

Future of Care (England) Consultation 2009

Consultation report



About M.E.

M.E. (Myalgic Encephalomyelitis/Encephalopathy) is a chronic, fluctuating illness, also known as Chronic Fatigue Syndrome (CFS) and sometimes diagnosed as Post Viral Fatigue Syndrome (PVFS). It affects over 250,000¹ people in the UK. Common symptoms include persistent exhaustion, un-refreshing sleep, poor concentration and memory, headache, muscle pain and digestive problems.

Patient surveys indicate that 25% of people with the illness are so severely affected that they become housebound or bedbound, some for many years. M.E. can affect anyone, at any age and from any ethnic group.

About Action for M.E.

Action for M.E. is the UK's leading charity dedicated to improving the lives of people with M.E. We have been at the forefront of the campaign for more research, better treatments and services since 1987, and we provide information and support to people affected by M.E.

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Cover illustration: posed by models, sourced from www.istockphoto.com

¹ Estimates of incidence based on a research paper by Gallagher et al in the Journal of the Royal Society of Medicine, December 2004, indicated a prevalence of 240,000 people with M.E./CFS in the UK and an incidence of 25,000 ie. a further 25,000 are affected per annum.

Executive summary

The purpose of this consultation was to collect data which would inform our response to the Government Green Paper *Shaping the future of care together*.

406 people with M.E. started the survey and 289 people completed it. Among respondents, women outnumbered men considerably (78% women to 22% men) and most people fell in the 41-65 age range (65%).

The survey asked people to rank the issues the Green Paper raises for people with M.E. The top three concerns were:

- whether the criteria used to assess my care needs will reflect the needs of a person with M.E. and assess them realistically and accurately
- whether I will manage financially if Disability Living Allowance /Attendance Allowance are phased out and replaced in full or part by services
- how much choice or control I will have over the care I receive.

Action for M.E. recommends the following improvements be made to current services in order to meet the needs of people with M.E.:

- up-to-date M.E. education and awareness training for all DWP staff and contractors involved in assessment and care delivery
- assessment procedures which reflect the fluctuating nature of certain conditions including M.E. and which clearly identify the people that really need care
- greater flexibility in the way needs are met to allow for fluctuations in health and individual circumstances
- creating a greater role for advocacy organisations in ensuring that disabled people have the right support to access the care they need.

As well as standardising care assessments nationally, Action for M.E. also asks the Government to make improvements throughout the care service, for consistency in quality of care, and the degree of choice people have in accessing care across the country.

Most people who responded to this survey felt that care should be paid for by the Government.

Our survey shows that half of respondents would be hit by any reduction in Disability Living Allowance. Many struggle to cope even with DLA. Some do not qualify under current criteria, but are badly in need of financial assistance to address the inequalities they face.

The impact of diverting disability benefits would be devastating, leading to:

- severe financial hardship for many, resulting in neglect, poverty and homelessness for some
- loss of the autonomy which is enabled by DLA and which is vital for dignity and self-esteem
- assuming current Social Service procedures would still apply, the introduction of means testing.

Action for M.E. calls on the Government to:

- commit to keeping the current disability benefits in place especially for people with fluctuating conditions including M.E. who are already a vulnerable and neglected group
- follow our recommendations for improvements to current social care services
- ensure that disability benefits and social care are offered to all those who need it.

Introduction

The purpose of this survey was to collect data which would inform our response to the Government Green Paper *Shaping the future of care together*.

The Paper talked about several key areas:

- forming a national care service with needs assessments which were standardised across England
- a new system of funding for social care
- diverting money from disability benefits such as Attendance Allowance into funding for Social Services.

In particular we needed to know what people with M.E. thought about:

- how it would affect them if Attendance Allowance (AA) or Disability Living Allowance (DLA) were scrapped?
- would Social Services be able to replace the things that benefits currently provided. Would this be better or worse?
- a nationalised assessment procedure?

We also wanted to make sure that people with M.E. were represented in the surveys of larger organisations and worked in partnership with Disability Alliance for a section of this survey.

We sought their views through e-mails, mail and a survey on our website.

Since the release of the Green Paper, some reassurances have been given about the plans for disability benefits. But as some messages have been contradictory, Action for M.E. wants to make sure that the Government has the concerns of people with M.E. in mind for any policy decisions they might make in the future.

Findings

406 people started the survey and 289 people completed it. As respondents could choose which questions they responded to we have also included numbers of respondents for each individual question throughout this report. Among respondents, women outnumbered men considerably (78% women to 22% men) and most people fell in the 41-65 age range (65%).

The greater the time period since diagnosis, the more respondents there were in each category:

- most people (38% of 340 respondents) had been diagnosed over 10 years ago
- 26% had been diagnosed 6-10 years ago
- 23% diagnosed 2-5 years ago
- 3% diagnosed less than two years ago.
- 1% had not yet had an official diagnosis.

