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Dear Dr Litchfield,

**Progressive conditions and the Work Capability Assessment: Submission for the Year 5 Independent Review**

On behalf of charities representing people with five progressive conditions, namely Cystic Fibrosis, Motor Neurone Disease, Multiple Sclerosis, Parkinson's and Rheumatoid Arthritis, we would like to collectively respond to the Year 5 Review and provide you with a dossier of case studies and statistical evidence to support our call for changes to the Work Capability Assessment (WCA), along with recommendations on how the system could be improved.

More information about the conditions we represent is provided in an **appendix** to this dossier.

For the Year 4 Review we submitted a dossier of evidence to show that the WCA does not effectively identify capability for work when a person is living with a condition that only gets worse over time.

We welcomed the publication of your recommendations in the Year 4 Review. However, we believe the Department of Work and Pensions (DWP) is not acting with enough urgency to adopt your recommendations, as well as those from earlier reviews, and improve the WCA system.

For the Year 5 Review, we had hoped to include additional recent data. We submitted an FOI request to the DWP to obtain up to date information. However, we are disappointed to report that whilst this was meant to have been received by Friday, 8<sup>th</sup> August, it has still not been received at the time of submission.

However, we still have evidence that the system continues to fail those with progressive conditions and is inconsistently applied, costly, and causes untold distress through repeated and unnecessary form filling, assessments and tribunals.

Here is one example of a person with Motor Neurone Disease (MND):

***“He said it was dreadful. He was ‘grilled for 45 minutes with his wife and was even asked if he felt like committing suicide. DWP had been told in advance that he has MND and he can hardly walk, and only very short distances with a lot of shuffling, so it must have been quite obvious to the person interviewing him.”***

There is growing political sympathy and interest in the WCA and the plight of those with debilitating progressive conditions. Over 100 MPs signed EDM 701 in the last parliamentary session on this subject<sup>1</sup> and many have written to the Minister for Disabled People, calling on the Government to change the process for those with progressive conditions.

The Work and Pensions Select Committee also has grave concerns over the WCA and has called for fundamental reform. In particular, it has censured the Department for not helping those whose conditions are worsening.<sup>2</sup> We hope the Year 5 Review will support the Committee’s findings and encourage a new approach to these assessments, especially because it comes at a crucial time, when the current WCA contract ends and a new one begins.

Our dossier concentrates on the current experiences of Employment and Support Allowance (ESA) claimants with progressive conditions throughout the ESA application process and makes recommendations for changes. Quotations within this dossier are from people with the conditions we represent who have been in touch with the charities, because they are distressed by their treatment at the hands of DWP and Atos.

### **Capturing why people are applying for ESA**

We recognise that the diagnosis of a progressive condition, even a terminal condition such as Motor Neurone Disease, or a life limiting condition such as Cystic Fibrosis, does not mean that someone is immediately unable to work. The vast majority of individuals with these conditions wish to work for as long as they are able to, not least because of the uncertain future they face, which for many will involve needing care and support and coping with the substantial emotional and financial impact of their condition.

It is also true that some of the conditions we represent relapse and remit, so for example in the case of Multiple Sclerosis or Rheumatoid Arthritis, people may have periods of days, weeks or months where their symptoms are in abeyance and they are more capable of work.

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<sup>1</sup> See progressive illnesses and ESA <http://www.parliament.uk/edm/2013-14/701>

<sup>2</sup> See <http://www.publications.parliament.uk/pa/cm201415/cmselect/cmworpen/302/302.pdf>

However, in the vast majority of cases we see applications for ESA are made when work has been given up reluctantly, as symptoms have become too severe, debilitating and unpredictable. Any partial relief from medication and other treatment may also have waned as the conditions we represent have progressed. In some cases people may have retired on medical grounds or been advised by their healthcare professionals to give up work.

