

Consultation response:

Improving Lives: The Work, Health and Disability Green Paper

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Submission details:

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Introduction

- i. Few conditions are as devastating as motor neurone disease (MND). It is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work. There is no cure for MND.
- ii. While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, talk, swallow, and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. Some people with MND may also experience changes in thinking and behaviour, and 10-15% will experience a rare form of dementia.
- iii. MND kills a third of people within a year and more than half within two years of diagnosis, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual.
- iv. A person's lifetime risk of developing MND is up to 1 in 300. It can affect any adult, but is more common in older people: it is most commonly diagnosed between the ages of 50 and 65. There are about 5,000 people living with MND in the UK, approximately 250 of them in Wales.
- v. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer-led branches and 3,000 volunteers. The MND Association's vision is of a world free from MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.
- vi. The Association is pleased to have the opportunity to respond to the Improving Lives Green Paper and to add our voice to proposals on work, health and disability.

To inform our submission we surveyed people living with and affected by MND and received 147 responses, which feature throughout our submission.

- vii. The Association is a member of the Disability Benefits Consortium and National Voices, and supports the points made in their responses to this consultation.

Response

In this response we first comment on concerns we have regarding some of the Green Paper's assumptions and proposals that will affect people living with MND. We then respond to some of the consultation questions in chapters 2, 3 and 5.

General comments

The Association acknowledges the Government's intention to reduce the disability employment gap and to create a system that offers "work to those who can, help to those who could and care for those who can't". The consultation paper, however, focuses heavily on supporting people into employment, and gives relatively little consideration to how to improve support for "those who can't". In addition, there is a lack of clarity on how the Government will ensure that it identifies those who are prevented from working through disability or illness, and how those people will be exempted from proposals aimed at "those who can."

MND is a rapidly progressive, severely disabling and terminal condition for which there is currently no cure. Once people become unable to work as a result of their MND, there is no prospect of any improvement to their condition. It is essential that people in this situation are not subjected to employment-related interventions which have no prospect of success. This would be unnecessarily stressful, anxiety-inducing and burdensome for people already coping with a condition of the utmost severity. It would also be a waste of the Government's resources. We are concerned that the Government's rhetoric around the "disability employment gap" fails to recognise that significant numbers of people face insuperable barriers to employment as a result of their health condition.

In particular, the Green Paper contains little to address the need of people living with terminal conditions, including MND. The proposals focused primarily on supporting people into employment would not be appropriate for people living with such conditions. Whilst in some instances the paper suggests that certain proposals should only happen "where appropriate", there is currently no detail to explain how this will be determined. The Association is therefore concerned that people living with MND could be subjected to inappropriate procedures that should not apply to them. To address this oversight we recommend the Government explicitly acknowledges that there is a group of people for whom work or returning to work is not an option, and clearly defines when the Green Paper's proposals will not apply to this group, either by virtue of their condition or through clear criteria for exemption.

The Green Paper's discussion of "work as a health outcome" again appears to discount or overlook the outcomes of those who will never be able to return to employment. Once someone living with MND has left work due to the severity of

their condition, they will continue to deteriorate and will not return to work. As people living with and affected by MND face a stressful and challenging period in their lives whilst coming to terms with their diagnosis and managing complex health needs it is imperative that the healthcare professionals they encounter are focused exclusively on their health and care needs.

Recommendations:

- The Government should explicitly acknowledge that there is a group of people for whom work or returning to work is not an option and clearly define the circumstances where the Green Paper's proposals will not apply.
- The Government must ensure their proposals contain safeguards so people living with rapidly progressing terminal conditions are not subjected to inappropriate interventions by healthcare professionals that would be unproductive, a waste of resource and cause unnecessary distress.
- During the development of any proposals relating to disability and employment, the Government should consider how they will affect people facing the unique challenges caused by rapidly progressive and terminal conditions such as MND.