Severity

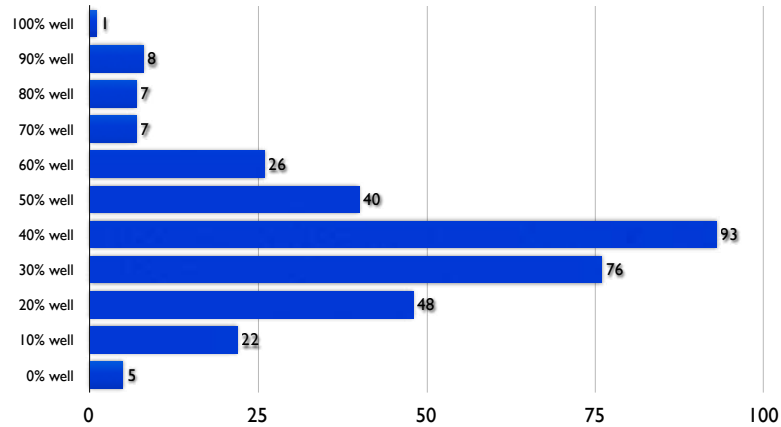
When asked about how severely affected they were currently, responses were spread out across the full range of possible answers. Most people (73% of 333 respondents) regarded themselves as 40% well or less.

Fluctuation

Asked about how they had felt on average over the last six months:

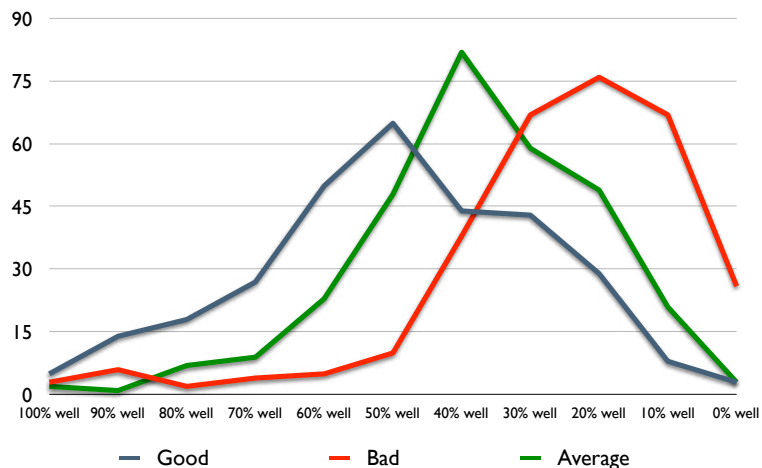
- On a good day, the highest percentage (21%) felt 50% well
- On a bad day 25% felt 20% well
- On an average day 27% felt 40% well.

How well or how severely affected are you at the moment



Total Responses: 333

Fluctuation of M.E.



Total Responses: 306

Care needs

When asked to consider which activities they could currently do, out of 321 respondents most people could usually do the following unaided:

- get out of bed (88%)
- get to and from the toilet (87%)
- use the toilet and attend to themselves (91%)
- shower/bathe or wash themselves (63%)
- get dressed or undressed (76%)
- feed themselves (91%)
- hold a 5 minute conversation (68%).

The activities people could not usually undertake unaided included:

- walk for 15 minutes (45%)
- drive a car (40%)
- cook a main meal (35%)
- go shopping (31%).

When asked to consider which activities they could do when their M.E. was at its worst, out of 319 respondents, many could usually do the following unaided:

- get out of bed (42%)
- get to and from the toilet (49%)
- use the toilet and attend to themselves (59%)
- feed themselves (56%).

But many could not usually:

- shower/bathe/wash themselves (47%)
- get dressed or undressed (38%)
- cook a main meal (81%)
- do light housework (88%)
- go shopping (90%)
- respond to official letters (72%)
- hold a 5 minute conversation (48%)
- walk for 15 minutes (93%)
- drive a car unaided (86%).

Extra costs of M.E.

84% of people (266 out of 318) told us they had extra costs because they had M.E.

Domestic costs

The most common extra cost relating to paid care was domestic help eg. shopping or cleaning, with 42% of 261 respondents saying either they paid for this or their family pays on their behalf.

13% paid for help with managing bills or correspondence.

Some also paid for personal care eg.

- washing and dressing (8%)
- an overnight carer (3%)
- respite holiday care (6%).

Considering extra domestic costs, of 239 respondents:

- 85% paid for extra heating
- 51% had extra telephone costs
- 50% had bought energy-conserving appliances
- 49% had bought blackout curtains
- 39% had extra laundry costs.

Most members had purchased adaptive clothing. Of 239 people who responded to this question:

- 57% of people had bought leg warmers or cosy feet slippers
- 15% had bought wheelchair wear such as a cape

Disability aids

The most common extra costs relating to aids to daily living (246 respondents) were:

- bathroom aids (37%)
- kitchen aids (36%).

These were closely followed by:

- adapted chairs/beds/sofas (29%)
- bedroom aids (19%)
- helping hands(19%)
- living room aids (17%).

Some people had also paid for house conversions and stair lifts.

Personal care

247 people told us about extra costs relating to personal care. The most common were:

- sunglasses (60%)
- pill boxes (49%)
- ear plugs/ protectors (48%)

Some respondents also talked about paying for exercise aids, incontinence supplies, grooming aids, dressing aids and remote personal alarms.

