's not a matter of like well you can't get in, you'll have to come in another day. They're not particularly what I would call sympathetic if it's going to affect them. They're quite sympathetic if it's not going to cost them anything...Trying to get a stair lift put in, they were moaning about what they had to pay for, and of course with the disability law they have to have access... It was very, very difficult at first. But now I just do the half days and that's fine."

(person with MS, South East England)

Similarly getting the changes made can be a lengthy and demanding process, causing a great deal of frustration:

"Getting into Access to Work took quite a few weeks to get organised... I accepted the post, and (standard) equipment was starting to arrive at my house, and I still hadn't had an assessment by Access to Work...Of course it wasn't suited to my needs ... It took a while to be assessed and it took a while to get all the equipment. In fact I'm still getting the equipment.

The biggest thing that annoys me about it is that I have to go and get all the quotes. I have to hand the quotes in and then they make a decision, then that has to go to my employer and they pay for it and then I get it. So it's really, really long winded. And I know their argument is that they actually want me to have the best choice and they want me to find the equipment I'm happy with, which I can understand, but it means

especially with regard to the car, I've spent at least 2 working days organising a car, which seems total waste of time in my new job."

(person with arthritis, South West England)

Some people had had very negative experiences with their employer and/or human resources (HR) and occupational health:

"I got no help from HR – I saw a job on the intranet, so applied and assumed it would be checked out. But occupational health had not checked it out – and it was as bad as the first one – I was working in audit – getting files reaching up to shelves, climbing on desks, chairs and bending down to pick case notes off the floor... I've been off work again for 10 weeks.

HR and occupational health had not done the job they should have been doing. The staff were inexperienced and didn't know how to handle the situation. The boss and HR did not have a good understanding of my needs. They were told about equipment several months ago that I needed to make job easier – but I still haven't received them. I've been told I shouldn't reach above my head or bend down or lift anything more than 4 kg – but none of that has changed either.

My employers don't take notice. They had a warning about the DDA and complying with it and nothing has changed."

(person with arthritis, East Midlands)

"I thought I could manage – so I didn't ask for support. It was admin and answering the phones I could cope with –but it was the extra hours in a stressful office, quite pressurised that made me ill...My boss was one of these people where work should come first as a priority. He was used to other employees giving a lot more time –the culture in the office was that you would work on...he didn't understand my condition at all – don't think he really tried to. Other staff were aware and said be careful."

(person with arthritis, Scotland)

Some people stay in a situation that doesn't suit them as they're afraid they won't be able to find another job:

"I've had to fight, you know there have been times when I've been on the phone to my husband in tears...If I left there I don't think I'd be able to get another job, and I don't want to give up work."

(person with MS, South East England)

Others have found it's simply not possible to make the changes necessary to enable to stay on at work:

"The biggest problem I've had apart from the grind of the physical pain is...the computer, because if I can't get the voice activated software working reasonably reliably then I can't even do voluntary work...And that's why when people say well actually the employer can make adjustments to the workplace, you need to be very specific about what adjustments that employer would have to be taking on...Because I've spent a huge amount of money trying to get it sorted out."

(person with arthritis, London)

Employers' understanding of MS or arthritis

Some people reported that their employer's lack of understanding of their condition had caused problems for them at work. The specific issues people mentioned were:

⇒ Employers or colleagues forgetting the person is disabled when their symptoms are not visible

"If you have a disability that's not terribly visible it's hard for people to remember that you are still nevertheless requiring special help and support. It's very hard to live with a disability that isn't obvious to other people."

(person with arthritis, London)

"Sometimes I feel guilty sitting down, because you look well and they can't see what the problem is...but they never say anything to me – they just leave me to it."

(person with MS, South West England)

"My employer can't tell I'm in pain from just looking at me. She doesn't understand the symptoms of my condition."

(person with arthritis, East Midlands)

"Sometimes because there's nothing to see physically, because you haven't got a plaster, sometimes when you're busy... sometimes they forget, slightly, and you have to say, actually I can't do that... Sometimes it's a little bit difficult, you have to protect yourself.... It's not intentionally being awkward, you have to remind people."

(person with MS, Yorkshire and The Humber)

⇒ Employers' lack of knowledge about the symptoms of MS or arthritis, particularly fluctuating symptoms

"People don't understand MS. Going to work I'm a normal person but by the time I've finished I'm a different person."

Employers need to have better understanding of MS. Sometimes you can come across as if you're drunk or on drugs and they don't know what to make of you... They don't understand how it works."

(person with MS, South West England)

"People don't understand that people with MS may use a wheelchair because of fatigue not mobility problems. Employers and Job Centre staff need educating about these issues."