"MND only gets worse, then we die. There's rarely enough support for health-related MND issues (e.g. counselling, care, equipment, PEGs, ventilators, wheelchairs, etc.) so having to worry about being evicted, paying bills and justifying why you can't work adds unacceptable layers of stress and worry."

Carers

The Association welcomes the inclusion of carers in the Green Paper but recommends more robust action in this area as we know carers of people with MND are not getting the support they need and deserve. The Government must acknowledge that caring responsibilities can constitute a substantial barrier to employment, particularly if carers do not receive the right support. In some cases, meeting the complex care needs of someone living with MND may require a partner or a loved one to leave work.

In 2015 the Association undertook a survey into the experiences and views of carers of people living with MND and found that over 50% of MND carers spend more than 100 hours per week caring, and 19% of respondents to our question said they cannot work due to their caring role.¹ Some of our Green Paper survey respondents highlighted the circumstances that required them to leave work,

"Was impossible for me to work and care for my husband. He had a mini tracheotomy, NIPPV, RIG and needed his chest suctioning up to 50 times in 24 hrs, there was NO carer qualified to deal with this and I cared for him 24 hrs by myself, many times being up all night."

¹ For more information about the MND Carers survey: <http://www.mndassociation.org/news-and-events/latest-news/supporting-carers-story-far/>

“Caring for my husband meant selling my photography business as I couldn't be away from him for long periods, i.e weddings can take 12 hours etc. Someone to check on him, make him a drink etc on those days would have been invaluable.”

In many cases the right support can enable carers to remain in or re-enter employment. However, too often this assistance is not forthcoming. The MND Carers survey found 33% of carers are unaware of their right to a carer's assessment and that 66% of carers receive no state benefit or carer's allowance.² In our Green Paper survey of people living with and affected by MND, 60% of carers who responded to a question on whether they received any support to remain in work while caring said no. Carer's Allowance needs reform to make it work better for carers and there must also be a mechanism whereby carers who are able to do some work are still able to top up their income through Carer's Allowance. Even where support is given it is often not enough. As one survey respondent told us,

“The best help I got was the allocation of care hours to help me with the daily routine. I get 17 hours a week, not enough given I work too and we have no family support or children. I have also been given counselling and medication.”

Finally, the Green Paper makes reference to carers who remain out of work once their caring role has ended. To create positive change the Government must acknowledge and address a lack of post-bereavement care and support, which makes it difficult to return to work after caring responsibilities have ended.

It is essential that people who have to leave work due to their caring role or wish to continue working whilst caring for someone living with MND should be supported by the system to do so. We recommend the Government takes robust action to ensure that carers are supported and their needs are met, both when out of work and whilst balancing work with their caring role.

Recommendation:

- The Government should review the barriers to employment created by inadequate support for carers and bereaved carers, and include proposals to address these gaps

2a. How do we ensure that Jobcentres can support the provision of the right personal support at the right time for individuals?

Given the highly complex health needs of people living with MND, it is essential that personal support offers are underpinned by the required specialist understanding of the condition and its impacts. It can be extremely distressing when people are asked to undergo procedures or interventions that are inappropriate for them, which we know sometimes happens. For example, as one of our survey respondents detailed:

² Ibid.

“Initially, I was contacted by the Job Centre Plus to attend back to work interviews and was told that my benefit would stop if I didn't attend. I can't speak on the phone so had to ask a family member to phone and explain I'm severely disabled. It was very stressful and I hope it won't happen again.”

Conversations about ill health and disability should come at the right time for people with MND, i.e. before someone has to attend a work search interview and develop a claimant commitment, to ensure that one is actually necessary and beneficial to the claimant. If it is not, as is likely to be the case with MND, then it should not take place.

The complexity, severity and rapid progression of MND means that generic approaches to personal support provision are likely to be unhelpful and to cause undue stress and anxiety to people living with the condition. It is therefore vital that all those providing advice and support to people with MND, including work coaches and other relevant Jobcentre Plus staff, should have access to specialist knowledge and understanding of the condition. Any Jobcentre staff providing advice to people living with MND must have received appropriate training and guidance to help them understand how progressive and terminal conditions affect a person's life and ability to work, and to enable them to have sensitive and knowledgeable conversations with people with MND.