Mobility

When asked about extra costs relating to mobility, out of 247 people, most had paid for:

- taxis to essential appointments (55%)
- walking aids (53%).

Many had paid for:

- manual wheelchairs (30%)
- wheelchair accessories (21%)
- mobility scooters (19%).

Also mentioned were trains and buses to essential appointments, wheelchair ramps, electric wheelchairs and adapted vehicles.

Orthopaedic equipment

Orthopaedic equipment had also caused additional expense. Of 239 respondents, many had bought:

- memory foam mattresses (42%)
- orthopaedic pillows (41%)
- back supports (28%)
- orthopaedic or coccyx cushions (23%)
- lamb sheepskins (7%).

Extra health costs

The vast majority of the 239 respondents who answered this question had additional health and wellbeing costs.

These included:

- nutritional supplements (80%)
- non-prescription medicines (54%)
- special dietary needs (67%)
- complementary therapies (58%)
- prescription medicines (70%)
- chemical free products (54%).

Other expenses were pressure sore prevention/treatment, light therapy lamps and oxygen therapy equipment.

Other costs not covered by the NHS

Responses to this section showed a wide range both of needs and solutions.

Many people spoke about the importance of their computer and internet connection costs. This not only enabled them to maintain a degree of independence, through online banking, shopping etc. but was also a way to keep in touch socially, and get much-needed support, advice and information which helped them to get through life with M.E.

Approaches to similar needs also varied from person to person as they had tailored solutions to their own personal situation. Several people used a number of complementary therapies to make the symptoms of M.E. more manageable.

Home maintenance/ domestic tasks that people would have done themselves, if well enough, were also an issue. Many respondents had to pay people to do domestic work which ranged from daily cleaning and ironing to gardening and decorating. On top of this were extra costs of chemical-free paints which would not aggravate any sensitivity symptoms that they had.

Chemical sensitivity also had impact on the costs of toiletries and groceries, with delivery charges a further factor.

Mobility was also a significant need, in particular getting to necessary appointments to see specialists, GPs and other sources of treatment. Again approaches were diverse, from paying for an electricity-assisted bicycle, to taxi costs, and even having to pay a private driver because they could not travel unaccompanied.

Travelling companions were another hidden cost for those that needed them. Even those who were able to have a partner or parent travel with them sometimes lost out on money for the household if that meant their companion had to take time off work unpaid.

Lots of people talked about reliance on carers being an additional concern, both in terms of the toll this took on their carer, and the fact that without them they might not cope.

Another important point to note from the survey is that care needs were complex with many people having more than one problem, which meant a flexible approach was needed in meeting these needs. For example, one person was also partially sighted and tended to fall a lot so their glasses often got broken and needed to be replaced. Another needed additional rent to allow them to live in a property with an extra bedroom because they were unable to share a room with their partner.

Importance of welfare benefits

When asked whether they could afford to pay for this care and support without government help, 68% (159 out of 232) said no, and 24% (56) said they could only pay for parts of it. Many stressed the part Disability Living Allowance (DLA) had to play in getting them the support they needed.

“My DLA award is crucial to my ability to maintain my health needs. I would be in dire straits without it.”

“If I did not have these facilities my health would suffer more and I would definitely need more support from the community.”

Many spoke about the fact that they had not been deemed eligible for DLA, or had not received the correct rate due to misunderstanding of M.E., with several stating that they felt the powers that be do not believe that M.E. is an illness at all, despite M.E. being recognised by both the World Health Organisation² and the National Institute for Health and Clinical Excellence³.

Those who had appealed against a benefits decision had found the process stressful to the point that their physical condition became worse. Others were deterred from appealing at all because they could not face it despite the financial hardship this incurred.

“I used to claim incapacity benefit, but found attending medicals and being treated like a time wasting criminal too hurtful, upsetting and exhausting.”

Lack of Government help led a number to financial hardship, debt and fears of becoming homeless. A few found it hard to cope even with Government help, but at least it provided something. Family members also provided a number of respondents with financial help, without which, again, they said they could not cope. Those who relied on carers said that without them they could not manage if they had to pay for equivalent services.

“I can barely afford to pay for items now, and went bankrupt this year due to continuous debts, a lot of them (incurred to pay for) aids to improving my life.”

2 World Health Organisation International Classification of Diseases Version 2007 (ICD-10)

3 NICE guideline CG53. Turnbull N, Shaw EJ, Baker R, Dunsdon S, Costin N, Britton G, Kuntze S and Norman R (2007). Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) in adults and children. London: Royal College of General Practitioners.

Several said they were completely unable to work and that they were totally dependent on the state for their income, others that without DLA they would not be able to afford the additional help they needed, and that this might make them even more dependent in the long run if they deteriorated. A particular area of concern was additional treatment, such as private consultations or complementary therapy, for those who found that conventional NHS treatments had not helped them to improve.

The survey went on to take a more detailed look at how disability benefits helped people with M.E. to manage.

