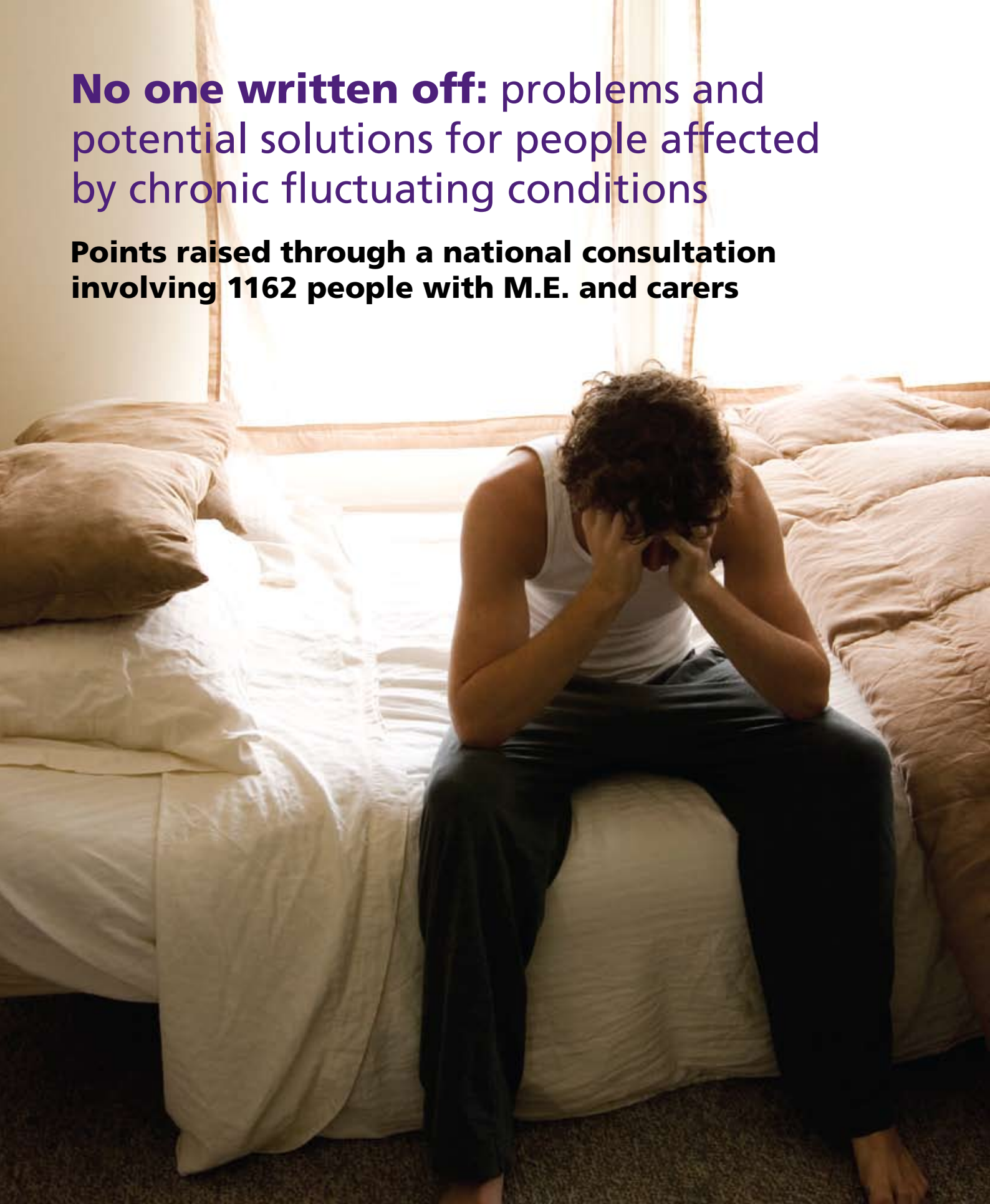


No one written off: problems and potential solutions for people affected by chronic fluctuating conditions

Points raised through a national consultation involving 1162 people with M.E. and carers



action for  **M·E**


The Princess Royal Trust
for Carers

**Disability
alliance**

In association with
people with M.E.
and their carers

Employment and M.E.

Case study 1

"I have had M.E. in different phases since 1990, following a vicious viral infection and subsequent gastro-enteritis. During this stage my symptoms were very much muscular and glandular. My employer (or more correctly my line manager) was very supportive during the initial post-viral illness which involved 9 months off work in two separate periods.

"I managed to return to work and over the next couple of years made a partial (70-80%) 'recovery' – or in hindsight was it a period of remission? The next 10 years were plagued with 'minor' relapses, frequently involving a month off work, when I succumbed to additional infections. During this period, I curtailed virtually all social activity (and sports, which would make symptoms worse) in order to try and keep working, in order to support my very young family.

"I also turned down the opportunities of promotion to try and stabilise my health.

"Six years ago I had a major relapse caused by a further viral infection and associated head injury which led to a whole new set of neurological (and alarming) symptoms: dizziness, vertigo, facial paralysis, multiple chemical sensitivities, difficulty swallowing etc.

"Initially my employers were (again) supportive. After six months I crawled back to work, believing that if I'd 'recovered' before, I could do so again. I relapsed badly.

"Three to four months later I tried again, working from home and worked my way gradually to part time in the office/part time at home. But again, despite all my best efforts I became even worse and was eventually dismissed on the grounds of medical incapability after 18 years service. I fought the decision with trade unions etc – but to no avail. Medical retirement was not offered.

"I have had to fight tooth and nail to get benefits ever since, to enable my family to survive."

What is M.E.?

Myalgic Encephalomyelitis/ Encephalopathy (M.E.) is a **chronic fluctuating condition**, also known as Chronic Fatigue Syndrome (CFS) and sometimes diagnosed as Post Viral Fatigue Syndrome (PVFS).

It is an invisible illness – people affected may not look ill. However, as the National Institute of Health and Clinical Excellence has recognised, M.E. can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions. It places a substantial burden on people with the condition, their families and carers.

There is no known cure.

How does M.E. impact on a person's ability to work?

M.E. affects physical and mental functioning. The illness is characterised by overwhelming post-exertional malaise or exhaustion, typically delayed by at least 24 hours, with slow recovery over several days. Other common symptoms include muscle pain, poor concentration, problems with memory and information processing, headache and digestive problems. People with M.E. may suffer from sensory disturbance eg. sensitivities to light, noise, chemicals, food intolerance – and lowered immunity.

In 2002 the Chief Medical Officer acknowledged that while many patients show some degree of improvement over time, only a small number recover to previous levels of health and functioning. A substantial number pursue a fluctuating course with periods of relative remission and relapse, and a significant minority become severely/permanently disabled.

Previous surveys by Action for M.E. – the largest UK charity for people with M.E. – have shown that 77% of adults with M.E. lose their jobs because of the illness¹, often in the prime of their working lives.

1 'M.E. – More than you know,' Action for M.E. survey of over 2,000 people with M.E. (May 2006)

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The full quantitative results of the surveys are available online as a series of graphs and pie charts and may be found at:

www.actionforme.info/survey-results.html

Acknowledgements

Action for M.E. would like to thank everyone who participated in the consultation.

People with M.E. who completed or tried to complete a survey or took part in the discussion forum expended valuable energy. We hope you were able to adapt your pacing programme to allow this, to limit the impact on your health.

Executive summary

“The government seems to think people actually LIKE to live their lives on benefits. The genuine claimants don’t want to be on benefits but have no choice.”

“People with M.E. should not be penalised financially for managing their fluctuating health when needs dictate.”

The premise of the welfare reform proposals seems to be that it is both desirable and possible for all but the most severely disabled to return to work. However, the Department for Work and Pensions has acknowledged that the situation may be more complex for people with chronic fluctuating health conditions. For this reason, it is essential that the impact of the proposed changes is carefully monitored.

Our survey suggests that only 18% of people with M.E. are in paid employment and of these, 13% are on long-term leave of absence due to ill health. Incapacity Benefit is – and ESA will be – a lifeline on which people with M.E. have no choice but to rely.

Consultation

In order to produce an informed response to the public consultation on the Welfare Reform Green Paper, published July 2008, Action for M.E. – the UK’s biggest charity for people with M.E. – developed two surveys and an online discussion forum to collate feedback on the proposals.

1162 people participated in the surveys and 53 actively participated in the forum. Although this is a good response, the survey was largely restricted to those with internet access and, critically, those well enough to attempt it.

All responses were collected, even if all questions were not answered.

886 people with M.E. and 65 carers completed questionnaires. Statistics quoted reflect the number of people who responded to a particular survey question, rather than the percentage of people who participated overall.

Summary of findings

1 The majority of people with M.E. surveyed want to work.

When asked, 'Would you like to be in paid employment, 728 people with M.E. who are no longer in paid employment responded. The majority (70%) wanted to work – and while some said they did not want to work because they were of retirement age (63 respondents), had caring responsibilities (18), were studying or planning to study (6) or did not need paid employment (5), the majority of those who commented (102) said, "I am just too ill."

Of those not in paid employment, 90% said that they were not well enough 'today' to undertake paid employment. 68% expected to work again but only if their health improved sufficiently. 13% did not expect to work again because of their health.

2 The prospects of many people with M.E. who are currently out of work being able to return to paid employment are likely to be poor, no matter how well motivated they are, because of the degree of long-term disability they experience.

"When I was desperately trying to get back to my job as a social worker, I made a 'back to work proposal' which was really pushing myself. My manager's response was that my proposal was 'good for me but not good for the service.' I guess that's the point: people with fluctuating conditions are likely to be regularly 'letting down' the system and employers – understandably – will want to keep away from this prospect."

The majority of respondents had been ill for some considerable time; 61% or 605 respondents had been diagnosed six or more years previously. In terms of severity, 53% (or 521 respondents) were 30-40% well. The largest single group of respondents was 40% well.

Of those who did feel well enough overall to do some paid work, 49% felt they could undertake just 1-5 hours work per week. When asked about the distance they could travel to work, 47% or 178 of people with M.E. said that they would have to work from home.

When asked, 'Which three changes would make it easier for those people who have M.E. who could work, to return to work and remain in employment?', 849 people responded:

- 57% said availability of part-time, flexible work
- 56% said increased understanding of M.E. amongst medical examiners employed by the DWP
- 52% said increased understanding of M.E. amongst employers.

220 people with M.E. who were not currently in work listed home working as the most helpful practical step that could allow them to work.

3 When people with M.E. do not work, it is because they are physically and mentally unable to sustain paid employment.

When asked which aspects of their illness presented them with the greatest barriers to gaining paid employment, 737 people with M.E. who were not in paid employment replied.

- 80% said overwhelming exhaustion
- 83% said cognitive problems
- 71% said fluctuating health
- 67% said post-exertional malaise
- 54% said sensory disturbance
- 53% said chronic pain

4 Unless carefully planned by a qualified health professional in full consultation with the person with M.E., increases in physical, mental or emotional activity can cause serious set backs in the recovery of people with M.E.