Recommendation

- The Government should ensure that conversations about ill health and disability come at the right time for people with MND. This should happen before someone has to attend a work search interview, to ensure that one is actually necessary and beneficial to the claimant. If it is not, then it should not take place.
- The Government should create, deliver and evaluate a programme of training for Jobcentre Plus work coaches that includes information on disability, progressive conditions and terminal illness. Work coaches must be properly equipped to have sensitive and knowledgeable conversations with people with MND and other conditions.

2c. What support should we offer to help those 'in work' stay in work and progress?

Adaptations and support

Support to help people living with MND remain in work for as long as possible, in line with their personal wishes and circumstances, is a key concern for the Association and we welcome the Government's interest in the issue. Although the majority of people with MND are unable to work due to their condition, those in the earlier

stages of the disease progression should be supported to remain in work should they wish.

Many people living with MND of working age wish to continue working post-diagnosis whilst they are still able to do so. This can be for a number of reasons, including but not limited to enjoying their work, wanting to be productive, and maintaining a 'normal' routine with the same level of social interaction that work brings for as long as possible. Some of the reasons people living with MND wish to continue to work while they still can are illustrated by the following survey responses we received:

"I enjoy my work and don't want to let this disease stop me from doing what I love and have worked so hard for, so I'll continue to work for as long as I can."

"I felt that I needed some sort of structured normality, after receiving such devastating news, slowly adjusting to a completely different life."

"My children were young, I wanted our family to be as "normal as possible", for as long as possible. Working was very much part of that."

It is therefore important that people living with MND who wish to continue working after their diagnosis are supported to do so until their condition makes work no longer possible. To do this, people living with MND will often require adaptations and support from their employer. 70% of respondents to the relevant question in our survey said they needed support or adaptations to continue working. As MND is a progressive condition, the support needed to continue working will increase over time until the condition reaches a stage where work is no longer possible. Given the need for adaptations and support, the Government's Access to Work scheme is crucial for people living with MND as a means of prolonging the length of time they can work.

"The government work scheme funded for equipment and training to enable me to continue working for several months longer until my body became completely non-functional."

We therefore welcome the announcement that with additional funding over 60,000 will be helped per year by Access to Work by the end of the Parliament, and urge the Government to ensure that it fulfils this commitment. However, to make sure those who need it are being supported by Access to Work we recommend the Government does more to promote Access to Work to disabled people and employers, and to ensure that it is equipped to cover the full range of support needed by those living with complex progressive conditions.

Transport

In addition, we would like to highlight the fact that the Green Paper fails to address the transportation needs of people living with disabilities. For people whose mobility is significantly restricted by their condition, getting to and from work can be a key barrier to remaining in employment. In this context it is particularly concerning that

many people with disabilities are seeing the mobility component of their support reduced as a result of the PIP reassessment process in part, due to the reduction of the eligibility criteria for the highest rate of support to 20 meters. Research conducted by the Disability Benefits Consortium shows that a total of 59% of respondents reported receiving a lower mobility award or losing it completely when transitioning from DLA to PIP.³ We recommend the Government does more to research and address the employment related transportation needs of disabled people and people with health conditions as part of the Paper.

Transition out of work

Whilst more should be done to ensure people living with MND remain in work for as long as they desire and are able to, there will come a time where the condition progresses to the extent that they are no longer able to work. The second key issue for the Association in answer to this question is around transitioning out of the workplace. For people with progressive conditions this is a significant omission from the Green Paper, which focuses primarily on supporting people to remain in and progress or return to work. Through our survey it became clear that there is a lack of process and awareness of what people living with a disability and their employers should do when attempting to transition out of work, which resulted in people living with MND having a mix of experiences often based on the helpfulness and understanding of their employer. As one survey respondent told us,

“I worked for a local authority. I have been given retirement with a full pension, made up as if I left at 65 (I was 46), which is great. But the process was poor. It should have been a straightforward process but the Human Resource staff simply could not get their heads around the progressive nature of the condition, and the fact that I would only worsen. Once they finally got an independent assessment of my condition, then it was OK. But the process took 18 months!”