Disability Living Allowance

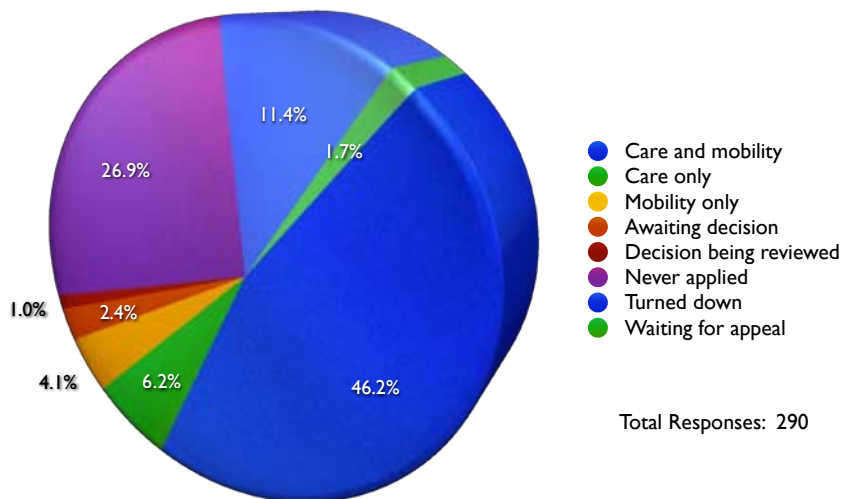
Most people (56% or 164 out of 290) claimed DLA whether both care and mobility components, or one component only.

A full breakdown of the DLA people received follows:

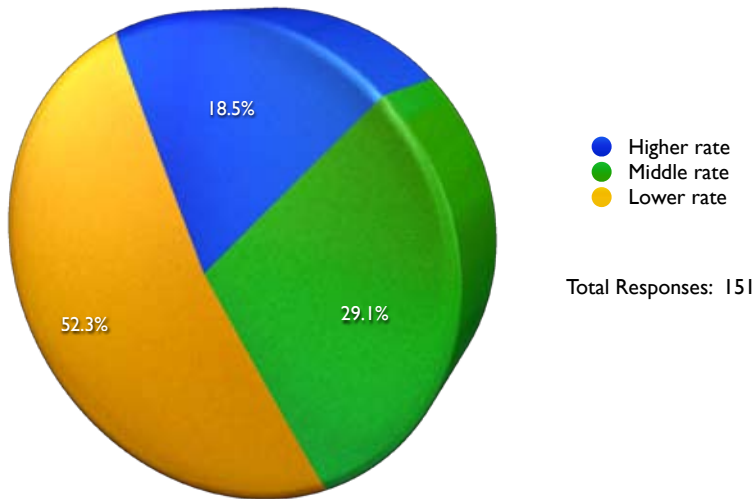
25% of people (39 out of 157) had to go to appeal or tribunal for DLA in the last three years, and of those approximately half (47% or, 28) had won their appeal.

Following the release of the Green Paper there have been conflicting messages about future plans for disability benefits. Initially press commentators and organisations such as Benefits and Work raised the alarm that DLA and AA could be scrapped entirely and the cash passed to Social Services. Then in a speech on October 27 Health Secretary Andy Burnham said that they had ruled out that DLA for under 65s would be bought into the National Care Service. According to our survey, if Disability Living Allowance was scrapped, 52% of the people who completed our survey would be affected.

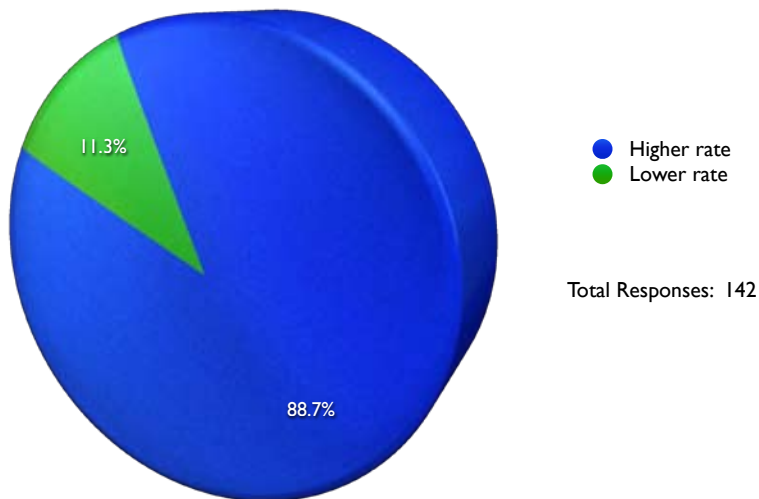
Are you in receipt of Disability Living Allowance?