- At some time, 76% of those currently working had had a relapse as a result of their employment.
- Of 709 respondents with M.E., not currently in work, 81% had not worked for at least three years. Of these 81% (573 people), 60% (426 people) had not been in paid employment for over five years and 20% had not been in paid work for 3-5 years. Not all were on benefits.

5 For those who can return to work, a 'graded return to work' must be centred around a person's health, not the needs or expectations of employers or benefits agencies, or the employee may well suffer a relapse.

"Occupational Health and my manager liaised with me to create a phased return plan, and I went back to work starting at three hours a day, four days a week. The plan was to increase my hours gradually every few weeks, but unfortunately after I'd been back at work for a

fortnight, I relapsed very badly and had to be signed off again.”

In the case of M.E., a graded return to work will not mean a return to previous hours within eight weeks or even eight months or longer. It may, for example, mean 2 x 2 hours of flexible work a week, some from home, over many months before any increase is possible.

6 The benefits assessment process places great stress on people who have often already lost a great deal to M.E.

“I did try some part-time work at different times but couldn’t cope. I had my benefits stopped once. It was devastating. If I hadn’t got children I would have killed myself.”

- 79% of people with M.E. who had taken part in a benefits assessment process said the process had affected their health (481 of 611 respondents)
- 48% had had a relapse as a result of a Personal Capability Assessment (273 of 574 respondents)

The prospect or possibility of being wrongly assessed and moved onto Jobseeker’s Allowance can only increase that stress.

7 The existing welfare benefits system does not take informed account of people with fluctuating conditions and respondents were not confident that the new proposals would address this.

“People who do not have the condition or know extremely, intimately well, how it affects someone just cannot seem to see what is really going on with this illness. Medical staff frequently overestimate how much I can do physically, even those who are familiar with M.E. I’m terrified at the thought of this assessment (the Work Capability Assessment) based on my past experience.”

Of 420 people with M.E. who had participated in a benefits assessment in the past three years.

- only 26% had experienced recognition that people with a long-term condition need time to recover from their illness before they can go back to work and only 11% had had recognition that time is needed to recover from an assessment
- 70% said tests for functionality and sustainability of activity were inappropriate
- 63% said there was no recognition of the fluctuating nature of M.E.
- 57% said that guidance for assessors was unsuitable

- 53% had encountered prejudice or disbelief during the process
- 48% said there was no consideration by the assessor of evidence from their own GP and 40% said that their GP’s evidence was disregarded. 44% said there was no consideration by the assessor of evidence from an M.E. healthcare specialist
- 48% said there was an assumption that the claimant was capable of work and 41% said there was an assumption that the claimant did not want to work
- 37% had encountered an assumption that employers will employ disabled people and 58%, an assumption that employers are able to support disabled people.

8 People with M.E. struggle hard to stay in work.

Only 18% of respondents were currently in paid employment. Of these, 79% had had to change their hours of work as a result of their illness, with a clear move to reduced hours.

45% had had to change their employment as a result of their illness, with a marked decline in the number of people working as managers and a notable increase in the number now undertaking clerical work.

Of the 719 unemployed people with M.E. who had previously been in paid employment, most (53%) used to work 25-40 hours per week and 25% worked over 40 hours per week.

80% of respondents (569 of 715) had had to stop work because of ill health.

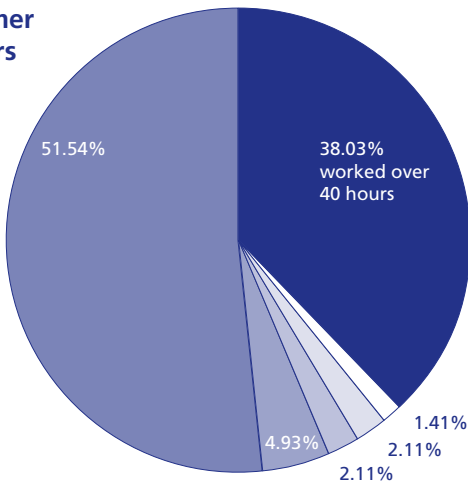
9 Some employers are supportive of existing employees who get M.E. but only to a point. Many do not support people with M.E. to stay in work.

“I was on Incapacity in 2004. I came off in 2006 when I started to feel better and do permitted work. I started off volunteering for 2hrs a week. I was offered a position and the hours were as and when I could manage. Superb! I managed to get my hours to 16hrs. I had a set back and was off work for 3wks to then be told I had a disciplinary! I was horrified and angry. The company I worked for had a system to do with illness and absence and I had gone over my days. They knew all about my illness prior to me taking on the position. It made work very difficult for me and the stress took its toll.”

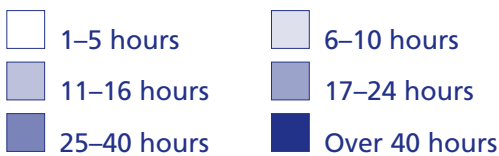
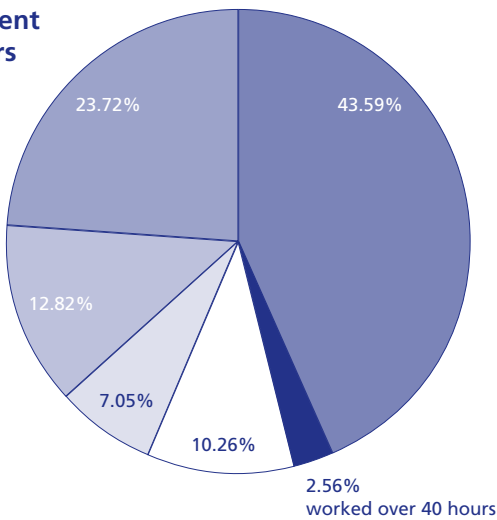
Many people with M.E. told us that even if their employer was supportive when they first became ill, after a year the support usually ended.

Comparison of current hours of work and former hours of work

Former hours



Current hours



When people with M.E. who had had to leave work were asked who advised them to leave, 35% (97 of 278 respondents) were advised by their employer’s human resources/personnel department, 19% by their line manager and 22% by occupational health.

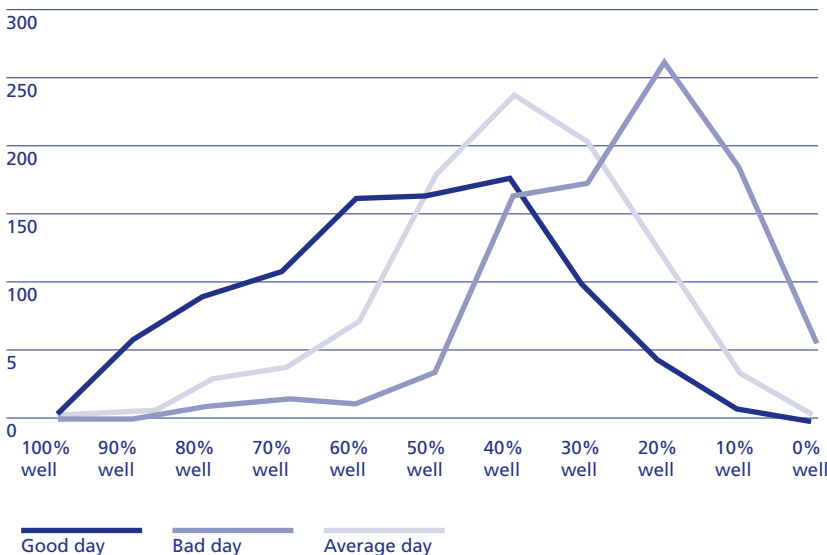
10 The greatest barriers people with M.E. face when they try to return to work relate to their health and the ability of employers to support people with a complex fluctuating condition:

“How many employers realistically would be flexible enough to accommodate a gradual entry (or re-entry) into the work place, if a healthy equally well qualified person had also applied for the vacancy? You’d appoint the healthy person wouldn’t you?”

- 60% of 655 respondents said people with M.E. who return to work will experience effects which will be detrimental to their long-term health
- 57% thought the jobs available would be too demanding of the health of people with M.E.
- 50% felt that not enough employers would want to accommodate the needs of people with M.E.
- 41% thought employers would not be able to accommodate the needs of people with M.E.

Of 158 people with M.E. who had tried to get back into employment, 46% found potential employers to be unsupportive (32%) or hostile (14%). Only 14% of people found potential employers to be very supportive (3%) or supportive (11%).

Fluctuation of M.E.



11 A review of the limits and timescales on permitted work would be helpful.

"Transition to paid work difficult with time limit on permitted work."

12 People with M.E. who are well enough to do some paid work need adequate support and understanding.

Participants who were in paid employment were asked to rank the three extra adjustments they would find most helpful.

- 42% said working from home would be the most helpful
- 37% said flexible hours
- 33% said having access to a quiet place to rest
- 32% said an understanding attitude amongst colleagues

13 It is not clear how an extended Pathways programme will help the majority of people with M.E. back to work.

When asked, 'Have you participated in Pathways to Work?', 92% (825 of 899 respondents) said no. 4% did not know. Of the 5% (42) people with M.E. who had participated in Pathways, while 16% had found it helpful (11%) or very helpful (5%), 46% had found it unhelpful (7%) or useless (39%).

Pathways does not in itself generate job vacancies suitable for people with mild to moderate M.E., nor does it create employers who are knowledgeable about and motivated to employ disabled people.

The current economic climate, with rising unemployment, makes the prospect of recently sick and chronically disabled people finding suitable employment particularly bleak.

Other considerations

i. Contribution based ESA

The new permitted work rules for Employment and Support Allowance put contribution based claimants at a disadvantage as claimants in receipt of Housing Benefit and Council Tax Benefit will find that any income over £20 per week that they earn will be means tested and their Housing and Council Tax Benefits will be reduced. This puts people in employment at a disadvantage compared to income based claimants who will be able to earn up to £92 per week without it affecting their benefits.

ii. ESA50 form

The ESA50 Limited capability for work questionnaire, published after the Green Paper, defines "mental, cognitive and intellectual functions" as "things like mental illness, learning difficulties and the effects of head injuries."

Although cognitive difficulties in concentration and memory are common and disabling symptoms of M.E., people with M.E. might not complete this section as they do not have a mental illness, learning difficulty or head injury.

iii. WCA

The Welfare Reform Green Paper builds on the new Work Capability Assessment for the new Employment and Support Allowance which has not yet been subject to scientific testing, monitoring or assessment over time.

iv. Work-related activity

Most respondents did not think that work-related activities would be useful: "If I could do any of the above (work-related activities), I could work." "I am well qualified already in many areas. I just need help to get better."

Action for M.E. has fundamental questions about the **condition management programmes** proposed under work-related activities. Who will provide these? The condition management programmes which exist for people with M.E. are based on limited evidence and must be carefully managed by patients working in partnership with healthcare professionals who have a good understanding of the illness. Even then, the National Institute of Health and Clinical Excellence states that patients can opt out of them if they wish. Any obligation to participate in any condition management programme will run contrary to the NICE guideline.

v. Access to Work

Flexible hours and, ideally, working from home were identified as the best ways to help people with M.E. who are able to work, back into work.