People living with MND will inevitably need to leave the workplace at some point as their disease progresses. The transition out of employment should be managed in a supportive way, with respect for the dignity and wishes of the person concerned, via clear process that works for both employer and employee. Where this is not the case, the experience can be very stressful for the individual involved. As one person with MND described it:

“The process was very difficult and quite traumatic. I found it emotionally challenging. I have now been medically dismissed.”

There is clearly a lack of knowledge among employers regarding what to do when someone living with a progressive condition needs to transition out of work. It is essential that people living with MND are able to plan their transition out of the workplace with the support of their employer so they can still work in line with their ambitions and capabilities but also have a clear exit pathway. For someone with a slower progression of MND, this could be more of a phased transition whilst those

³ DBC, Big Benefits Survey 2015-2016, January 2016

with a more rapid progression would need a swifter transition. It is important in any case that the transition process includes getting high quality and accurate information and advice about how to do so. This would ensure that both people with MND and their employers are better informed about their options, rights and responsibilities in the workplace, and make it easier to manage a planned transition out of work. We recommend the Government reviews how people with progressive conditions transition out of the workplace and undertakes action to promote good practice that meets the needs of people leaving employment as well as their employers.

Recommendations

- The Government should promote Access to Work to disabled people and employers, and to ensure that it is equipped to cover the full range of support needed by those living with complex progressive conditions.
- The Government should explicitly include consideration of transition out of the workplace within its proposals to improve employment-related support, in order to promote good practice that meets the needs of people leaving employment as well as their employers.
- The Government should review the impact of reductions to mobility support on employment for people with disabilities, and ensure that it addresses the transportation needs of people living with MND and other disabling conditions as part of its work on employment and disability.

2f. Should we offer targeted health and employment support to individuals in the Support Group, and Universal Credit equivalent, where appropriate?

The Association believes that to offer any kind of employment support to individuals in the Support Group fundamentally changes its nature and is inappropriate for people living with MND. People are placed into the Support Group when it is judged that they face severe barriers to employment as a result of their health needs. It must be recognised that for a person living with MND, which is always a progressive condition, there is no possibility that their condition will subsequently improve following this assessment. Any further employment-related interventions after this point have no prospect of success, and would only subject people to unnecessary stress and anxiety. The Government should therefore recognise that once people living with MND are placed into the ESA Support Group, they will no longer be capable of work or returning to work.

This point also applies to other terminal and progressive conditions. We suggest that the Government abandons any plans for employment-related interventions for ESA Support Group claimants. Should the Government decide to take forward proposals changing the employment support offer to those in the Support Group, it is absolutely essential that people living with MND in the Support Group are excluded from targeted health and employment support on the basis that it is a rapidly progressive and terminal condition, and that clear measures are put in place to make sure there is no possibility of this happening.

Recommendations

- The Government should abandon its plans to extend employment-related interventions to ESA Support Group claimants.
- Should the Government decide to take forward proposals changing the employment support offer to those in the Support Group, there should be an explicit exemption for people living with terminal and progressive conditions such as MND, alongside clear measures to ensure that they are not subjected to inappropriate interventions.

2i. How can we best maintain contact with people in the support group to ensure no-one is written off?

The Association believes that being placed in the Support Group without any kind of contact with DWP regarding work capability is the most appropriate outcome for people living with MND who have left work due to their condition, given the disease's progressive and terminal nature. In principle, we would challenge the assumption that people in the support group are being written off, given they have undergone a Work Capability Assessment that has found them not fit for work and unable to undertake work related activity. However, on a basic practical level, maintaining contact with people with MND in the Support Group under this proposal would be a waste of the DWP's resource and would cause unnecessary distress for people who have no prospect of returning to work. We recommend the DWP does not maintain contact with people living with MND in the support group and should the proposal go ahead, provide assurances that people living with MND would be excluded.