For example, a Cystic Fibrosis social worker in Nottingham told us:

***“So much of our time is spent challenging ESA decisions that are clearly ridiculous. It’s so frustrating and such a waste of time and everyone’s effort. We supported a young man who, the week before his WCA, had been told at clinic that his condition had progressed to the point that he should consider retirement on medical grounds, to protect his health. He was put in the Work-Related Activity Group. At the first of his regular interviews, the adviser only needed to look at him, on oxygen support and clearly weak, to say that he should not be in the WRAG.”***

Another person with Rheumatoid Arthritis told us:

***“I have been diagnosed and living with Rheumatoid Arthritis since 1990. I continued to work up until 31 December 2011, at which point I retired on grounds of ill health because I was a midwife and I could no longer cope with the physical activity, the hours and the terrible fatigue. They even tried to adapt my job for me, but I couldn’t even cope with the revised terms. I applied for ESA just before I retired, because I was concerned about my huge drop in income and I need the financial support to pay for everyday living.”***

However, there is no attempt by the DWP to capture this information early on. This is vitally important as there are circumstances in which someone may be found to have limited capability for work or for work-related activity for a medical reason that is not picked up in the ESA descriptors.<sup>3</sup> ESA regulations allow for individuals whose health would be at risk if they were found fit for work, to be entered into the Support Group or Work Related Activity Group (WRAG), as appropriate.

As these rules are exceptional and do not form part of the main assessment, ESA claimants are reliant on Atos healthcare professionals and DWP decision makers to correctly interpret and apply them. As a result, these rules are often overlooked. Questions around non-functional descriptors do not even feature on the ESA 50 form, despite efforts by Professor Harrington to reform it.

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<sup>3</sup> ESA regulations 29 and 35 (2008) [http://www.legislation.gov.uk/ukxi/2008/794/pdfs/ukxi\\_20080794\\_en.pdf](http://www.legislation.gov.uk/ukxi/2008/794/pdfs/ukxi_20080794_en.pdf)

Harrington commissioned a group of charities representing mental health and fluctuating conditions to meet with DWP to suggest changes to the ESA 50 form. This group included the MS Society, Parkinson's UK and the National Rheumatoid Arthritis Society. This group, set up by Harrington, suggested the form capture highly relevant considerations such as:

- prognosis,
- whether the condition is incurable, life threatening or uncontrollable,
- whether someone was medically retired,
- whether someone has been advised against certain activities or to take precautions by their healthcare professional,
- whether they had accidents at work and had to leave their last role due to safety concerns; and
- how frequently their condition has resulted in hospitalisation.

These are all factors which DWP decision maker guidance<sup>4</sup> and DWP guidance to Atos state are important to make a full assessment including around the “substantial risk” criteria. However, unfortunately few of the suggestions made by this group around gathering contextual information were incorporated by DWP into the new form.

Instead, the overemphasis on the points based descriptors rather than risk to health rules continues to find many seriously debilitated individuals awarded 0 points and deemed fit to work. As one Parkinson's UK support worker said of a recent case:

***“She was assessed as having 0 points and told she is fit to work and I would also love to know her prognosis and how they got around section 27(b) saying that working will not worsen her health. To me, going over the criteria with her and having ten years plus experience in social security tribunals, I thought she hands down met the criteria for a no fuss claim to the support group, but they have given her nothing –it makes me have steam coming out of my ears when I see how they are treating this hard working lady as though she chose to get Parkinson's or something – her quality of life is so low at the moment, she has three care visits a day and no money.”***

**Recommendation 1: The ESA 50 form must be amended to capture information about why individuals have had to give up work, including any risk posed to their own health and whether their condition is progressive. The risk to health rules should be consistently applied by assessors and decision makers at every assessment, to ensure these criteria are not overlooked.**

### **Progressive conditions and the WRAG**

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<sup>4</sup> For example see paragraph 42195 of the DWP decision maker guidance [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/297540/dmgch42.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/297540/dmgch42.pdf)

A strong indication of how inappropriate the WCA currently is for this group of people is provided by the number of people with progressive conditions that have been placed in the WRAG.