Not all people with M.E. are able to work with a computer screen for long periods. However, investment in technology could allow more people to work from home at times and at a pace which reflects their health needs.

Conclusions

Action for M.E. has welcomed the Government's desire to help people to remain in work, to simplify the benefits system and to increase the higher minimum income guarantee from £86.35 to £102.10 for those with the greatest need. We also welcome the increased budget for Access to Work.

However, we have fundamental concerns about:

- the ability of the assessment process to assess accurately the functionality – and the sustainability of functionality – of people with chronic fluctuating conditions like M.E.

As the model of illness implicit in existing DWP practice and in the proposed reforms makes no allowance for chronic, varying and relapsing illnesses, it institutionally discriminates against such conditions. The fact that people with M.E. cannot readily convey the reality of their illness experience on existing assessment forms or in early assessment interviews shows that from first interaction, such illnesses are discriminated against.

- the ability and inclination of employers to make reasonable adjustments to allow ill or disabled people to stay in or return to work
- the impact on the health of people with M.E. of an increased expectation to work, within the DWP, Jobcentre Plus and associated agencies and within society
- the increased stigma, prejudice and misunderstanding which people with 'invisible' illnesses may face, in society and in the workplace, as a result of the Green Paper proposals
- the possibility that inadvertently – in an attempt to improve the lives of those claimants who would genuinely benefit from a process of rehabilitation and a return to employment – the system will not only let down but penalise the few who need help most, including people who have complex chronic illnesses, some of whom may never be fit enough to return to work.

Recommendations

We need to see a fundamental shift in attitudes amongst DWP assessors to illnesses like M.E. and amongst employers to taking on people who have a disability or chronic fluctuating condition.

In order to address this, we ask the DWP to:

- recognise that for a significant number of people with M.E., their limited and variable capabilities will make finding suitable work an unlikely prospect
- ensure that there are sufficient safeguards in place to protect people who are genuinely unable to work from being pressurised into unsuitable work or work-related activity prematurely, when a return to such activity could be detrimental to their health
- review guidance on M.E. for new and existing assessors and other DWP staff, to ensure full and impartial assessment of the claimant's actual functional ability and the sustainability of their functional ability in a work environment
- monitor and continue to monitor the progress of people who move from Incapacity Benefit/ESA to Jobseekers Allowance, to make sure that people with chronic fluctuating conditions are not 'bounced' in and out of work, on and off benefits, by rules and procedures which do not recognise the nature of their condition
- ensure 'lighter touch' reassessments for those more severely affected by chronic fluctuating conditions, as the pressures of assessment can lead to relapse
- consider reviewing the rules on permitted work
- consider extending the 104 week rule
- introduce measures to encourage employers to retain and take on staff who have long-term conditions which limit the way they can work, eg. highly flexible hours and the option to work from home
- encourage investment in technology to support home working for those people with long term fluctuating conditions who are able to use it
- ensure that employers and employees support home workers or people who require adjustments including very flexible hours or a very gradual phased return to work

We also strongly recommend that:

- the wording of the *ESA50* Limited capability for work questionnaire is changed, to “By mental, cognitive and intellectual functions we mean things like mental illness, learning difficulties, the effects of head injuries or other conditions in which mental, cognitive and/or intellectual impairment are key symptoms”
- contribution based ESA should be reviewed so that contribution based claimants are not penalised for working.

Action for M.E. will be monitoring the impact of welfare reform on people with M.E., to ascertain the effects on health and well-being.

Consultation report

Background to the consultation

In July 2008, the Government published its Welfare Reform Green Paper, *No one written off: reforming welfare to reward responsibility*, inviting comment by 22 October 2008 through a public consultation.

In order to respond to the Green Paper in an informed way, Action for M.E. worked in partnership with the Disability Alliance, The Princess Royal Trust for Carers, local M.E. support groups, individuals with M.E. and their carers across the UK to carry out an extensive nationwide consultation.

At the time this took place, it was not clear how the proposals might differ in detail in those countries to which Westminster had devolved government. As a result, this report represents the response of people with M.E. to the Green Paper as announced in Westminster in July 2008. The charities will respond to regional variations separately if necessary after those variations have been made clear.

The consultation involved two online surveys – one for people who have or who have had M.E. and one for carers – both of which were available in hard copy if required.

In addition, an online forum was set up to discuss ten specific questions raised in the Green Paper which were most relevant to people with M.E. or their carers.

Participants

1162 people participated in the surveys and 53 actively participated in the forum. Although this is a good response, the survey was largely restricted to those with internet access and, critically, those well enough to attempt it.

All responses were collected, even if all questions were not answered.

886 people with M.E. and 65 carers completed questionnaires. Statistics quoted reflect the number of people who responded to a particular survey question, rather than the percentage of people who participated overall.

Respondents who have or have had M.E.

Of those responding to the survey for people who have M.E. or who have had M.E., 95% currently had M.E.

79% were female and 21% male. 87% lived in England, 8% in Scotland, 3% in Wales and 2% in Northern Ireland.

The overwhelming majority were of working age. 6% were aged 18-25 years, 30% were aged 26-40 and 62% were aged between 41-65 years.

Carers

Of those responding to the survey for carers, 70% were female and 30% male. Just under 6% of carers were aged 18-25, 24% were aged 26-40 years, 65% were aged 41-65 and just under 6% were aged 66 years and over. 87% of the carers who responded live in England, 8% in Wales and 3% in Scotland. Less than 2% live in Northern Ireland.

22% had M.E. themselves and 31% had some other long term disabling condition.

Employment

"I miss work but too ill."

"I need to get better first."

"Oh if only I could!!!!"

"I would love to be able to earn a living again but could probably manage a maximum of 1 hour a day or 2 hours every other day – how could I live on that? And how many employers out there would be able to accommodate that level of employment?"

Out of 779 people with M.E. who were not in paid employment, who answered the question, 'Have you previously been in paid employment?', 92% said yes and 8% said no.

Out of 982 people with M.E. who responded to the question, 'Are you currently in paid employment?', 18% said yes and 82% said no.

When asked, 'Would you like to be in paid employment?', 728 people with M.E. responded. The majority (70%) wanted to work – and while some said they did not want to work because they were of retirement age (63 respondents), had caring responsibilities (18), were studying or planning to study (6) or did not need paid employment (5), the majority who commented (102) said, "I am just too ill":

"I would love to be in employment but am far too ill for this to be a reality at the moment. As soon as I am well enough I would not hesitate to go out to work."

"My health fluctuates so much that I don't think an employer would accept/cope with me."

"How are you going to get a bed-bound person to work?"

"I already feel pushed to my limits with just trying to look after myself and my daughter."

"For me personally, my life was living hell until I quit my job, and it took months of 'slowing things down' until I realised that I actually could feel a lot less awful if I stuck to a baseline. If I overdo things even slightly, things will spiral downwards again."

"How many employers are in a position to take on a person for one day a week with all the red tape and additional costs that go with employing someone?"

People with M.E. currently in paid employment

"As I only work for 3 hours a day I often come home and collapse into a chair. I am then unable to do anything for the rest of the day. When I am unable to recover enough the next day I have to take a day off. I have had to take as many as 3 days off before I feel able to go back to work."

"I was a full time secondary school teacher, but could not cope with the demands of teaching having M.E. After a year of absence I tried to return part time, but could not cope and have been working full time (with variable success) as a teaching assistant in a school for children with special needs for the last 3.5 years. I do try to pace myself, but find working full time hard. Ideally, I would like to work a shorter week but cannot afford to do so, having already taken a considerable drop in pay through giving up teaching. I know I should investigate benefits, but the thought of wading through confusing paperwork is rather daunting."

Of the 18% currently in paid employment, 91% are employed by someone else and 9% are self employed.

37% described their role as professional, 30% as clerical, 9% as service and sales, just over 6% as managerial, just under 6% as technical, 6% academic and research, 5% manual and 1% craft.

When they participated in the survey, 2% were working over 40 hours per week, 38% were working 25-40 hours per week, 20% 17-24 hours, 11% 11-16 hours, 6% 6-10 hours, 9% 1-5 hours. Over 13% were on long term leave of absence due to ill health.

79% had had to change their hours of work as a result of their illness, with a clear move to reduced hours.

45% had had to change their employment as a result of their illness, with a marked decline in the number of people working as managers and a notable increase in the number now undertaking clerical work. There was also a shift away from manual work and a decrease in people working in services and sales.

At some time, 76% of those currently working had had at least one relapse as a result of their employment.

Table 1 Changes in hours worked after onset of M.E. (see pie chart p 7)

Hours worked per week	Before M.E.	Now
1-5 hrs	1%	9%
6-10 hrs	2%	6%
11-16 hrs	2%	11%
17-24 hrs	5%	21%
25-40 hrs	51%	38%
Over 40 hrs	38%	2%

Table 2 Changes in type of work undertaken after onset of M.E.

Nature of work	Before M.E.	Now
Managerial	21%	6%
Professional	37%	37%
Technical	1%	6%
Academic or research	5%	6%
Clerical	12%	31%
Service and sales	12%	9%
Manual	11%	5%
Craft	0%	1%

Unemployed

Of the 709 people with M.E., not currently in work, who told us how long it had been since they were last in paid employment, the overwhelming majority (81%) had not worked for at least three years.

Of these 81% (573 people), 60% (426 people) had not been in paid employment for over five years and 21% had not been in paid work for 3-5 years.

90% (682 out of 762 people) said that they were not well enough to undertake paid employment at the time of the survey.

68% expected to work again but only if their health improved sufficiently. 13% did not expect to work again because of their health. 3% were looking for paid employment and 2% did not need to work.

Of those who did feel well enough overall to do some paid work, 49% felt they could undertake just 1-5 hours work.

26% said they thought they could work 6-10 hours and 15%, 11-16 hours. 10% said 17-24 hours and only one person felt they could work 25-40 hours.

Previously in paid employment

Of the 712 people with M.E. who had previously been in paid employment, 8% were self employed and 92% were employed by someone else.

Most (53%) used to work 25-40 hours per week and 25% worked over 40 hours per week.

11% worked 17-24 hours, 6% worked 11-16 hours, 3% worked 6-10 hours and 1% worked 1-5 hours.

569 people (80% of 715 respondents) had to stop work because of ill health. Of the 715 respondents:

- 46% said they were “forced to leave because of ill health”
- 13% said that they “decided to leave because of ill health”
- 10% were “advised to take ill-health retirement”
- 8% were “advised to leave because of ill health”
- 3% “decided to take ill health retirement”
- 2% were dismissed

Table 3 Types of work undertaken by people with M.E. who were previously employed, compared with people with M.E. who are currently employed.