Recommendation

- The Government should abandon plans to maintain regular contact with people in the ESA Support Group.

3a. Should the assessment for the financial support an individual receives from the system be separate from the discussion a claimant has about employment or health support?

Once no longer capable of working it is essential that people living with MND have access to the financial support they need as soon as possible and given the nature of the condition, are not subject to inappropriate focus on any aspect of employment support other than transitioning out of the workplace. We know there are already problems with the current system. As one survey respondent told us,

"My husband died in 2013. To suggest that people with MND are able to work shows complete lack of understanding of MND and its impact. My husband was put under considerable stress having to prove he was unfit to work. He would have loved to work if he could have. MND is a thief, it takes everything. Sufferers need support not to be made to feel that they are malingerers."

The Association is concerned that the creation of two separate assessments will complicate the process of accessing support. Additionally, the process of mandatory reconsideration or appeal could become more burdensome. It is essential that any reforms to the WCA process have the effect of reducing, rather than increasing, the burden on individuals, families and loved ones.

There is substantial evidence that the WCA process frequently produces inaccurate results and contributes to heightened stress and anxiety among claimants. The number of appeals of ESA assessments has been growing over time, and in the period July-September 2016 ESA appeals accounted for 39% of total tribunal receipts. 62% of ESA appeals were revised in the claimant's favour.⁴ The Disability Benefits Consortium's 2015 Big Benefits Survey found that 92% of respondents who had had a WCA (n=274) agreed or strongly agreed that the assessment was stressful, while 88% agreed or strongly agreed that the assessment made their health worse because of stress/anxiety.⁵

Consequently, we recommend that the Government should undertake a full review of the WCA process, with a view to carrying out major reforms rather than focusing on separating financial and health assessments. This should include a fast-track process for people with a confirmed diagnosis of a severe, progressive and terminal condition such as MND.

In addition, the Association welcomes plans to launch an online ESA claims process. However, this must be accessible for people living with MND who may rely on communication aids and devices to complete it. We recommend the DWP ensures that any online ESA claims process is tested by people with lived experience of severe and disabling conditions to ensure that it is fully accessible to people with disabilities.

Recommendations:

- The Government should undertake a full review of the WCA process, with a view to carrying out major reform. This should include a fast-track process for people with a confirmed diagnosis of a severe, progressive and terminal condition such as MND.
- The DWP should ensure that any online ESA claims process is tested by people with lived experience of severe and disabling conditions to ensure that it is fully accessible to people with disabilities.

3d. How might we share evidence between assessments, including between Employment and Support Allowance/Universal Credit and Personal Independence Payments to help the Department of Work and pensions benefit decision makers and reduce burdens on claimants?

In principle, the Association welcomes the Government's intention to find ways to improve the benefits award process and reduce the burden on claimants. For people

⁴ Ministry of Justice (MoJ), Tribunals and Gender Recognition Certificate Statistics Quarterly July to September 2016 Statistics bulletin, 8 December 2016

⁵ DBC, Big Benefits Survey 2015-2016, January 2016

living with MND a non-burdensome process is particularly important given the stress and challenges when coming to terms with their diagnosis. As one respondent to our survey told us in reference to accessing benefits,

“It was very stressful, at a time when I was coming to terms with my terminal illness.”

We acknowledge that the sharing of assessment evidence could help streamline the process. However, the Association anticipates that the proposal for sharing evidence between assessments will bring about significant challenges relating to the sharing and protection of sensitive information of claimants and an administrative burden that the department would have to manage.