We found that 45% of new claimants with Cystic Fibrosis, Multiple Sclerosis, Parkinson's and Rheumatoid Arthritis, assessed between 2008-2011 were placed in the WRAG.<sup>5</sup> Due to the lack of requested FOI data from the DWP, we cannot provide more recent statistics, although we will be sure to update the review team as soon as we receive these.

The placement of claimants with progressive conditions into the WRAG is a contradiction in terms. Whilst an assessor accepts that the claimant is too ill to presently work and their condition is only likely to deteriorate, they are still placed in a group defined by DWP as "*people who, by definition, are expected to move towards the workplace with help and support.*"<sup>6</sup>

We believe many people with these progressive conditions are simply not accruing enough points for the Support Group and therefore being placed in the WRAG. The Work and Pensions Select Committee identified this as a serious issue and singled out the WRAG as a catch all group, which is inappropriate for people with conditions that are only likely to get worse.

Claimants are also given a medical report form (ESA85A), which provides an expected prognosis of return to work. DWP has confirmed that this prognosis is based on when someone will have "*recovered to the point where it is likely to be reasonable for them to look for work.*"<sup>7</sup> It will be this timescale that also triggers a review and further assessment.

Again, such prognosis reports directly contradict the definition of a progressive condition and it is upsetting and distressing for claimants to receive a report based on "*recovery*". The prognosis statements selected range from 3 months, 6 months, 12 months, 18 months, two years and finally, "*unlikely in the longer term*" (see below). One woman with MS told us:

***"I cannot begin to explain how unbelievable the report written was -including contradicting itself in various parts and saying that I would be "fully recovered" in 6 months - I have a degenerative and incurable condition. We typed TWO pages of A4 script detailing FIFTEEN different mistakes or misrepresentations. I have subsequently completed 2 more ESA50 forms (that's 3 in 2 years) and had already started to get anxious about going through the whole thing again until ATOS pulled out and I believe it***

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<sup>5</sup> DWP Work Capability Assessments outcomes: Medical condition breakdown after the effect of appeals. September 2012. Found on ad hoc analysis page <https://www.gov.uk/government/publications/workcapability-assessments--4> and records all new claims from October 2008 to November 2011

<sup>6</sup> DWP impact assessment regarding the time limiting provisions of the WRAG, 20 April 2011 <http://www.dwp.gov.uk/docs/esa-time-limit-wr2011-ia.pdf>.

<sup>7</sup> Work and Pensions Select Committee on 21 November 2012. Dr Bill Gunnyeon, Chief Medical Officer of DWP stated: "***Prognosis, as you know, is a difficult thing anyway. It is always an assessment of when you think, all things being equal, someone will have recovered to the point where it is likely to be reasonable for them to look for work.***"

***will delay another assessment. I live in dread of any brown envelope coming through the door.”***

As we recognise above, some people with progressive conditions are able to work. However, if it is recognised that an individual cannot work at the time of the assessment (i.e they score enough points for placement in the WRAG) and that they have a progressive condition, it is vital that additional measures are put in place. We strongly believe that placement in the WRAG based on a prognosis for recovery should only be made if it can be justified using evidence provided by an appropriate medical professional which clearly states that improvement is very likely.

Claimants we speak to are not asked by the Atos assessor if they are planning future treatment with the possibility that their condition could improve, or if they could “adapt” in time to return to work. In fact, we know of many cases where the converse has happened, and compelling medical supporting evidence is disregarded.

***“You’ll remember the huge wait for PIP for a client of mine whose condition is rapidly progressing. We now have issues regarding her ESA application which went in in early 2014 following her early retirement from the NHS on ill health grounds. She was a senior practice nurse. ATOS were the NHS scheme’s medical advisors and in the letter from the NHS Pension Scheme to her they quote her Neurologist’s report: ‘Given the evidence on the nature, severity and clinical course of the above progressive neurological condition, there is no likelihood of a return to work fitness.’ This information was included in her application. My contact at DWP has spoken to ATOS who say they haven’t seen this and are going to arrange for her to undergo a medical! It is over 20 weeks now since she applied.”***