Nature of work	Previously employed, now unemployed	Currently employed – before M.E.	Currently employed – employment now
Managerial	14%	14%	6%
Professional	35%	40%	37%
Technical	5%	3%	6%
Academic or research	3%	6%	6%
Clerical	23%	22%	31%
Service and sales	10%	7%	9%
Manual	8%	7%	5%
Craft	2%	1%	1%
Total responses	701	177	176

3% were made redundant or their company closed and a small number left to have children, return to education or for other reasons.

The survey asked, "If you were advised to leave or take ill-health retirement, who gave you this advice?" Of the 278 who responded, 97 people (35% of respondents) were advised by human resources/personnel, 22% by occupational health, 19% by their line manager. 14% were advised by family/friends and 4% by independent advisory services.

However, another 97 people (35%) ticked 'other' (eg. 'consultant', 'GP,' 'trade union') and 206 people left qualitative comments.

Extensive qualitative feedback revealed a typical pattern. People with M.E. become ill, take what is often for them an uncharacteristic period of sick leave, return to work prematurely, struggle, relapse, take further sick leave, negotiate reduced hours, return to work part-time on reduced income, spend all days off feeling ill and resting, unable to undertake other activities such as domestic tasks or social activity, eventually relapse again and again take sick leave until the contract is terminated or the employee is advised to resign.

"Attempted return to work approx 6/7 yrs ago, a phased return before ready. Wanted to give it a go so didn't lose job. Returned 1 hr a day as physio assistant, building up to 2 1/2 over time. Did nothing outside work. Too much. Struggled. Caught cold and relapsed. Made condition much worse. Been gradually downhill since and wish hadn't gone back."

"In 1999 I had a major relapse as a result of exhaustion at work and had to stop working for nine months. I then tried to return to work according to a schedule decided for me by the company. This involved starting out working for 2 hours twice a week increasing this to 3 hours 3 times by the 3rd week, then 5 times after that and so on. However I was just far too ill to manage the initial period without getting worse. I could not properly undertake the tasks that I used to do previously or even lighter duties that my employer suggested."

"I had not recovered from one session of work before the next one was due. Nevertheless I forced myself through the allotted hours and went to see the company doctor for a review after two weeks, explaining even this amount of work was having a detrimental effect on my health. He did not appear to understand about M.E. and insisted I increase anyway. I went back to my GP who signed me off work completely again. When I was still not well enough to return to work after several more months, my employers ended my contract with them. I have remained too ill to work ever since."

Others are unable to return to work at all:

"I was totally pole-axed one weekend in September 2002 by a flu-like illness. The muscle pain/weakness/inability to stand or walk meant I was unable to leave my bed let alone my house. Despite struggling to see doctors and private practitioners in a desperate hope of treatment and recovery, I was never able to return to my job as an oncology radiographer working in the NHS."

"Although my immediate boss had been amazingly supportive in keeping my job open for me and would have helped in adapting things for my return, after two years of waiting/hoping for my return the powers that be had to step in and dismiss me on grounds of ill-health. I have since been medically retired in my early 40s! I thoroughly enjoyed being a radiographer and was devastated to be struck down by illness in the peak of my career."

"I would love to work again if I was well enough. I am a highly qualified individual who had a great career ahead of me when this illness struck. I get very angry at the presumption that we are all lazy and choosing not to work. How about finding medical help for people with long-term neurological disorders? How about recognising in a civilized country the benefits system is supposed to be there to help people whose lives have been destroyed through no fault of their own?"

Ill health as a barrier to work

"I have re-trained twice since leaving the civil service over 10 years ago when I was diagnosed. Once as a learning mentor and once as a Higher Level Teaching Assistant. I thought that the school holidays would allow me to rest but the job was so intense that I spent each school holiday recovering from the term before. I am now on prescribed rest periods of 20 minutes 4 times a day and a pending visit to the pain clinic! My priority is my family and too tired and too ill to please employers."

"Although I would ideally like to be in employment, I know that I am not well enough because I have tried and in the process made my condition relapse."

"It is difficult to imagine that employers will welcome members of staff who may or may not be available for work when required. It may also be that existing staff would resent what they might view as preferential treatment, thus causing potential problems within the existing workforce."

Although 2% of people with M.E. who responded to the survey had not yet received an official diagnosis (one in five people wait more than two years to get a diagnosis²), 12% had been diagnosed within the past two years, 25% within the past 2-5 years, 27% in the past 6-10 years and 34% were diagnosed over 10 years ago.

On 'a good day', 10% felt 80% well, occasionally experiencing mild symptoms when resting and unable to do some activities which require physical exertion.

More (19%) felt 40% well on a good day, with moderate symptoms when resting, and moderate to severe symptoms after any form of physical or mental activity. This meant that they were unable to carry out any strenuous duties but could carry out light activities for one to three hours per day, as long as they had adequate rest periods.

However, the physical and cognitive symptoms which affect people with M.E. fluctuate in nature and severity, so 'bad days' often follow good.

On a bad day, 28% of respondents felt 20% well, experiencing moderate to severe symptoms when at rest, mostly unable to leave the house and possibly confined to a wheelchair or bed for much of the day, unable to concentrate and only able to carry out a few activities relating to personal care eg. having a wash.

19% of respondents were functioning at 10% and 6% experienced severe symptoms on a continual basis, were bedbound and incapable of living independently, needing a great deal of practical and social support.

Severity and fluctuating symptoms

When asked which symptoms presented them with the greatest barriers to gaining paid employment, 737 people with M.E. replied:

- 80% said overwhelming exhaustion
- 83% said difficulty with cognition, information processing, concentration and/or memory ('brain fog')
- 71% said fluctuating health
- 67% said post-exertional malaise
- 54% said sensory disturbance (eg. sensitivity to light, noise, chemicals)
- 53% said chronic pain
- 20% mentioned other symptoms eg. *"Mobility problems, balance problems, bladder and bowel problems, drop things, visual problems."*
- 15% said co-morbid depression.

When asked, 'If you think the new proposals will not make it easier for people who have M.E. to get back into work, what will be the (three) biggest problems?' Selecting from a range of answers:

- 60% of 655 respondents said people with M.E. who return to work will experience effects which will be detrimental to their long-term health
- 57% thought the jobs available would be too demanding of the health of people with M.E.
- 50% felt that not enough employers would want to accommodate the needs of people with M.E.

² 'M.E. 2008: what progress,' Action for M.E. survey of 2,763 people with M.E. (May 2008)

Other barriers to work

"No employer is going to take on an employee who has such wildly fluctuating health & accommodate their needs. It is not financially viable, no matter how well qualified or experienced they may be – FACT."

When asked if there were other barriers to gaining paid employment, apart from their ill-health, 603 people responded. 17% said 'no other barriers.' However,

- 41% thought employers would not be able to accommodate the needs of people with M.E.
- 34% felt that appropriate help would not be available for people with M.E.
- 23% said 'employers not taking on people with health problems.' 20% said 'lack of suitable employment.' 8% thought their skills were out of date and 5% cited transport problems.
- 21% thought the jobs available would be too low-paid to make coming off benefits worthwhile: *"Could not cope financially on the reduced hours I am able to work"*
- less than 3% said they were financially better off on benefits
- 19% thought it would cost so much to provide the support necessary to enable people with M.E. to work, that it would not be cost effective for the Government to move people off benefits.

8% identified other problems, such as age or "I would have to change career but am not well enough to retain new info at moment."

Permitted work

Some respondents expressed frustration over the 52-week permitted work limit, given that M.E. can have a very prolonged recovery time.

"Transition to paid work difficult with time limit on permitted work."

"One of the main things which would help is further flexibility in the benefits system, so that permitted employment would become a permanent option for those whose health does not improve further. At present I believe permitted work only lasts a year (unless it's Supported Permitted Employment, which is hard to obtain). However, some people with M.E. will require that sort of benefit assistance long-term and it should be much more easily available."

"The permitted work period should be extended – as it can take awhile for people with ME to develop full stamina, strength and health once back in work."

Case study 2

"I am in the position where I am just about to try to go back to work for the first time since being diagnosed with M.E. 4 years ago. I have got a job with the bank admin staff at the local NHS which means you are employed on an *ad hoc* basis when they need you and you don't ever have to accept the work. I have said I will commit to 1 day a week to start. I rang the local Jobcentre up to explain and they said for me to ring the Incapacity dept. When I rang them they said I was only allowed work under the permitted work rules so can only work for 52 weeks and then I have to either stop working or stop claiming. They said I was not allowed to do anything different unless I was exempt from the medical assessment. So from my point of view I need to see a relaxation on the 52 week rule as I can't see the DWP letting people with M.E. being exempt from the medical but at the same time my condition has not improved over the last 2 years so I may never be well enough to work more than 1 day a week. It takes between 3-6 months for me to see if I can sustain an increase in activity so unfortunately 52 weeks is nowhere near long enough to see if I could sustain working enough hours to come off IB."

Case study 3

"I was working full time when I became ill in Feb 06. Two months later I gradually started working (an hour at a time twice a week) in the same job, being paid travel expenses only, whilst in receipt of statutory sick pay. Then I very gradually built up my hours until it had increased to about 10 hours per week (2 hours per day, 5 days a week). This took about 7 or 8 months! 6 months after getting ill my SSP ran out so I was able to apply for and be awarded IB. By this stage I had also applied for, and was allowed to do, permitted work (PW). This meant I could be paid for the work I was doing, within the PW limits.

"By Jan 07 I had to leave that job because they and I couldn't cope with the uncertainty of not knowing how long it would be before I could be working full time again. At this stage I searched desperately for another job with just 2 hours per day, 5 days a week but couldn't find one so I ended up taking a job for 5 hours a day, 5 days a week at a bank. I had to stop receipt of IB and I struggled to cope with this massive increase. I believe it caused me to

relapse. In the end I gave in and cut my hours back, which meant I went back onto IB again, as well as doing 10 hours of permitted work (the maximum I can do on my hourly rate).

"I am currently applying to be allowed to continue in my job at the bank, beyond the 52 permitted work limit. I am trying to get it to be counted as Supported Permitted Work, (by finding a suitable support worker,) as this could then continue for an indefinite period, ie. until I can manage more than 25 hours/ week. This is the amount I would have to work to earn enough to break even with the IB + wages of approx £80, that I receive now.

"The main problem is the restrictive nature of the permitted work rules whilst on IB. I wish if you worked above the earnings limit you just lost your IB £ for £ instead of the full amount as this would enable a stepped increase in hours, subject to agreement by your employer, which, financially would be far more secure, and (there would be) less likelihood of relapses."

Workplace attitudes and adjustments

"Find it hard to cope with being around people as most do not understand the illness."

Participants who were in paid employment were asked: "If your current employer has made arrangements to enable you to remain in paid employment, what arrangements have been made?"

- 38% (64 respondents) worked flexible hours
- 31% (52 people) had understanding colleagues
- 24% (40 people) received time off for medical appointments and treatments
- 17% (28 people) worked from home.
- 24% (40 of those who responded to this question) had no adjustments in place at work to accommodate their illness.