(person with MS, East of England)

⇒ Employers' lack of understanding of the impact of MS and arthritis

"What they didn't understand is that if I get a cold, or anything like that, it affects my legs. So I'm really trying to keep away from people with colds. If a normal person gets a cold, they feel tired etc, but when I get a bad cold, it tends to really knock me off my legs, and I try to explain that... One time I had a really bad cold and I didn't go

into work for a week, and the only comment I got was 'I thought you'd had the flu jab'...That just shows you their understanding. Because I'm a jolly sort of person and because I don't look sick apart from using my crutches, they haven't got any understanding."

(person with MS, South East England)

⇒ Lack of flexibility in work

"Had I worked with a person who understood that some days I was struggling just to do the basic hours, the job would have worked out more successfully. They should have been more flexible."

(person with arthritis, Scotland)

"I have so many hospital appointments you wouldn't believe – How do I work and go to the hospital? My first boss was brilliant about it but my current boss asks to me to take leave. With so many appointments I'd have no holidays left and you can't always take appointments when you're not at work because clinics only run on certain days."

(person with arthritis, East Midlands)

"I couldn't see me working for the private sector. Because I really don't think they would tolerate the fact that sometimes I can't work in the week so I work on a Saturday, that kind of thing."

(person with arthritis, South West England)

"And I think that is the biggest, biggest problem is that there are days when I wake up and I feel absolutely yuk, and I don't work...Because I can juggle my days round, I think, I'm staying in bed today, I'll do it tomorrow. And that's fine. So whoever your employers are they have to be very flexible."

(person with arthritis, South West England)

⇒ Lack of moral support

"The bosses keep away from me. My impression it's because they can't cope with the emotional side or if you're feeling down. But they let me do my job and they don't ask me to do more than I can."

(person with MS, South West England)

What support do people need to stay in work?

Many of the interviewees described how the intervention and support of the Shaw Trust had been essential in helping them to stay in work. Some of the vital services provided by this national charity included:

⇒ Help with adapting the physical workspace

"Shaw Trust had a word with my employer and then got funding to help adapt the workplace - a new chair and handrails where there were steps."

(person with MS, Wales)

⇒ Educating and informing employers about different conditions

“My immediate manager understands my MS because Shaw Trust spoke to them and asked them if they understood it and gave them some literature to read – just to make them fully aware of what the condition was”

(person with MS, Scotland)

⇒ Help with getting to and from work

“At one point I couldn’t drive my car and they helped me get taxis to work... Luckily I had a very nice woman from Shaw Trust who knew exactly where I was coming from and she fought for me. And she got Access to Work involved, and she fought for the stair lift.”

(person with MS, South East England)

⇒ Help with requesting or negotiating changes in the job or workplace

“The Shaw Trust came to the meetings as well and were very supportive.”

(person with MS, Wales)

“You get various government guidelines coming out about what you’re entitled to to help you at work. But just because it’s in writing doesn’t mean your manager will do it...And it’s hard to push for it, to rock the boat.”

(person with arthritis, East of England)

⇒ Help with resolving conflicts with employers

“While I was off in the hospital the office I was using was taken over by someone else. I was told there was not room for me in the new building which was near where I live...they were saying I would need to go somewhere else...where the access problems were difficult and it was a long way away. There was one person saying there’s no place else for you – you’ve got to come here and he started allocating cases for me that were in that town so I had to go there to do it...I felt a bit victimised then...I was told if I didn’t like it I could go to the unions and I didn’t want to do that, I didn’t want to make enemies of people. But I mentioned it to Shaw Trust who mentioned it to my line–manager and the situation was resolved. Shaw Trust told them about the DDA [Disability Discrimination Act] – making them more aware of their legal obligations.”

(person with MS, Wales)

“It’s nice to have them [the Shaw Trust] behind you. They’re just there as a back up for you.”

(person with MS, South East England)

⇒ Ongoing support

“They come twice a year and they go through all the ‘How are you keeping’ and whether anything else needs adapting for you and do a health and safety check. I’ve been well looked after really.”

(person with MS, Scotland)

⇒ Paying people's wages, which is seen to be an important motivation for employers to keep their disabled employees

"The employer didn't have to pay all my wages and that's an incentive for them – they were getting somebody a bit cheaper."

(person with MS, South East England)

"I get support from the Shaw Trust who pay part of my salary – it makes it easier for my employers."

(person with MS, South East England)

Getting to and from work

For some people, travelling to and from work has been the barrier to staying in work rather than the demands of the job itself. Some people had given up looking for work, because they couldn't find a job close enough to home.