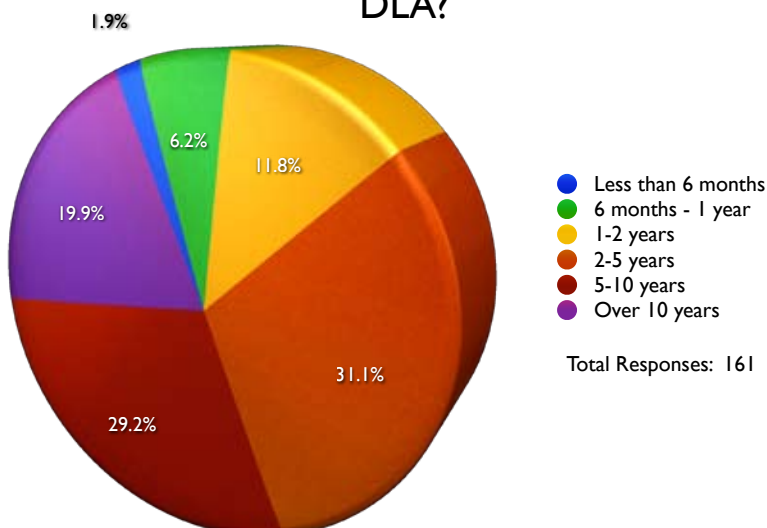
What Disability Living Allowance care rate have you been awarded?



What Disability Living Allowance mobility rate have you been awarded?



How long have you been in receipt of DLA?



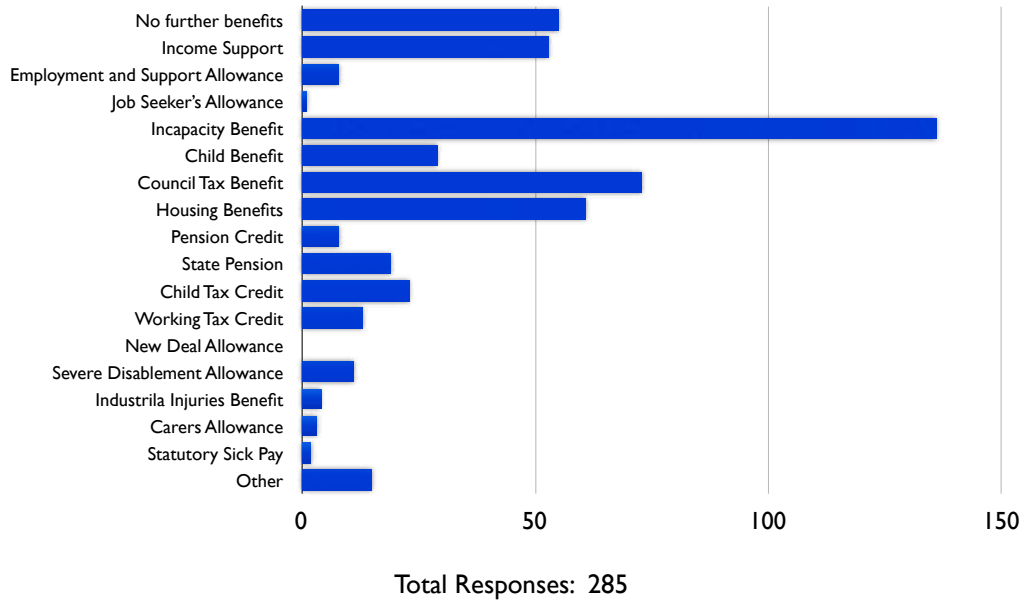
Attendance Allowance

Only one of our respondents said that they received Attendance Allowance (AA), and the vast majority had never even applied, however it is worth noting that only 10 people aged 66 or above completed the survey.

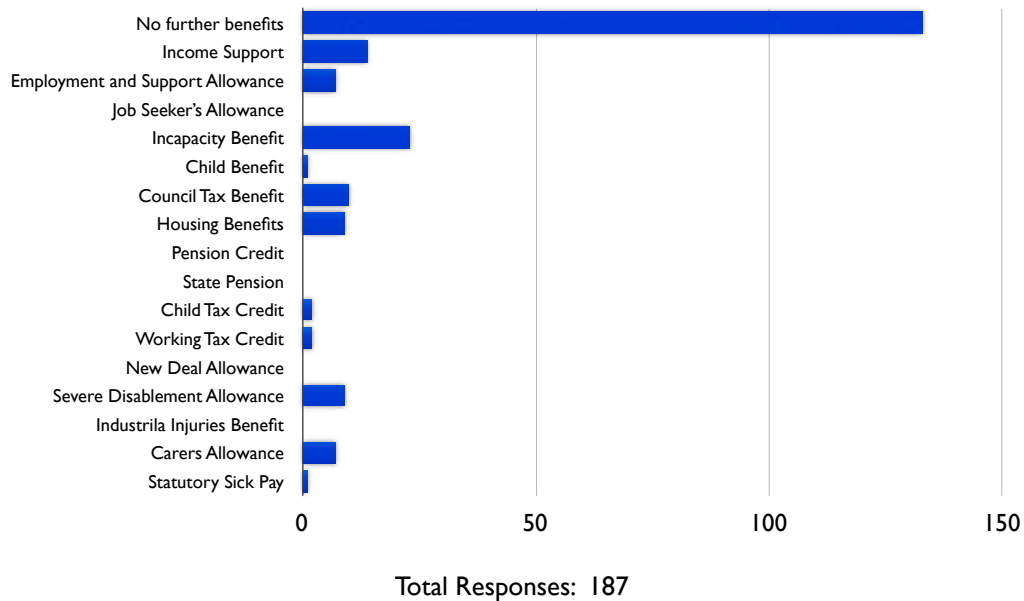
Further benefits

The following graphs summarise the responses we received on benefits other than AA and DLA.