When asked, "If further adjustments are required, which of the following would help?", frequent breaks (13%) were also amongst those commonly cited.

When people with M.E. who were not currently in paid work, were asked the same questions, they too rated flexible hours (66%) and working from home (53%) most important. Frequent breaks (34%), a quiet place to rest (29%) and understanding colleagues (27%) were deemed helpful.

Supportive / unsupportive employers

People with M.E. are often forced out of work: *"I had to attend a Medical Incapacity Hearing, where I was sacked."*

"I asked to change my pattern of work and was told no. I'd rely on pills, unpaid leave and sleeping weekends to act as a plaster over the cracks. The company were not interested because I had become unreliable. Pressure was brought to bear to remove me from post. I quit the company just short of three years working there."

"After a year off sick, I was told by human resources that I would have to take ill health retirement if I was not well enough to return to work. I was a senior staff nurse at XXX hospital. I was actually not treated very well. I understood that I couldn't be on sick leave long term, but they could have treated me better than they did."

"I continued working for two and a half years after being diagnosed. My employer initially allowed me to work part time for about 2 months and then found me another line of work that I could cope with. My condition continued to get worse but would not allow me early retirement on health grounds. I finally took voluntary redundancy. After a year I found that I could not manage on the pension and had to apply for IB & DLA."

People who participated in the survey recognised that: *"Businesses are not convalescent homes."*

"For people with M.E. the problems are worsened by its invisibility and its variable nature. That automatically makes you 'awkward' and 'unreliable' in the eyes of any employer. An employer is there to make profit."

"Why should other workers have to carry a colleague who is unwell often? Who can blame them?"

"I now have such a bad employment record on grounds of ill health that few employers will touch me. Put it this way, I wouldn't recruit me."

Of 158 people with M.E. who have tried to get back into employment, 46% have found potential employers to be unsupportive (32%) or even hostile (14%).

40% were neither supportive nor unsupportive. Only 14% were supportive (11%) or very supportive (3%).

Lack of supportiveness may reflect lack of accurate information and understanding about the illness. Only 1% of people with M.E. who had tried to get back into work said they had found potential employers to be very well informed about the illness.

5% said they were quite well informed – but 94% reported that employers were not well informed about the illness. 27% were even misinformed about M.E.

41% of those not in paid employment had stopped looking for work a year ago or more.

Most (58%) people with M.E. who were currently employed described their employer as supportive (33%) or very supportive (25%) and 24% said they were neither supportive nor unsupportive. 8% said they were unsupportive and 3% described their employer as hostile.

Of those who were employed, 42% described their employer as quite well informed (37%) or very well informed (5%) about the illness, although the person with M.E. may have provided the employer with information themselves. However, a significant number were not informed about the illness (18%) or less informed than they should be (31%). 3% were misinformed about M.E.

Case study 4

“I worked full time as a designer until I became ill. After a year off sick I returned to my job part time on 18 hours (3 days of 6 hours). During this time I had several relapses and long term sick. My employers were supportive up to a point. They allowed flexible working so I could swap my days if I felt unwell. I could start at a later time. When off sick HR would visit to discuss ways to help me return. I always went back on phased hours to allow a more gradual return to my full hours. My health was worsening and I was struggling to cope with traveling to the office and the hours spent there.

“Eventually I was able to work occasionally from home but was expected to attend the office at least once a week. I asked if I could home-work permanently, so I could pace myself better (two colleagues with the same job role already home-worked). I thought it would be straight forward especially as I’d had the occupational health doctor agree to it plus a disability employment adviser suggest it to them. I was told a home assessment would be needed before it could happen.

“After several long term absences last year I was dismissed on ill health, with no assessment ever being made for my home-working. They said I’d be too isolated at home, the office would be short of a person, plus only 2 people could home-work at one time! Being supportive only happened when the HR manual gave the answers. When it didn’t, and it needed more effort and for them to really listen to my needs, they gave up quickly.

“After 12 years service, being open and honest about my condition, home-working was the difference between me staying in work or being unemployed.”

Case study 5

“I have been with my current employer since 2001. My illness began in Oct 04, I continued to work full-time until July 06. By Sept 06 I was unable to work. Between July 05 and July 06 I stopped all activity outside of work (previously very active plus physical job) to try and stay at work. I was signed off work until March 08 from which time I have worked just 2 hours per week term time only.

“During my sickness absence I had Occupational Health meetings 3-4 monthly followed up by meetings with my employer and a representative from personnel on behalf of the school. After a year’s absence I was asked to consider if I would relinquish my full-time contract of employment and/or be dismissed on the grounds of inability to perform the job for which I had been employed due to ill-health (due to the nature of the illness I was unable to give a date at which I could resume full-time employment, if at all, even on a return to work basis).

“I was always hoping to recover and was concerned that dismissal due to ill-health would render me unemployable in the future. I asked my employer to consider employing me within my department on a voluntary basis a few hours a week to see if I could maintain this (my post had been filled by someone on a temporary contract and this was to work alongside this person).

“My employer decided this was a solution for both the school and myself. In return for my full-time contract I have a revised contract for up to 6 hours per week, I have been unable to build up to 6 hours and continue on 2 hours per week for which I am paid. My employer although not fully understanding the nature of M.E. has subsequently made it possible for me to work on a very part-time basis and has made it clear that I can work on a different day if I am not good on my work day.”

Case study 6

“Over the last four years I have attempted voluntary work and also tried with the help of a good friend/prospective employer. A quiet room was provided, and every allowance made that we could both think of. No matter what we tried I was unable to. In the process of trying each year I suffered a relapse on every occasion and have, to date, not regained the ground I lost during the relapses. Each relapse means more medication and longer recovery. I also found it very depressing to keep trying and failing.”

Back to work proposals

“I would like to work one day a week and pace myself the rest of the week as advised at clinic.”

New Deal

920 people answered the question, ‘Have you participated in the New Deal?’. Of these, 89% (820 people) said no.

Of the 60 people who had participated in New Deal, while 20% found it helpful (14%) or very helpful (6%), **nearly 55% found New Deal unhelpful** (17%) or useless (38%). 26% found it neither helpful nor unhelpful.

Pathways to Work

899 people with M.E. answered the question, ‘Have you participated in Pathways to Work?’. Of these, 92% (825 people) said no. 4% did not know.

Of the 5% (42) people with M.E. who had participated in Pathways, 16% had found it helpful (11%) or very helpful (5%).

However, **46% had found Pathways unhelpful** (7%) or useless (39%). 37% found it neither helpful nor unhelpful.

“I am only on my second appointment so at this early stage can say that I have been impressed by the honest approach from the staff – they acknowledged their ignorance and responded well to me sending them the Action for M.E., Kings Hospital and Kent & Sussex ME Society websites to read and learn from.”

“The occupational health worker from Pathways has been excellent. But the office recently moved to this area and the new person I am assigned to has been useless, doesn’t return calls. I have asked for help returning to work and received none. The OH worker has continued to be supportive despite having to travel from mid Wales to see me and is attending my IB appeal with me.”

“The woman I saw was very young and inexperienced. She gave me no emotional support at all and she gave me some very confusing advice. I left feeling stressed out and despairing.”

“Even though I am in an exempt category the DWP tried to force Pathways to Work on me, and the people I dealt with at JobCentre Plus and other related benefits staff led me to believe that had I not been able to prove my exempt status to them – which I only did with great difficulty because they do not believe in playing the game by the rules – I would have been in for a very tough time at the hands and a very severe relapse of my M.E.”

"I had to find Pathways from doing my own research, the lady didn't know anything about this help and she works for the job centre. Maybe their staff should be better informed."

"Enquired about it but they could not help with my needs and actually wanted me to go against medical advice and start work even though specialist had said not for another year and then very very slowly."

"Unfortunately the advisers do not seem to understand about Chronic Fatigue and depression. They keep saying that people are better when they work. Personally I find the meetings very stressful, you clearly understand that they are not interested at all in your conditions and difficulties and they are not qualified (ie. psychologists or neurologists) to give proper support. They seem to be treating everybody the same way, regardless of the condition."

It is not clear how an extended Pathways programme will help the majority of people with M.E. back to work.

Work-related activities

"Employment support is only relevant when you are well enough to work"

278 people who were not in paid employment were involved in some sort of education or activity. 42% undertook voluntary work, 25% distance learning, 17% undertook some other form of unpaid work, another 17% were doing a short leisure course, 9% were attending further or higher education and 8% were doing a short vocational course.

When asked whether they would like to be involved in work-related activities to help them back into work, 480 people no longer in work responded. 59% said they would like to do voluntary work.

However, most did not want to do specific job searches (61%), condition management programmes (56%), work tasters (53%) or training programmes (51%) and 51% did not want help in finding paid employment.

305 people gave their reasons in additional comments. Examples:

"I know this sounds pathetic but would not be able to manage any of these except on a really good day and with lots of help!"

"I'm already doing a few hours voluntary work a week, which I would like to build up if at all possible. But much as I love the vol job I haven't been able to increase my hours since I started a year ago – because of ill health."

"I am not capable of doing any of these (work-related activities) due to the severity of my illness. If I could do any of the above, I could work."

"I am well qualified already in many areas. I have undertaken hundreds of hours doing voluntary work. I just need help to get better."

"With high level academic and professional qualifications no one seems interested in helping me to retrain. The training programmes I have seen assume you do not know how to write a cv or switch on a computer."

"Trying to learn new things, for me, is very difficult. My lack of concentration and the sudden fatigue at trying to think about things overwhelms me."

"Was doing voluntary work and retraining but made myself too ill to continue. 13 months later not returned to the level of health I was at."

Will the new proposals work?

"Benefits of scheme only apply to mildly affected who probably work if they can already."

The survey asked, 'Do you agree that the new proposals for providing more support for people to get back into work, will make it easier for people with M.E. to get back into employment?'

879 people responded. While 10% thought the new proposals would make it easier for some people to get back into employment, 43% did not:

"For those who are well enough and want to go back to work it may make it easier. For those who are not well enough but want to go back it may make it easier but with disastrous results for their health. Those who are not well enough may be forced to look for work, attend interviews courses etc likewise with disastrous effects on their health. The stress of frequent assessment may make those who are moderately-severely ill much worse. There needs to be much more education of doctors as well as benefits assessors and employers and employees. I've met with horrible prejudice when trying to do part-time courses to get myself fit to work and have been made worse by the effort involved."

The majority (47%) did not know.

"Can't relate to this question at all. All the support in the world isn't going to enable me to get up, get dressed, get to a workplace and do something (however minimal) on anything approaching a regular basis."

What would help people with M.E. to stay in or return to paid employment?

“First, acknowledge the proven health benefits of establishing a baseline and then pacing against it, by considering symptoms at their best, worst and average over a given time period.”

The survey asked, ‘Which three changes would make it easier for those people who have M.E. who could possibly work, to return to work and remain in employment?’