One person with MS had left her job, even though the workplace had been adapted for her, simply because she could no longer manage the commute to work.

"I was working in Swansea – my employer rang Shaw Trust and I got aids to help – but it was too long a journey, 40 miles each way – so I had to give up."

(person with MS, Wales)

Access To Work has been helpful for some people in helping them overcome travel problems:

"Access to Work helped to pay for an electric wheelchair as I live close enough to work to use the chair to get to work and use it at work."

(person with MS, South East England)

2.5 Peoples' views on the proposed changes to regulations surrounding incapacity benefit and employment

One of the interviewees expressed great concern about the proposed reforms to incapacity benefit. She was particularly worried about being assessed and losing her benefit. She explained:

"I always have that fear that one day the letter's going to come through the door taking it [incapacity benefit] away from me...Especially when I hear that there are going to be reviews of incapacity benefit, that always sets off alarm bells. I don't feel at all secure in it, I always think what would I do if they came along and said you don't qualify for it any more. It's a very insecure situation to be in."

And as much as the government says it isn't about cost-cutting of course people are going to think that it is. And I think that the communication around it needs to be very sensitive...organisations like Arthritis Care and the MS Society have got a huge job to do in terms of reassuring their constituents that they're going to be in there talking to ministers, that they're going to be in there dealing really hard with this issue, because

it must affect an enormous amount of people...And if people are frightened and worried and stressed then it's going to make their condition worse."

(person with arthritis, North West England)

Another interviewee was concerned about the narrow focus of the reform and how the assessment process seems to be limited to a person's 'physical' capacity for work:

"You can't just narrowly focus on going back to work and incapacity benefit. The system has to look at the person's whole life, their responsibilities to their families etc – and work out what's best for each individual."

(person with MS, East of England)

People fear that the reforms will result in people with disabilities being forced back into work, without proper attention being paid to whether that work is suitable:

"As a disabled person, I think that the government has lower expectations of me than they do of non-disabled people."

(person with MS, South East England)

"JobCentre staff are driven by a points system to get as many disabled people onto a course or in a job as possible. Targets are all about numbers – not quality – so people could get forced into unsuitable jobs."

(person with MS, East of England)

"My biggest concern is that the government will railroad people. If they had a question, 'Can you get on and off the floor?' - I've failed. But it doesn't mean I can't do a job...The government really, really need to understand that you can't have a set of criteria and that's it. Because it doesn't work like that...I think the people with the disabilities need to say, look this is what I can do, they need to be able to go in and say I can do this, rather than saying what can't you do... to say look I can do computer work for this many hours, or I can drive my car. They need to be encouraged to explore what their skills are rather than what they can't do and then find a job that fits those skills."

(person with arthritis, South West England)

3. Main themes and conclusions

Applying for incapacity benefit

- Some people with MS or arthritis have had bad experiences when being assessed for eligibility for incapacity benefit. Some assessors do not fully understand the nature of these conditions. As a result, the assessment process may not uncover the genuine difficulties experienced by people with fluctuating symptoms or hidden disabilities.
- Any assessment of whether a person with MS or arthritis is able to return to work needs to consider the wider issues for that individual, in particular their financial

circumstances, their responsibilities to their family and the impact of working on their quality of life.

Finding work

- People with MS or arthritis who want to work may need additional support in finding suitable jobs, in particular helping them come to terms with and develop a realistic picture of their capacity for work. This should involve DEAs working with individuals to develop strategies for returning to work, starting small and building up their capacity over time. The danger is that some people may have too big an expectation and take on too much too soon, only losing confidence and falling back even further when they find they are unable to manage.
- DEAs with a disability are more likely to provide the support and advice that people with disabilities need, because they can empathise with their clients, drawing on their own knowledge and experience. DEAs without this understanding may not have the 'right' conversations with their clients and may unintentionally direct people into unsuitable work.
- Even with high quality support provided by Job Centre staff, people with disabilities may not be able to find suitable employment because of a lack of jobs, and the prejudice and misunderstanding of employers.

Staying in work

- The key for people in work is providing moral support to help them negotiate changes in working conditions and to ensure employers actually meet their legal requirements. Disabled employees may feel their position to be more vulnerable and may be less willing or feel less able to confront their employers. The support from independent, voluntary organisations, such as the Shaw Trust, seems to be better able to address these issues than that provided through Government Programmes.
- Practical support to change the workplace needs to be appropriate and timely. Seeking this support should not become a burden for employees with a disability.

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www.twocanassociates.co.uk

Further information about the MS Society can be found at www.mssociety.org.uk

Further information about Arthritis Care can be found at www.arthritiscare.org.uk