Which of the following further benefits do you receive at the moment?



Which of the following further benefits have you had trouble getting access to?



What impact would it have if DLA was phased out (and replaced by social care services?)

Several people wanted to highlight that DLA gives them the best level of independence possible. Some spoke about wanting to be self sufficient and using DLA money to pay for things as they needed rather than depending on state care. There were concerns that they would have less freedom to decide how their budget was spent. They also talked about the fluctuating nature of M.E. and how under the current system they are able to tailor how they spend the money to cope with ever changing needs. This also means resources are not wasted, for example, they can cancel help if they feel well enough to do more.

"As a disabled person, I have so little control over my life. To have that control taken away by Social Services (as well as the inevitable delays) would be very distressing."

"There is no way I would be able to pay the extra costs of disability without my DLA being given to me to spend myself. I am able to be flexible with what needs are priority at a given time based on the fluctuation of the illness, and spend accordingly."

Others worried that M.E. would not be properly recognised and that on top of this, Social Services are under-funded. When competing with others in terms of priority, people with M.E would miss out, or the support provided by Social Services would not be as much as was paid out through DLA/AA.

"Social Services have been underfunded for years. At the moment they give very little. I am quite sure they would not be funded to the same amount being paid out on DLA & AA. Like myself there are many people being cared for at home. Who is going to provide the care home facilities, other than private homes which are expensive, since (some) Local Authority care homes (were closed down) years ago. For those who have M.E. alone I feel sure there will be no assistance for them."

"My experience since I have been unwell is that chronic fatigue is not recognised by the Government and to that end they will ensure that this is an area that will not receive adequate funding - in any form."

"Will this mean monies, for those who may have been in receipt of DLA/AA directly, being diverted from their needs to the needs of another service that the council deems necessary when there are financial restrictions?"

Other worries were that Social Services did not provide the same kind of help as they paid for with DLA, so they would have to do without. Examples were heating, internet access, blackout curtains, ear protectors, household maintenance, special foods, taxis, alternative medicines and ear protectors.

"My concern would be that if the Care component of my DLA is phased out, would Social Services still be able to provide me with an identical benefit, without any restrictions and allow me the freedom of choice regarding what or how I spend that money? I do not believe that they would."

They also worried that there was not enough variety in Social Service care to accommodate the diverse needs of people with M.E., for example meals on wheels would not meet the needs of a restricted diet.

"I have the care component because I cannot cook a meal for myself. My husband has to cook my meals for me, and we use only organic ingredients to avoid toxins. I would imagine that social care services would not provide me with this same service and if they did, it would cost the government considerably more than £18 per week."

Again people were concerned that when being assessed, Social Services would not understand how the condition fluctuates, or not recognise the illness, and that this would work against them.

"I think that I will not then be entitled to any help as in the past whilst Social Services may sympathise with my problems, they have been unable to assist me because I do not have the same needs or fit into any one category on a daily basis (ie. what I need help with may vary from day to day or month to month)."

"I cannot see how Social Services can possibly provide the care I need, as and when I may need it, due to the fluctuating nature of M.E."

They also had concerns about how qualified Social Services were to meet the needs of people with M.E.

Only one person felt that there may be a benefit to Social Services taking over as it may take the pressure off people with M.E. having to plan and arrange their own care.

"I don't have care allowance, but if people do, and they use it for care help through the Social Services, surely that must be a good thing, as the Social Services have to manage it rather than the M.E. person, so less stress for them."

Devolved responsibility

We also asked respondents to say what they thought might happen if DLA or AA funding is passed from the Department for Work and Pensions to local councils to distribute. The overwhelming majority were strongly against this for a number of reasons, but several issues came through consistently.

There were concerns that local councils did not have the expertise necessary to assess need appropriately, particularly with this often misunderstood and overlooked condition, or that local council bureaucracy would be overwhelming for people with M.E., especially those with cognitive impairment.

Many people spoke of a postcode lottery with variation in how different authorities provided care. They worried that there would be no right of appeal whereas the DWP is at least a nationally visible and accountable organisation.

Others felt that the Social Service system is over-stretched and under-funded as it is and that this would make matters far worse, resulting in long waiting lists for services. Even if DLA money was added to Social Service funding, they felt this would only get swallowed up by existing deficits.

“(Social Services) are not competent to make proper assessments, are unaccountable for their mistakes, oversights (etc)... There is no independent appeals process and if you complain to any outside body they don’t want to know.”

Also, there were fears that DLA/AA funding would become means tested, in line with current Social Service procedures. This was a particular worry for those who already relied on carers in the same household, such as partners or parents, because if benefits were removed but others in the household were managing to work, the income from DLA/AA would not be replaced under means testing, increasing dependence on the carer even more.