849 people responded, rating the top three changes required as follows:

- 57% said availability of part-time, flexible work
- 56% said increased understanding of M.E. amongst medical examiners employed by the DWP
- 52% said increased understanding of M.E. amongst employers

Encouragement and support of home-working would also be helpful: *“To encourage companies to support productive home-working, the DWP should offer funding assistance towards useful technology ie. laptop, mobile, Blackberry, webcam, conference-enabled telephone, ergonomic work station.”*

35% wanted increased understanding of M.E. amongst back-to-work support providers. 18% chose financial help for people to stay in work eg. allowance to pay for extra support required, another 18% thought more incentives were needed for employers to hire and retain people with disabilities or long term conditions and 18% said continued support from support providers was required following employment.

11% rated financial support for employers to make appropriate changes/adjustments. 10% thought there should be harsher penalties for employers who were not willing to make ‘reasonable adjustments’ for M.E. under the Disability Discrimination Act. 6% thought a good practice guide for employers should be developed and 5% rated legal aid for people with M.E. who are discriminated against. 7% said ‘other.’

Travel to work

As M.E. is characterised by abnormally high fatigue following even minimal physical, mental or emotional exertion, travel to work can be a significant factor, defining what and how much work-related activity can take place.

Most of the people with M.E. who participated in this survey were only able to work from home or within a short distance of home.

Of 174 people with M.E. who were currently in work, 10% worked from home and 55% travelled less than 5 miles. Only 26 (15%) travelled 11-20 miles and 14 (8%) travelled over 20 miles.

169 told us how long they spent travelling to work. 120 people (71% of people who responded) spent less than 30 minutes travelling. Of these, 50 people (30%) spent 16-30 minutes, 46 (27%) spent 5-15 minutes and 24 (14%) spent less than 5 minutes travelling.

Most of those who travelled to work, drove (96 people, 56% of respondents). 27 people (16% of respondents) took a bus or train. 11 (6%) got a lift, the same number walked and less than 4% got a taxi. No-one cycled.

Of 379 people not in work, 178 (47%) felt they could not travel to work and that they would have to work from home. 94 people (25%) felt the maximum distance they could travel would be 0-2 miles, 62 (16%) said 3-5 miles, 38 (10%) 6-10 miles, 5 (1%) said 11-20 miles and 2 people (0.5%) said over 20 miles.

92 (28% of 325 respondents) said the maximum time they would be able to spend travelling to work was less than 5 minutes. Most – 143 people (44%) – said 5-15 minutes. A further 71 (22%) said 16-30 minutes. Only 19 people thought they could travel for 30-60 minutes and none of those currently not in work felt they could travel for over an hour.

Welfare benefits

"The government seems to think people actually LIKE to live their lives on benefits. The genuine claimants don't want to be on benefits but have no choice."

"The entire benefits system is designed around static conditions, not fluctuating ones like ours."

"I was diagnosed two years ago and I have been shocked at how difficult it is to get any benefits. I find the whole thing very depressing and stressful. It is bad enough living with an illness that robs you of anything near a normal life, work, family and relationships and then to be refused benefits is just awful. I am sick of dealing with so called 'professionals' who don't understand M.E."

"I know that my symptoms vary so much that I cannot envisage any employer would take me on, and I am also extremely concerned that if I started work I would lose all my benefits which have taken so long to get in place. And if work made me more poorly I would really have to struggle to go through all the claiming again."

Incapacity Benefit

"I realised my loss of earnings for the 10 years I have had M.E. would have amounted to £250,000! But of course I would rather be ill and on Incapacity Benefit of around £4,800 per annum than enjoy exotic holidays and a healthy lifestyle!"

61% of respondents (606 people) were in receipt of Incapacity Benefit (IB) and of these, 70% had been in receipt of IB for over two years (just over 26% said 2-5 years, another 26%+ said 5-10 years and another 26%+ said over 10 years).

11% had received IB for 1-2 years, 6% for 6-12 months and 4% less than 6 months.

10% (63 people) had been to appeal in the past three years. Of these 87% (55 people) had won their appeal, suggesting that they should have been awarded the benefit in the first place.

A further 2% were waiting to go to appeal.

Income Support

18% of respondents (180 people) were in receipt of Income Support (IS) and of these, 73% had been in receipt of IS for over two years (25% said 2-5 years, 23%+ said 5-10 years and another 25%+ said over 10 years).

Again, 11% had received IS for 1-2 years. 11% had received it for 6-12 months and 5% for less than 6 months.

Once more, 10% (18 people) had been to appeal. Of these 83% (15 people) had won their appeal, suggesting that they should have been awarded the benefit in the first place.

Jobseeker's Allowance

Less than 1% of respondents (7 people) were in receipt of Jobseeker's Allowance (JSA).

Of these, 42% (3 people) had been in receipt of this benefit for 2-5 years, c28% (2 people) had received JSA for less than 6 months and 14% (one person) for 7-12 months.

One person (14%) had had to appeal against sanctions and had won their appeal.

Other benefits

35% of participants received no other benefits. Of those who did, the most common was Disability Living Allowance (44% / 411 people). We know from other recent surveys³ that 37% of people with M.E. who were in receipt of DLA in March this year had had to go to appeal within the last three years and of these, 72% had won their appeal.

Most commonly received among the other benefits listed were Council Tax Benefit (20%), Housing Benefit (16%), Child Benefit (13%) and Child Tax Credit (11%).

"For several years I had a husband to support me. Then after I divorced I was a single parent and claimed benefit for that but I did try some part-time work at different times but couldn't cope. I had my benefits stopped once. It was devastating. If I hadn't got children I would have killed myself."

³ 'M.E. 2008: what progress,' Action for M.E. survey of 2,763 people with M.E. (May 2008)

Assessment for welfare benefits

"I've been to hell and back with the benefits agency before. This time they were very helpful but still things were wrong. I understand there are problems, methods, timetables etc but it doesn't take into account anyone who's really ill. They do try, they have improved, but unless you fit neatly into their box it's a real battle."

"You have to be well enough to fight. Guilty until proved innocent."

"My GP attended a seminar organised by the private company that is contracted to carry out the medicals for the DWP. It was made clear that the medical report should be aimed at reducing, or preferably eliminating, claims for benefits."

Our recent survey indicated that appropriate training for medical assessors gives continued cause for concern. Based upon previous experiences, many find proposals to further engage the private sector in medical assessments alarming and are concerned about the potential for profit to be put before patient.

Work Capability Assessment

"I am terrified that the decision of whether I have the basics of food and shelter is in the hands of strangers who will base their decisions on forms I will find impossible to fill in and on the luck of the draw of having a doctor who truly understands M.E. or not."

When we asked people with M.E., 'Do you think the Work Capability Assessment (WCA) will accurately identify which people with M.E. should go in the Support Group and which should go into the Work-Related Activity Group?', 899 people responded.

67% did not believe the WCA would accurately identify which people with M.E. should go in the Support Group. Only 2% thought it would provide accurate assessment and 31% were not sure.

When asked why they had responded in this way, 627 people commented. Examples:

"Previous experience of DWP doctors getting medical assessments totally wrong."

"I don't have great confidence in the abilities of the assessors to understand the problems faced by people with M.E. based on my own experiences with the benefits system."

"I do not trust a system that has been set up by people who say all we need to do is to help people return to work. I do not need a carrot of benefit or a stick of it being taken away. I need someone to find out why I am ill and produce a cure. I have the skills to find a training course and find a job, I do not have the health."

"I can be relatively alert at 11am and feel able to go through an Assessment – and then at 3pm on the same day my head will have 'silted' up and I will be totally unable to comprehend the most basic of instructions – in short, a zombie. To me this inconsistency is one of the most damaging aspects of M.E., and the most frustrating."

When asked, 'Do you agree that the new Work Capability Assessment (WCA) will make it easier for the DWP to assess accurately the functional ability of people with different levels of ability to work (ie. easier compared to the existing PCA)?', 887 people responded.

The majority (52%) were not sure. 44% did not think the WCA would make it easier for the DWP to assess functionality compared to the existing PCA and 4% thought it would.

405 people gave their reasons. Examples: *"Because the health of people with ME fluctuates wildly. Symptoms appear days after activity. How can this be investigated?" "Experience of claiming IB suggests this won't happen." "The lower descriptors have been abolished. Someone with fewer grave medical problems, but a variety of less serious ones, which together have a substantial cumulative effect on their ability to work, are likely to be mis-identified."*

Assessment process

420 people with M.E. (420 of 890 respondents) had participated in a benefits assessment in the past three years and 397 had not. 73 people were not sure / could not remember.

Those who had participated in a benefits assessment were given a mixed list of positive and negative circumstances and asked if they had experienced any of them during a capability assessment.

- only 26% had experienced recognition that people with a long-term condition need time to recover from their illness before they can go back to work and only 11% had had recognition that time is needed to recover from an assessment
- 70% said tests for functionality and sustainability of activity were inappropriate

- 63% said there was no recognition of the fluctuating nature of M.E.
- 56% said that guidance for assessors was unsuitable
- 52% had encountered prejudice or disbelief during the process
- 47% said there was no consideration by the assessor of evidence from their own GP and 40% said that their GP's evidence was disregarded. 44% said there was no consideration by the assessor of evidence from an M.E. healthcare specialist
- 48% said there was an assumption that the claimant was capable of work and 41% said there was an assumption that the claimant did not want to work
- 37% had encountered an assumption that employers will employ disabled people and 38%, an assumption that employers are able to support disabled people.

When asked, 'has the benefits assessment process affected your health in the short term or long term, 611 people responded and of these, 79% of people with M.E. said yes, the benefits assessment process had affected their health. When asked how, 479 responded.

"Every time I have had a benefits assessment, either for Incapacity Benefit or DLA, my health has suffered as a result. The process is too detailed and exhausting for me and causes relapses. In 2002 my doctor wrote a letter requesting that I be visited at home for the Incapacity Benefit tests because I was too ill to attend the centre but the benefits agency still refused to accommodate this and I had to travel to see them, causing further deterioration of my condition.

"I also find that the long and arduous forms that need to be filled in again and again for each review an overwhelmingly difficult task. I need to dictate them for someone to fill in and this demands more energy than I can cope with. The last lot of DLA forms took us nearly 3 months to complete and I had to stop all treatments for my health in order to concentrate on this. This was in the summer of 2007 and a year later I have still not recovered from this."

Responses to questions specifically raised in the Green Paper

"The sad truth is that some people will never recover their health and return to work. This fact must be accepted by the DWP through recognition of the complexity of this illness, backed up by full benefits."

Action for M.E. facilitated an online forum with discussion threads on each of ten questions raised in the Welfare Reform Green Paper.

The following chapter is drawn from the comments posted on the forum, with particular thanks to CF for drawing them together and to MS for facilitating the forum.

When is the right time to require ESA claimants to take a skills health check? (Q 8 in the Green Paper)

The time for a skills health check should be negotiable between the person with M.E. and the DWP, with a parameter of three to six months into the start of benefit receipt to undertake the assessment. Extensions to this parameter should be available following further negotiation, with the DWP liaising with the person with M.E.'s physician if they need to 'confirm' continued disability.