Another person with MS told us:

***“Because I provided evidence from my GP, consultant and MS nurse I felt that this should have been given the due consideration it warranted. The fact that my form of MS is progressive was not appreciated/understood by the doctor who assessed me and recommended that ‘appropriate medication’ would improve my condition!”***

**Recommendation 2: Contracted assessors should be obliged to seek further evidence to clinically justify their recommendations on likely return to work before being able to place anyone with a progressive condition in the WRAG, whether a new claimant or those being reassessed under Incapacity Benefit.**

The Work and Pensions Select Committee has also highlighted how the new contract for assessments should focus on improving training about progressive conditions for assessors. We very much welcome this recommendation and believe this is absolutely essential given the experiences we hear. However, we believe that training on progressive conditions should also

be required for DWP decision makers. The guidance from DWP to its assessors and decision makers contains no explicit “red flags” on progressive conditions – particularly around Incapacity Benefit migration. The pieces are then picked up later in the process, sometimes at back to work interviews, which are cut short when advisors realise the person cannot go back to work.

One person with Parkinson’s told us:

***“The DWP transferred me from Incapacity Benefit to ESA and as part of the process I had to attend a Work Capability Assessment. After the assessment I received a call from an assessor at the DWP wanting to ask more questions about my Parkinson’s Disease (PD) as the result of my WCA was apparently inconclusive - despite me having had PD for 13 years!! A couple of weeks later I received a letter to say that I had been put in the Work Related Activity Group. To cut a long story short, after several requests for medical statements, it arrived, was completely erroneous with a statement that my condition is not expected to change. Now we’re in the midst of reconsideration and meanwhile I’ve had to attend my first back to work interview. The advisor cut short my interview and said they would simply contact me by phone as clearly I was not going to be able to get back to work. The stress and anxiety all of this has caused me has made my PD symptoms much worse.”***

Finally it is often the case that people with the conditions we represent do not even realise they have been placed in the WRAG, because the wording of letters is so opaque. In some cases, it is only when the benefit ceases after 12 months that they understand what has happened. Moreover it is only if they ask for their medical report that they see what their “prognosis” of return to work is.

**Recommendation 3: There must be more comprehensive training and guidance issued to assessors and decision makers about progressive conditions so that people with these conditions are dealt with appropriately. Experts on progressive conditions, including the organisations making this submission, must be included in this process.**

**Recommendation 4: All letters placing people in the WRAG should state clearly what the expectation is of this group, and contain a prognosis statement that sets out the expected return to work date.**

### **WRAG and the return to work “unlikely in the longer term” prognosis**

Not only are claimants with progressive conditions being placed in the WRAG with prognosis statements which are not routinely justified by further medical evidence, but our charities have also observed a growing trend of claimants being placed in the WRAG with prognosis statements of “unlikely [to return to work] in the longer term”. This is particularly an issue during Incapacity Benefit reassessments where claimants are migrated over to ESA. At first DWP denied the existence of these prognosis statements despite many migrated Incapacity Benefit

claimants coming forward with the reports.<sup>8</sup> However, there have been more recent acknowledgements.<sup>9</sup> In February 2014, the Department revealed that 99,200 people had been given the prognosis “unlikely to return to work in the long term”.<sup>10</sup> All of the charities making this submission have come across cases of individuals being given this prognosis and yet still being placed in the WRAG. The FOI request mentioned in the introduction to this submission specifically asks for data on the number of people with this prognosis who have been placed in the WRAG. We have not yet received an answer to this request but will update the independent review team as soon as a response is received.