One respondent felt that if assessments included means testing, poorer people would benefit, and the very rich would manage with their own wealth, but those in the middle would suffer, as any savings they did have would soon be eaten up. Several people were concerned that this was penalising those who had struggled to save for a ‘rainy day’ and favouring those who may not even have tried. They felt that this was not fair, and that irrespective of savings, they had already paid their contribution through taxes.

“Any savings acquired by past hard work, frugality or other means - eg. selling your car because you can no longer drive due to illness - are used to maintain basic living and disability costs now and in the future. To be penalised for this is very unfair, especially when others who may not have managed their lives in such a way, have everything paid for them.”

It was clear that if DLA was phased out, considerable numbers of people with M.E. would be left with severe financial difficulties. For those who already struggled, the situation would be unthinkable. On top of this, the care that Social Services could provide would not be adequate to meet their needs, leaving many unable to cope and causing their condition to deteriorate further in the long term. There would be huge losses in the level of independence they could achieve.

“No-one wants to be ill or to live on benefits, which are a lifeline but that’s all. Being unable to work and having no potential to work in the future is a bleak outlook and a source of grief.”

Care issues raised by the Green Paper

274 respondents told us what they felt were the top three care issues they felt they faced as a person with M.E. from the following options:

- no concerns about personal care
- increasingly complex care needs as I get older
- lack of specialist social care services for all older people
- lack of funding for social care for people with long-term conditions in my area
- care costs I may not be able to meet if I lose benefits
- lack of specialist social care services for people severely affected by M.E.
- reliance on family/friends to provide daily care
- mobility costs I may not be able to meet if I lose benefits
- lack of understanding of M.E. amongst social care assessors
- M.E. 'competing' with other local needs for social care funding
- lack of understanding of M.E. by the benefits assessors.

The areas of most concern, in order of priority, were:

- lack of understanding of M.E. by the benefits assessors, with 127 people ranking this in their top three
- lack of understanding of M.E. amongst social care assessors (114 people)
- reliance on family/friends to provide daily care (113 people).

Several people said that all the statements were important to them and they could not choose.

Some made individual suggestions such as:

- a general lack of understanding or recognition of M.E.
- concern about the pressure their carers were under or what would happen if they were unable to care for them in the future
- social isolation and lack of adequate medical services.

Current care packages

Of 73 respondents, 38% said they had a care package in place currently, but only 11 out of 49 said the package met all of their needs.

When asked about their experience of being assessed for a care package 60% of the 68 people who responded said "poor," "very poor," "bad" or "very bad".

One of the most common reasons for a negative response was staff who did not understand M.E. and that they were offered help which was not suitable.

"M.E. was shoved backwards and forwards between departments."

People spoke about the stress of the lengthy processes and that they found the assessment interview itself too taxing both physically and mentally. There were several very concerning accounts. One person described being neglected and left at risk of starvation and dehydration. Another respondent of great concern felt so bullied during the assessment interview that they attributed a subsequent relapse to the experience. One person agreed with the assessment which was made, but the promised care was never put in place.

A few people did speak about their positive experience, reflecting the quality that everyone should have access to. One person's assessment was conducted by someone from an advocate group rather than Social Services and was very informal, and everything they said they needed was agreed. Several others said that social workers had been very helpful.

Some identified areas where they felt the staff had been willing but the system prevented them from helping, such as assessment forms which were not flexible enough to record fluctuating or 'unconventional' needs.

Nationalised care assessment

272 people told us their views on plans for a nationalised care assessment:

- 41% thought this was a bad idea
- 48 % didn't know
- Only 11% who thought it was a good idea.

One person commented that a nationalised care assessment was only a good idea if the actual services available across the country did not vary either. Again people spoke of a postcode lottery, and one said that we cannot assume that someone in a rural area has the same access to services as someone in a city. They were worried that plans implied a 'one size fits all' approach. Some also spoke of

variation in quality of assessments across the country, including in relation to M.E. specifically. Would a nationalised care system help address this?

"I would like to think that each assessor would be unbiased and fair, but prejudice exists and if assessors are overworked and hard pressed, they are likely to be influenced by a previous, existing decision."

Some comments talked about ideas to make the system fairer ie. if you had the same assessment, you should have the same level of care throughout the country, and that people needed regular assessments as their needs change.

"The system must be transparent, robust and even handed."

Several people felt that plans for a nationalised care service were reasonable provided they had an adequate assessment to start off with. If you were unfortunate enough to have a poor assessment, you might then get stuck with it even if you moved. Many felt that there was not much hope of an adequate assessment due to misinformation and prejudice about M.E.

Questions raised by Disability Alliance

151 people chose to look at three questions supplied by Disability Alliance, our partner organisation, which was also doing a survey.

These looked at:

- key features of a fair, simple, affordable care service
- models of care funding
- in reference primarily to older people, whether residential care should be funded from the estate of the person when deceased.

Key features of a fair care service

147 people told us which issues were important to create a new care service that is fair, simple and affordable. In order of popularity, the top responses were as follows:

- personalised care (managed as far as possible by the person needing support.) (123 people)
- joined-up services between health, social care, councils and other agencies. (113)
- a standard needs assessment process across England. (101)
- information and advice services. (99).