We are also concerned that this proposal would replicate the impact of inaccurate or inappropriate assessments across the system. Our survey of people living with MND found that of people who had been assessed for either ESA or PIP, over 30% felt the assessment process wasn't appropriate and didn't produce an accurate outcome. When taking PIP as an example, we are concerned by the latest DLA to PIP reassessment outcomes data which indicated that 13% of people living with MND had their award decreased.⁶ Given the progressive nature of MND, these outcomes seem inappropriate and we are concerned that if decisions are based on evidence that has generated an inappropriate outcome in one part of the system, it may inform a similarly inappropriate outcome in another. As a result we reiterate our recommendation for a full review and reform of assessment processes, as in our answer to question 3a above.

There is also a risk that people may be discouraged from engaging with public services if they believe that information may be shared between agencies and decision-makers without their knowledge and consent. Any sharing of data between assessments must therefore be subject to the explicit consent of the individual concerned in each case.

Recommendations

- The Government should undertake a full review of the WCA process, with a view to carrying out major reform. This should include a fast-track process for people with a confirmed diagnosis of a severe, progressive and terminal condition such as MND.
- Any sharing of data between assessments must be subject to the explicit consent of the individual concerned in each case.

3f. Building on our plans to exempt people with the most severe health conditions and disabilities from reassessment, how can we further improve the process for assessing financial support for this group?

⁶ DWP Official Statistics, Personal Independence Payment: April 2013 to October 2016, Accessed via: <https://www.gov.uk/government/statistics/personal-independence-payment-april-2013-to-october-2016>

The Association welcomes the Government's commitment to end ESA reassessment for those with the most severe conditions, and notes the Secretary of State's statement that if a condition "has made you unfit for work and which can only stay the same or get worse it would be pointless to bring someone back for reassessment."

MND is progressive, severe and terminal in all cases, and there is no prospect of an improvement in the condition as time goes on. It therefore meets the Secretary of State's description above. In order to fulfil the Secretary of State's commitment, everyone living with MND who has been assessed as unfit for work should be exempted from the reassessment process.

This exemption should be applied to everyone with a confirmed diagnosis of MND, or by the use of clear criteria that would include all those living with MND in the support group without exception. An exemption of this sort would provide vital reassurance to people living with MND who know they will never be well enough to return to work, and enable them to focus on maintaining their wellbeing and quality of life for as long as possible. We recommend the Government exempts people with a confirmed diagnosis of MND from ESA reassessment by virtue of their condition, or by establishing clear criteria that will ensure everyone living with MND in the support group is exempt.

The Association also welcomes the proposal to develop a more appropriate process for people with severe conditions and disabilities to access financial support. Given the severity of MND as a progressive, terminal and seriously disabling condition in all cases as outlined above, any process should cover all those living with the disease. Although the Green Paper doesn't set out how such a process might work, we would recommend the simplest and most appropriate way to ensure those with a severe condition such as MND access financial support is to create a fast-track system that can be offered to people living with MND and other especially severe conditions on the basis of a confirmed diagnosis.

Recommendation

- We recommend the Government exempts people with a confirmed diagnosis of MND from ESA reassessment by virtue of their condition, or by establishing clear criteria that will ensure everyone living with MND in the support group is exempt.
- We recommend the Government creates a fast-track process for people with the most severe conditions, including MND, to access financial support by virtue of their condition.

5a. How can we bring about better work-focused conversations between an individual, healthcare professional, employer and Jobcentre Plus work coach, which focus on what work and individual can do, particularly during the early stages of an illness/developing condition?

As highlighted throughout this response, the Association believes that once a person living with MND has reached the stage where they have to leave work due to their

health they should be supported to have access to financial support and be exempt from any employment support activity. Prior to this and given the rapidly progressing and terminal nature of MND, discussions between someone living with MND, their employer, healthcare professionals and the Jobcentre should focus on supporting those who wish to remain in work to do so, but also on supporting individuals through the transition out of work. As detailed in our general comments section, the primary focus of healthcare professionals should be to meet the health and care needs of people living with MND. The health and care needs associated with MND are extremely high and complex, and healthcare professionals should not be distracted from the core task of supporting people to live and cope with the condition for as long as possible.

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