The method of assessment should be entirely person-centred. We would suggest that home-based visits from well-trained, knowledgeable DWP staff (divided over a number of meetings if best for the person with M.E.'s symptom management), online self-disclosing assessments, combined with detailed input from both the physician/consultant involved with the person with M.E.'s care and the primary home-carer (if applicable) would work best.

A method for the DWP to assess symptoms across the day and/or over a four-week period would be a way to illustrate both the unpredictable, fluctuating nature of ME, plus confirm the person with M.E.'s inability to maintain stable health and energy throughout the day/week/month. This method would have to be non-invasive and respectful – perhaps a simple paper or online recording system that can be logged by the person with M.E. at the end of each day? The rating scale provided in the Appendix could be useful.

Should ESA customers be required to attend training in order to gain the identified skills they need to enter work? (Q 9 in the Green Paper)

People with M.E. should not be required to attend training for the same health reasons that they should not be required to undertake work.

In fact, if a person with M.E. decides they are well enough and would like to undertake some training, they should be encouraged first to examine their motivations before going ahead. We are all under intense pressure (politically, culturally and economically) to be working and earning. In addition, people with M.E. are often extremely frustrated by the limits which their condition places on them and keen to get back to 'normal life.' Taking on an inappropriate role at the wrong time can often lead to severe long-term relapse. If *not working* will support remission/recovery, this must be recognised and people with M.E. should be respected and supported in making that difficult choice and their benefits should be continued.

However, if the person with M.E. considers that training is the best choice for them (after input from their primary physician and perhaps a DWP-funded independent occupational therapist), the training should be delivered in a supportive, person-centred way.

Any training should be home-based or at a local venue, delivered in bite-sized chunks with flexible deadlines, online or via DVD/CD-Rom.

The subject matter of the training is a contentious issue. What are "identifiable skills" and who is doing the identifying? A person may have the skill and intellect to run a multi-national company, but lack the physical ability to type half a letter a day. A confusion of those two poles of ability by the DWP could lead to dire health consequences.

The person with M.E. should lead the way in identifying the skills and career path they had prior to illness, and what skills they feel they could call on today. They should be advised on whether their current skills could be considered laterally, with some tailored training enabling them to move across industries to a more supportive market. Vitally, this market should be one the person with M.E. actively chooses to participate in, not an "if the shoe fits, wear it" approach to work so often promoted by DWP.

Whilst training is ongoing, benefits must remain in place. If the person with M.E. decides to stop the training due to health reasons, the benefits must not be threatened. Once training is completed, if no suitable job can be found, the person with M.E. must not feel they have to take any job available or stand to lose their benefits.

The DWP should offer incentives to organisations for employing people with M.E. and other chronic fluctuating conditions, and should deliver appropriate education to these companies to ensure that the person returning to work is supported and the limitations of M.E. and other fluctuating illnesses are properly understood.

Voluntary agencies for people with fluctuating conditions could be incentivised and enabled to provide suitably graded return to work and work-related activity for people with such conditions.

Do you agree that the Work Capability Assessment and Work-Focused Health-related Assessment should be re-focused to increase work-related support? (Q14 in the Green Paper)

Employers should be educated about fluctuating conditions such as M.E. to ensure they comprehend the particular challenges of the sufferer, and the illness' impact upon working. This information should be delivered by the DWP as part of the returning-to-work package for the claimant and companies must fully 'sign up' and verify their commitment to an inclusive, supportive and flexible working environment. The DWP's educational message should be developed in consultation with leading M.E. charities, people with M.E. and a respected business network such as the Chamber of Commerce.

Once the person with M.E. finds appropriate work, the individual should have a network of support within that organisation – a mentor/ champion, a disabled worker's network with senior level support. The company and person with M.E. should also be periodically interviewed by the DWP to confirm that the company is upholding their side of 'the deal' to deliver supportive working practices and workplace environment. If they are found to be failing the person with M.E., there should be some level of penalty. Hard to enforce a penalty, but being removed from a DWP publicised register of 'gold star' organisations which support returning-to-work disabled people could perhaps be incentive enough.

What expectations should there be of people undertaking the personalised support which will be offered in the Work Related Activity Group? Could people who are in the Work Related Activity Group be expected to undertake a specific job search? (Q15 in the Green Paper)

Support must be delivered in a genuinely person-centred way – listening to the individual, working creatively with them to uncover the most constructive and supportive route back into work.

A specific job search could be agreed between the person with M.E. and their key worker within the Activity Group. The key worker could then be empowered to advocate on behalf of the person with M.E. to research the best working opportunities and interview prospective employers regarding their disability and inclusiveness policies, for example.

People undertaking the personalised support must be assured that their benefits are not in jeopardy if their planned return to employment doesn't work out (due to relapse or work proving to be detrimental to the ongoing stability of their health). They should be encouraged to try finding avenues back into employment if they choose them, and be supported, through the re-instatement of full benefit in the event of employment falling-through, for being proactive and brave enough to take this route.

How can the Government make Access to Work more responsive to the needs of claimants with fluctuating conditions? (Q16 in the Green Paper)

Access to Work must be person-centred and use the knowledge and experience of the person with M.E. to shape their wish-list for returning to work.

First, acknowledge the proven health benefits of establishing a baseline and then pacing against it, by considering symptoms at their best, worst and average over a given time period (a day, week, six months etc).

At this point, the person with M.E. should also lay out what kind of workplace environment they need to sustain their health. This could be the option to work from home, having a quiet space within the office to retreat to periodically, modified technology, or simply the knowledge that your colleagues and manager are on your side, not against you.

Next, Access to Work should consider the skills the person with M.E. is offering, plus their ambitions for working, and sensitively advise which skills could help get them back into their desired workplace, suggesting funded training options to enhance their commercial viability.

Bringing this thorough groundwork and preparation together, Access to Work can then draw up an individualised profile of the person with M.E. and advocate on their behalf, 'selling' the package of skills and experience the person with M.E. can offer against a given company's commercial needs. If a job offer is extended, Access to Work should continue their advocacy by feeding into the contract negotiation process to ensure that fair parameters and review dates are put in place to legally acknowledge the fluctuating nature of M.E.

In addition to these practical steps, assertive education of companies and staff regarding M.E. is essential to dispel the myth of 'the malingerer with yuppie flu' which unfortunately still exists in some quarters. Roll this education out using a combination of audience-friendly scientific research, real-life examples and an open-door policy to questions regarding the illness, which would be fielded by medical experts.

This approach could go some way towards growing understanding and compassion within the workplace. Get the Chief Executive and senior management on board and put in place a zero tolerance attitude across company to M.E. prejudice. If the culture of the workplace changes, half of the battle will be won.

What additional flexibilities in the system or forms of support would claimants with multiple and complex problems need to enable them to meet the new work-focused requirements proposed in this Green Paper? (Q17 in the Green Paper)

In the first instance, the DWP needs to change its perspective on disability, which currently views all disabilities as static. This starts with the DWP acknowledging their lack of understanding of fluctuating conditions, then rectifying this through meaningful consultation with people with M.E. medical experts and leading M.E. charities. The DWP must listen to what people with M.E. need to help them return to work, and then commit to delivering a tailored and flexible system informed by this feedback. This flexible approach should inform a general policy towards supporting individuals with fluctuating conditions, but should also cascade down to individualised support.

The person with M.E. should have a knowledgeable support worker who would work with them to identify their baseline for workplace activity. By doing this groundwork before the person with M.E. returns to work, the expectations on both sides can be clear and supportive of long-term health stability.

In addition, a modernised benefits system must be introduced whereby an individual with a fluctuating condition can receive top-ups to their benefit should they relapse.

People with M.E. should not be penalised financially for managing their fluctuating health when needs dictate. Instead, they should be encouraged to recognise signs of imminent relapse and be empowered by the DWP to negotiate a scaled-down work pattern, a system of rest periods or a complete break (with an immediate return to benefits). By working according to this model, the intense pressure (both financially and emotionally) that a person with M.E. feels to control an essentially uncontrollable illness would hopefully be assuaged. Ideally, this would then enable the person with M.E. to feel supported in managing their health fluctuations, without detriment to their status within the workplace or a significant loss of income. This acknowledgement of M.E.'s complexities, combined with reducing the emotional and financial burden that comes with relapse, could perhaps even lead to more days in work overall.

DWP should actively encourage businesses to create more home-working opportunities where people with M.E. can commit to completing particular tasks / projects, executed through their own system of time and energy management. For instance, if the person with M.E. feels well enough for one hour's work in the morning and one hour in the evening, they do the work remotely then. The focus shifts to completing the task given, rather than having to present yourself at an office for a certain number of hours and be 'seen' to work. In other words, being respected as a responsible, motivated adult who wants to work and get the job in hand completed, but on your own terms. To encourage companies to support productive home-working, the DWP should offer funding assistance towards useful technology ie. laptop, mobile, Blackberry, webcam, conference-enabled telephone, ergonomic work station.

What are the key features of an action plan for employees and employers that would best support the employee to take the steps to make a swifter return to work? (Adapted from Q18 in the Green Paper)

"How is 'a swifter return to work' defined by the DWP? A swifter return than the employee's actual recovery rate?"

It is not possible to rush or push towards a remission of M.E., no matter how swiftly you want (or need) to return to work. People with M.E. have to be enabled to let go of relentlessly chasing better health in order to achieve even a shade of progress. They must be supported by the DWP over a significant period of time in order to stabilise their health, not be pressurised by unrealistic expectations that they will be fighting fit by a certain date.

The sad truth is that some people with M.E. (and other chronic conditions) will never recover their health and return to work. This fact must be accepted by the DWP through recognition of the complexity of this illness, backed up by full benefits. In terms of an action planning approach, we would suggest the following:

- M.E. education for employers and staff with an open door policy for any questions about the illness, fielded by specialists. By myth-busting and clarifying the severe, biological nature of this illness, colleagues will be more supportive and adaptive to the person with M.E.'s needs
- a team of independent experts (ie. specialist physician, occupational therapist, physiotherapist) support the person with M.E. in identifying their work activity baseline according to pacing principles
- this baseline of work activity needs to be signed up to by the employer before the proposed return to work and encoded in a legal framework to protect the person with M.E.'s rights
- regular review of the activity baseline by the person with M.E. and their DWP support team, ensuring the baseline continues to serve stable health
- if the baseline needs to adjusted (up or down) the DWP support team advocates alongside the person with M.E. with the employer
- if working hours have to be reduced to support continued health, the DWP will top-up income

- if the person with M.E. has to remove themselves from work for health reasons, they are immediately reinstated on full benefits.

It is perhaps easier for large corporations with more financial and human resources to be adaptive towards a returning employee with M.E. Smaller businesses may find it less easy to accommodate a person with M.E. because of budgetary constraints and less staff to take on redistributed work. The DWP needs to recognise that some businesses will struggle to deliver a supportive returning-to-work package despite their best intentions, and assist them with material contributions towards adaptive technology etc.