Several respondents had specific suggestions to make. A number called for an appeals process, accountability and transparency to the public. One talked about unbiased medical assessments which were designed to get people help rather than screen them out. Others asked for more flexibility in the assessment to reflect individual needs. Better education on M.E. was repeatedly called for, as was removal of the postcode lottery.

"The standard of service provided by the various departments of Social Services nationwide can and probably will vary somewhat thus making it a lottery, as depending on where you live could decide the amount of money you receive rather than how ill you are."

Models of care funding

144 people gave their views on the funding models put forward by the government. In order of popularity:

- 46% were in favour of the government paying for all care services.
- 20% supported people buying insurance for care (with a bit of government funding.)
- 19% made their own suggestions, and the remaining options were considerably less popular.

One person raised a concern if the insurance approach was adopted. They felt that claims might be deemed ineligible if M.E. was regarded as a psychological condition, and asked whether the state would take a different stance. Another was concerned they would even be accepted to an insurance scheme as they had difficulty getting life cover.

Thoughts about means testing or paying part contributions varied - some felt that it was reasonable for those who were significantly better off to contribute something towards the most vulnerable. A small number felt that individuals had a responsibility to help themselves where possible, and that if they could reasonably pay for their own care, then they should. Others felt that they had already done their bit by contributing to national insurance, and one specified that people over 65 specifically should not pay contributions. Another felt it was unsustainable for the Government to pay for everything.

Paying for care services from the estate of the deceased

61 out of 146 people (42%) supported a payment system which allows residential care and accommodation costs to be charged upon a person's estate when they die, rather than having to sell their home when they need residential care. 49 (34%) responded don't know and 36 (25%) said no, they did not support this system.

Conclusion and recommendations

"It is the understanding of M.E. and acceptance of its disabling symptoms by Social Services etc. which is of most concern."

151 people chose to rank the issues the Green Paper raises for people with M.E. The top three concerns were:

- whether the criteria used to assess my care needs will reflect the needs of a person with M.E. and assess them realistically and accurately. (120 people included this as one of their top three issues).
- whether I will manage financially if DLA/AA are phased out and replaced in full or part by services.(74 people).
- how much choice or control I will have over the care I receive. (63 people).

National care service

The Green Paper says that the Government want to build a National Care Service that is fair, simple and affordable, and that in this new system we should be able to expect: prevention services; national assessment; a joined-up service; information and advice; personalised care and support and fair funding.

The Government also says that, in order to make the National Care Service work, we will need services that are high quality.

Whilst Action for M.E. commends the six principles put forward, huge improvements need to be made to current services in order to meet the needs of people with M.E.:

- up-to-date M.E. education and awareness training for all staff, but especially those involved in assessment and care delivery.
- assessment procedures which reflect the fluctuating nature of certain conditions like M.E. and which adequately identify the people that really need care.
- greater flexibility in the way needs are met to allow for fluctuations in health and individual circumstances.
- consider whether there is a greater role to be played by advocacy organisations in ensuring that disabled people have the right support to access the care they need.

Standardised care assessment

Action for M.E. would like to acknowledge that standardising care assessments might have potential to improve the 'postcode lottery.'

However, the current process is of grave concern to people with M.E.

We are asking the Government to make improvements throughout the care service, making the quality of care, and the degree of choice people have in accessing care consistent across the country.

Funding

The Government is suggesting three ways in which the National Care Service could be funded in the future, which they have called Partnership, Insurance and Comprehensive

Our survey showed that most people who responded (46%) felt that care should be paid for by the Government, yet the Government has ruled out this approach without asking because it says that it would put too much pressure on people who are working.

Of the options the Government did offer, our survey showed that the insurance option was more popular than partnership or comprehensive, that is: buying insurance to pay for care, and getting a bit of Government funding. However, this was still only chosen by a fifth of respondents.

Funding must also be allocated as appropriate to meet the needs of the individual and not according to where they live.

Disability benefits and Social Services

One of the most concerning issues for people with M.E. was the proposal to divert disability benefits to Social Services.

The impact of diverting disability benefits would be devastating, leading to:

- severe financial hardship for many, leading to neglect, poverty and homelessness for some
- loss of the autonomy provided by DLA which is vital for dignity and self-esteem
- assuming current Social Service procedures would still apply, the introduction of means testing.

Means testing would take away the freedom of disabled people to look after what little savings they may have and plan for the future as they see fit. DLA was introduced as a non-means tested benefit introduced to redress the inequality in the levels of poverty found in disabled people's incomes as opposed to those without a disability.

Our survey shows that half of respondents would be hit by any reduction in DLA. Many struggle to cope even with DLA. Some do not qualify under current criteria, but are badly in need of financial assistance to address the inequalities they face.

In summary, Action for M.E. calls on the Government to:

- commit to keeping the current disability benefits in place especially for people with chronic fluctuating illnesses such as M.E., and even more importantly for those who are so severely affected that they are either bedbound or housebound.
- follow recommendations given here for improvements to current social care services.
- ensure that disability benefits and social care are offered to all those who need it.

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