***“A client with severe Rheumatoid Arthritis was initially reassessed on paper in 2012 from indefinite Incapacity Benefit given in the 1990s and placed into the WRAG. At the time, she'd had RA for 34 years since the age of 22, having had to give up work as a teacher at the age of 29 while suffering from severe stomach ulcers due to her medication, and following her first of many joint replacement surgeries. Despite acknowledging that she had a significant level of disability, ATOS gave her a prognosis of returning to work within 12 months. She tried to undertake the necessary work related activities to the consternation of her family and medical professionals. During this period her condition worsened. Whilst in the WRAG, she faced significant difficulties with the actions that were required of her and suffered a number of falls, and she was told off the record by a potential employer that they didn't want to take her due to concerns about her health. When she was reassessed in 2013 via a face to face consultation it was advised that a return to work was unlikely in the longer term. However she was yet again placed in the WRAG and required to take steps towards employment.”***

Such statements are totally contradictory to the purpose of the WRAG. According to DWP guidance to Atos assessors the prognosis ‘in the longer term’ can be given in the WRAG: “Where at assessment you find a substantial degree of functional impairment resulting from a serious medical problem which is chronic or will inevitably deteriorate further, even with optimal treatment”.<sup>11</sup>

DWP guidance offers no definition of what “longer term” means and the prognosis can still result in placement in the WRAG. This puts claimants with progressive conditions, which assessors have recognised ‘will inevitably deteriorate further, even with optimal treatment’, at risk of sanctions and the time limiting of this group.

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<sup>8</sup> Sheila Gilmore 13 September 2013. To ask the Secretary of State for Work and Pensions how many individuals placed in the work-related activity group since 2008 have received a prognosis statement that specifically advises work is unlikely in the longer term. Mr Hoban: **There is no such prognosis as being unable to return to work in the longer-term.**

<sup>9</sup> See [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/277230/foi-72-2014.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/277230/foi-72-2014.pdf)

<sup>10</sup> See [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/277230/foi-72-2014.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/277230/foi-72-2014.pdf)

<sup>11</sup> See Work Capability Assessment Handbook, DWP, paragraph 3.10.1.2.

<https://www.gov.uk/government/publications/work-capability-assessment-handbook-for-healthcare-professionals>



The Work and Pensions Select Committee explicitly recommends that the DWP needs to address this anomaly by “*placing claimants with a prognosis of unlikely to experience a change in their functional abilities in the longer term, particularly those with progressive conditions, in the Support Group and not the WRAG*”.

We urge the Year 5 Review to endorse this Select Committee recommendation.

We would like to emphasise that we believe the existence of the prognosis ‘unlikely to return to work in the longer term’ is a very useful mechanism for appropriately identifying those who have health conditions which are either progressive or very unlikely to improve. However, this has very little meaning whilst those receiving this prognosis are still being placed in the WRAG. We would urge that when a claimant is given this prognosis, in recognition that improvement in their condition is very unlikely even with ‘optimal treatment’, they should be placed into the Support Group as a matter of course.

**Recommendation 5: If the prognosis statement selected by a contracted assessor is that someone is “unlikely to return to work in the longer term” then these individuals should be placed into the Support Group, rather than the WRAG.**

#### **Support Group and repeat assessments**

Even when those with a progressive condition have been appropriately placed in the Support Group, they are not free from repeat assessments – DWP has said it believes this would be “writing people off”.<sup>12</sup> However, we believe this is incorrect – everyone in the Support Group can choose to engage in voluntary work, training, or work itself and are obliged to report long term improvements in their condition.

We welcomed the Year 5 Review recommendation that regular recall for assessment in the Support Group for some deteriorating conditions was “*neither practical nor compassionate*”. The Year 4 recommendation said that recall of people with severe or degenerative brain disorders in the Support Group should be extended to five years and then performed only on a paper basis unless otherwise justified.

While the principle of this recommendation is welcome, we would request further clarification of its scope and implementation. Firstly, there remains a lack of clarity over what conditions are covered under the classification of severe or degenerative *brain disorders* specifically and we would wish to see conditions such as MS, Parkinson’s, Motor Neurone Disease to be explicitly included in that definition.

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<sup>12</sup> Mark Hoban. 13 April 2013 column 434W.

<http://www.publications.parliament.uk/pa/cm201213/cmhansrd/cm130417/text/130417w0002.htm> . Even for claimants who are unlikely to see an improvement in their health and who are unlikely to sufficiently adapt to their condition, it is important that we do not write them off completely.