What approach might be suitable to assist partners of benefit claimants (carers) who can work into employment? (Q20 in the Green Paper)

Most importantly, let us not forget that carers are already working in an exhausting and demanding role, albeit a role that society currently does not give the recognition, remuneration or support it deserves.

A carer may be physically able to work and have a few hours in their schedule of caring available to undertake some work, but that does not mean they should be working. It becomes a question of person-centred choice, led by the carer themselves. If the individual believes they are best-placed as a full-time carer, with their few hours' off per week kept free for unexpected medical emergencies or the business of running a household, it is their right to choose how to manage their time and their lives. They should not be penalised by the DWP for making the valid choice to care.

However, if the carer believes that working in another environment would enhance their quality of life and/or bank balance, they should first be assured by DWP that should circumstances dictate, they can return to caring at any stage after taking on a job with an immediate reinstatement of benefits in place and no penalties.

The carer should also be supported in their step back into work by the DWP funding like-for-like care for their unwell loved-one, delivered by qualified, experienced staff. Thus, if the cared-for individual relapses or cannot thrive without their primary carer, the carer would be empowered to return to their caring role as soon as their notice period allowed (with experienced staff in place until such time as the carer becomes available again). With these financial and quality care measures in place to support the carer and the cared-for, the

pressure around this potentially fraught transition could be relieved and therefore be more likely to result in a successful, long term return to work and the ongoing good health of the cared-for individual.

The benefits system must appreciate the tentative steps that need to be taken whilst a carer attempts to return to work. It must be appreciated how this return to work may require a number of false starts whilst the carer and cared-for negotiate what works best for them. An acknowledgement of the trial and error quality of finding the right balance needs to be built into the system of DWP support, with benefits being reinstated immediately if work has to be abandoned to return to caring, and a budget available to top up carer's benefits if they have to scale down their hours of work to nurse their unwell loved-one through a period of relapse. These 'false starts' could be reduced or prevented by appropriate support from DWP. A key worker could be assigned to work alongside the carer to identify skills, training gaps and funded training opportunities, advocate with suitable employers etc, and thus build a profile of the most sustainable launch-pad back into work.

DWP must work to educate businesses about the importance of the carer, so this vital role is acknowledged more within both business and society at large. By enhancing respect of the caring role, practical steps can then be taken by businesses to enable them to meet their market objectives whilst supporting a staff member who also cares for someone.

More part-time working options should be created, in addition to a flexible hours culture. Home-based working options should be made available with take-home technology such as laptop, mobile and Blackberry supplied. To underline their commitment to helping carers return to work, DWP should offer funding assistance to companies which seek to facilitate their staff to both work and care concurrently.

Businesses could build a number of paid 'carer's leave' days into their contracts so the carer doesn't have to use annual or sick leave to manage unexpected health crises at home. 'carer's leave' could also be used as a respite day for the carer ie. a day to themselves for rejuvenation.

By recognising the carer as the societal lynchpin they are, providing a few extra days' paid leave per year alongside progressive and flexible working options, businesses would ensure they had a staff member who was committed to the company and its product, and who worked hard because they felt validated and appreciated.

What are the next steps in enabling disabled people, reliably and easily, to access an individual budget if they want one? Should they include legislation to give people a right to ask for a budget or will the other levers the Government has got prove sufficient? What are the safeguards that should be built in? How can this be done? (Q21 in the Green Paper)

Although individual budgets could give people with M.E. greater control, in the experience of those forum members who knew about individual budgets, the system is complicated and individual budget holders would require assistance to manage their budget, not least because people with M.E. have problems with concentration, information processing and memory.

Would moving carers currently on Income Support onto Job Seekers Allowance be a suitable way of helping them to access the support available to help combine caring with paid work or preparing for paid work? (Q 23 in the Green Paper)

The problem here is in the name of the benefit: as jobseekers, carers would be expected to undertake additional work when they already have a job as carers.

Carers should have their own benefit created just for that purpose.

Conclusion

"This whole benefit reform is first and foremost a cost-cutting exercise. Whilst, of course, it's reasonable to expect those that are fit enough to work, to do so, unfortunately genuine claimants are getting caught up in the purge."

"I appreciate there is abuse of the welfare system but penalising people who are ill is brutal and easy."

"Ours is not the only condition that fluctuates between 'bad days' and 'better days' – many illnesses go through stages like this."

The welfare reforms appear to fit best a model of ill health in which an individual falls ill and is subsequently out of work, but can be rehabilitated to near-normal functioning and be enabled to return to work fairly rapidly. This may apply to acute conditions with a clear cause, where evidence-based treatments are widely available on the NHS, and there is a good prospect of a permanent cure.

The model of illness implicit in existing DWP practice and in the proposed reforms makes no allowance for chronic, varying and relapsing illnesses and thereby institutionally discriminates against M.E. The fact that sufferers cannot readily convey the reality of their illness experience on existing assessment forms or in early assessment interviews shows that from first interaction with the DWP such illnesses are discriminated against.

Our evidence clearly demonstrates that prejudicial attitudes and practice are embedded in DWP assessments. Many patients have complained about assessors having explicit attitudes of disbelief, an unwillingness to take the illness seriously and an unwillingness to find out more about it.

Our survey found that the vast majority of people with M.E. lack neither the skills, training, motivation nor aspiration to work: *"I wish to be better and never wanted to leave teaching, if I was well again I should very much want to teach."*

They are limited by fluctuating symptoms which are characteristic of the illness, notably post-exertional malaise or exhaustion, typically delayed by at least 24 hours, with slow recovery over several days.

This means that, in all but the mild or more moderately affected, people with M.E. are, by definition, unable to sustain levels of functionality which other people take for granted.

Until greater public investment in research identifies better treatments for people with M.E., DWP assessors and employers must become more understanding and accepting of the limitations of chronic fluctuating illness and better educated and enabled to provide people with M.E. with the support they need to remain in or return to work, when they are well enough.

Employers

Our survey shows that people with M.E. suffer as a result of the current assessment system and that employers are still very reluctant to employ people with health problems.

Action for M.E. is seeking resources to produce a guide to good practice in employing people with M.E., in partnership with employers, which will draw on the experiences and ideas submitted by people who participated in our surveys and online forum.

Benefits procedures

“Unless there is a revolution in understanding about M.E. amongst the DWP staff and employers the same problems will exist.”

“They are playing Russian Roulette with people’s lives.”

Too often, both our medical adviser and our welfare rights adviser speak to people who are dismissed from work because of their illness, and are forced into a downward spiral of increasing poverty and ill health, marked by benefit applications and appeals.

Safeguards must be put in place to prevent this situation and to ensure that new procedures do not exacerbate this further by ‘bouncing’ people with M.E. in and out of work or work-related activity, on and off different benefits, in and out of more frequent and increasingly severe relapses.

Meanwhile, it will be very important for the Government to monitor the impact of the new system on those with fluctuating conditions, including M.E., for a considerable period of time, as the new system ‘beds in.’

Action for M.E. will invite people who are assessed for ESA to inform them about their experience of the process and their progress through the system, in order to assess:

- whether those with mild M.E. (70% functioning and above) are put into the work related activity group, to what extent the help on offer facilitates a return to paid employment and whether that return to work is sustained without adverse effects on health

- whether those with moderate M.E. (40-60% functioning) are allocated to the Work Related Activity Group or to the Support Group; whether those placed in the Work Related Activity Group become more ill as a result of the demands put upon them; and whether sanctions will be imposed if they genuinely cannot meet the requirements of the ESA conditions for this group, making them financially worse off
- whether those with severe M.E. (0-30% functioning) are quickly recognised as eligible for the Support Group; whether they are able to qualify without having a medical assessment which could make their condition worse
- whether prospective employers are willing and able to make adequate ‘reasonable adjustments’ for people with different levels of M.E., given the physical and cognitive limitations of the illness
- the quantity and type of jobs that in practice fit round the more significant mental and physical limitations imposed by the illness, where some ‘reasonable adjustments’ can be made by employers.

Support to help people to stay in work or to make a gradual return to work is very welcome. No-one who participated in our survey objected to the idea that people who can work should be enabled to work, rather than rely on welfare benefits.

However, there is real fear that without a fundamental sea-change, throughout the DWP and amongst employers, the proposals outlined in the Welfare Reform Green Paper will force people who are genuinely ill into work or work-related activities before they are well enough, to the detriment of their long-term health.

“Girl from the dole office rang up threatening me about 6 months ago saying I had to get back into work. I said brilliant! I will post you a house key – come round and pick me up anytime you like! Oh, and can you please get me out of bed, give me my medication, wash me, dress me and carry me to the car and the same coming home please. I wasn’t trying to be nasty, I just think they all assume we are lying about our condition instead of working with us to help us all back to work. How on earth can we do voluntary work (let alone paid work) if we cannot even get ourselves up and washed? It’s such a financial strain having no income. Why can’t these people realise we are desp to work and don’t WANT to be stuck at home on our own, day in day out, taking no part in life whatsoever?”

Appendix:

wellness / severity scale

Survey respondents who were affected by M.E. were asked: "How well or how severely affected are you at the moment? Please choose the situation below which matches your current situation most closely." Options given:

- **100% well:** I have had no symptoms when resting or following activity for at least three months
- **90% well:** I have no symptoms when resting. Occasionally, mild symptoms may follow activity
- **80% well:** Occasionally I experience mild symptoms when resting. The symptoms are more noticeable following activity. I can't do some activities which require physical exertion
- **70% well:** My symptoms are mild when I am resting. I can't do some tasks which involve physical exertion
- **60% well:** My symptoms are mild or moderate when I am resting. My ability to carry out normal daily tasks varies
- **50% well:** I experience mild to moderate symptoms at rest and moderate to more severe symptoms following physical and/or mental exertion. I can't carry out any strenuous physical tasks but I am able to perform light activities for several hours a day, as long as I have adequate rest periods
- **40% well:** When I am resting my symptoms are moderate. They are moderate to severe symptoms following any form of physical or mental exertion. I can't carry out any strenuous duties but I am able to carry out light activities for one to three hours a day, as long as I have adequate rest periods. I am not usually housebound
- **30% well:** I experience moderate to severe symptoms when resting. Severe symptoms follow any physical or mental activity. I can do light tasks for one or two hours during the day. I am often confined to the house and may require wheelchair assistance at times
- **20% well:** I experience moderate to severe symptoms at rest. I may only be able to carry out a few physical activities relating to personal care such as having a wash. I am often unable to leave the house and may be confined to a wheelchair or bed for much of the day. I can't concentrate for more than short periods
- **10% well:** My symptoms are severe, even at rest. I am bedbound and housebound for much of the time, have real difficulties with many aspects of my own personal care and need a great deal of practical support. I have significant problems with memory and concentration
- **0% well:** I experience severe symptoms on a continual basis. I am bedbound, incapable of living independently and need a lot of practical and social support.



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Disability alliance

Disability Alliance
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