The Year 5 Review should also recognise that the same principle also applies to other severe and debilitating progressive conditions such as Cystic Fibrosis and Rheumatoid Arthritis. As with severe and degenerative brain disorders, once in the Support Group it is highly unlikely the person will be able to regain function enough to return to work. To continue to reassess them at regular intervals causes unnecessary distress and is costly. We therefore urge the Year 5 Review to extend the recommendation to severe and degenerative physical conditions.

A person with Rheumatoid Arthritis told us:

***“I used to work as a police officer within the Metropolitan Police. I was retired on medical grounds after being injured on duty and subsequently developed both rheumatoid arthritis and type 1 diabetes. I was awarded an ill health pension and a 100% injury award for life as they determined that my earning capacity was nil and I couldn’t work at all anymore. I duly claimed and received an indefinite Incapacity Benefit award. When I was reassessed for ESA I was initially put into the WRAG. I went to see my MP and asked to make a complaint both of mal-administration against the DWP and one to Iain Duncan Smith directly. Within three weeks I received a letter to say I was now being put in the Support Group. Within two years of this decision I received the ESA50 again, triggering reassessment. It is absolutely disgusting and a waste of money to be reassessing those who have been declared unfit to work for life.”***

Eight months on, there has been little progress from the DWP on this recommendation and we share the Select Committee’s call for DWP’s scoping work to begin without further delay.

There were exemptions from the Personal Capability Assessment for Incapacity Benefit (the WCA precursor)<sup>13</sup> for people with:

- A severe mental illness involving the presence of mental disease, which severely and adversely affects a person’s mood or behaviour, and which severely restricts their social functioning, or their awareness of their immediate environment.
- Tetraplegia.
- Paraplegia, or uncontrollable involuntary movements or ataxia which effectively renders the sufferer functionally paraplegic.
- Persistent vegetative state.
- Severe learning disabilities.
- Severe and progressive neurological or muscle-wasting disease.
- Active and progressive forms of inflammatory polyarthritis.
- Progressive impairment of cardio-respiratory function which severely and persistently limits effort tolerance.
- Dementia.
- Dense paralysis of the upper limb, trunk and lower limb on one side of the body.

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<sup>13</sup> Originating in 1995 regulations <http://www.dwp.gov.uk/docs/a3-4381.pdf>

- Multiple effects of impairment of function of the brain and/or nervous system causing severe and irreversible motor sensory and intellectual deficits.
- Manifestation of severe and progressive immune deficiency states characterised by the occurrence of severe constitutional disease or opportunistic infections or tumour formation.

We believe it is necessary to update some of these categories, adopting this approach of listing conditions, disabilities or illnesses that merit inclusion in the ESA Support Group. This approach is much more preferable than the status quo of no prompts at all for assessors and decision makers.

Even people with terminal conditions such as MND have “fallen through the net” because the lack of suitable prompts – as illustrated below:

***When Paul (not his real name) was diagnosed with MND in January 2013, it quickly became obvious that he would not be able to continue working as a carpet fitter. While his upper body strength remained strong, weakness in his legs meant that working was not an option. Reluctantly, he started to claim Employment and Support Allowance and was examined by ATOS, on March 27. They ruled that Paul was fit to work as he had upper body strength and could work while using a wheelchair.***

***Paul said, "No-one seemed to realise that MND is a degenerative disease and one which is terminal. I can understand that the Government want to make it difficult for the wrong people to claim benefits, but this is entirely different. I couldn't believe I was being treated this way."***

***It emerged Paul had been given a DS1500, a form which is issued to patients who are terminally ill and whose death can reasonably be expected within six months, but JobCentre Plus seemed to have ignored it and appeared reluctant to follow up. Paul got help from an advisor part funded by the MND association, who acted on his case. She said: "Once I had found the DS1500 and found someone who knew what they were doing, it took just three hours for the original decision to be overturned."***

***Paul's benefits were then reinstated and were backdated.***

**Recommendation 6:** The DWP should adopt a list of progressive and other incurable conditions which signal to assessors that the Support Group is likely to be suitable, and that they should justify placement in the WRAG with further evidence. For this group who are placed in the Support Group only light touch reviews at the longest possible interval should be carried out. This list should include those with severe and degenerative brain disorders such as MND, MS and Parkinson’s but also complex physical conditions such as Cystic Fibrosis and autoimmune diseases such as Rheumatoid Arthritis.

**Poor quality assurance mechanisms by DWP**

In our Year 4 Review submission we used parliamentary questions to identify that 70% of new claimants with these conditions have been reassessed two or more times on the same claim and 11% of these are then found to have officially experienced an improvement in their condition at reassessment. We are unable to provide an update to these figures as requested FOI data from the DWP had not been received at the time of submission.

We frequently hear of people with the conditions we represent being told they have got better and switched between groups, eg. Support Group to WRAG, or WRAG to “fit to work”. Again, as with the initial inclusion in the WRAG, we can find no evidence that assessors are seeking to clinically justify an individual’s improvement at reassessment, by seeking medical reports and further evidence to substantiate their findings. The evidence points to a “snapshot” WCA which may find a person performs better on the day, without acknowledging both the progressive and potentially fluctuating nature of the condition.

DWP is also not collecting data on which conditions are being transferred from long term Incapacity Benefit to the WRAG - something which might help quality assure the process given these are claimants whose condition will have deteriorated while on Incapacity Benefit.<sup>14</sup> Worse still, many Incapacity Benefit claimants are being transferred to the WRAG “on paper”. The numbers of people subject to this process are huge - 145,000 Incapacity Benefit claimants were placed in the WRAG without being seen by an assessor between September 2011 and November 2012.<sup>15</sup>

***“After reluctantly giving up work after reducing my hours, I applied for Incapacity Benefit. This year I was sent a form to fill in for Employment and Support Allowance as it has replaced Incapacity Benefit. It was not easy to do but I outlined all my difficulties very clearly. I received a letter from the Department of Work and Pensions to tell me I was assessed as being able to return to work eventually and put into the Work Related Activity Group (WRAG).***

***I naively assumed that having a progressive neurological condition, that had forced me to give up work, and my condition having got worse since being on Incapacity Benefit, alarm bells would ring. I had thought even those with the most basic medical training would understand that the unpredictable and debilitating symptoms now make the prospect of working impossible. If I could work I would gladly do so.***

***I appealed this decision and after many months on the morning of the appeal Tribunal I was rang up and told not to attend as the Tribunal had set aside the decision and put me into the Support Group.***

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<sup>14</sup> Paul Burstow 12 September 2013: To ask the Secretary of State for Work and Pensions when he plans to publish figures on incapacity benefit reassessments and decisions by condition group. **Mr Hoban: The Department has no plans to publish figures on incapacity benefit reassessments results by condition group.**

<sup>15</sup> See answer to Paul Burstow MP 11 February 2014 column 583W  
<http://www.publications.parliament.uk/pa/cm201314/cmhansrd/cm140211/text/140211w0002.htm>

***In the interim I was invited to attend the Job Centre to talk about my return to work plan, which in the end took place over the phone with the advisor saying he could not think of any support that would be relevant to my situation.”***

**Recommendation 7: The DWP should operate a comprehensive quality assurance process of both assessor recommendations and the decision making process to improve the consistency of decisions. This should focus on why people with a progressive condition have been assessed as improved and whether there was any supporting clinical evidence to justify why. Particular focus should be on reassessments of those on Incapacity Benefit as this cohort will have progressed in disability over many years. Incapacity Benefit claimants with progressive conditions should not be placed in the WRAG on the basis of a paper based assessment.**

### **Reassessments and tribunals**

The Year 4 Review also recommended a minimum six month period between successful appeals and recalls for assessment, and for tribunal review recommendations to be accepted as the default period for review. This was accepted by DWP subject to further policy discussions. It is now eight months after this recommendation was made and, to our knowledge, no progress has been made. The Work and Pensions Select Committee has also been highly critical of the frequency of reassessments and the slowness of the DWP's response. We still hear cases of people with conditions we represent winning their case and yet receiving another form a few months afterwards to fill in, which is very distressing for these individuals.

Also of concern is that tribunals continue to be bound to make a ruling based on the evidence at the time of the original decision. This is extremely wasteful and costly, as well as stressful for the individual. For those with progressive or deteriorating conditions this is also incredibly problematic.

***“I have had Parkinson's for 15 years. I was asked to fill in the questionnaire. Within days I received a report that said work was unlikely in the longer term but I was in the WRAG. Reconsideration was refused so I went to appeal. By now this is a year and a half on. The judge started proceedings by making me aware that the tribunal and any details were to relate to the date my appeal was submitted. Nothing about my deteriorating condition could be taken into account. I feel like one apple in a very badly made barrel.”***

**Recommendation 8: The DWP should adopt the recommendation of the Year 4 Review swiftly, in order to reduce the frequency of reassessments. Tribunals should be allowed to take into account deterioration of someone's condition.**

### **Contributory ESA time limit and other WRAG sanctions**

On the basis that the WRAG is correctly identifying those with a real prospect of recovery and who could do something about their situation, the following sanctions have been introduced:

- After one year the person's contributory ESA is means tested. The person will need to rely on savings or a working partner if they aren't eligible for income related ESA.
- Those in the WRAG who are not in receipt of Disability Living Allowance/Personal Independence Payments are subject to the benefit cap
- Those on income related ESA WRAG with up to and including a 12 month prognosis are now being mandated onto the work programme and can be subject to voluntary work experience and mandatory work placements (the latter of which is open to sanctions).
- Those in the WRAG will have considerably less income when Universal Credit is introduced than those in the Support Group.
- The WRAG (not the Support Group) has limited uprating of the benefit to 1% between 2013 and 2016.

Most cruel has been subjecting those with progressive conditions in the WRAG to time limiting after a year with the expectation they should be "recovering" their ability to work. For significant numbers of people in this group who have made years of contributions, the fact that this is now disregarded is galling as well as financially damaging.

***"The financial impact on having ESA stopped led to my wife having to apply for pension credit. Having worked for 43 years with no unemployment it leaves you totally demoralised with the system. I recently received my fourth Atos Limited capability for work questionnaire. Then I got a letter to say I'd been placed (again) in the WRAG having not been seen by an assessor".***

We question why anyone with a prognosis in the WRAG of more than 12 months to return to work should have their benefit time limited, given the DWP's own assessor is providing a report that a return to work will take the person longer than a year.

Conducting unnecessary reassessments seems like a particularly futile pursuit, especially given the huge backlog of 700,000 ill and disabled people waiting for their ESA assessment. This appears to have led to some losing their benefit before even being assessed.

***"A gentleman aged 63 with Parkinson's and Alzheimer's with whom I completed the Work Capability Assessment forms last June. He has not been called for a medical assessment and has just received a letter saying that his ESA will cease in June. I have telephoned the DWP and ATOS both of whom say the other agency should be able to tell me when his medical assessment will be so I have had no success in moving the process forward. He is now living on DLA and meagre savings and cannot comprehend what is happening to him"***

**Recommendation 9: The end of time limiting of contributory ESA for those in the WRAG with a progressive condition as a matter of principle, with immediate attention given to those whose return to work prognosis is more than 12 months according to the contracted assessor.**

### **Conclusion and recommendations**

The WCA fails to recognise the situation for those with a progressive condition who have had to give up work. DWP has made changes to the WCA for those with cancer and terminal illnesses and we urge the Department to introduce these common sense changes for those with progressive conditions. We therefore make the following recommendations:

- 1. The ESA 50 form must be amended to capture information about why individuals have had to give up work, including any risk posed to their own health and whether their condition is progressive. The risk to health rules should be consistently applied by assessors and decision makers at every assessment, to ensure these criteria are not overlooked.**
- 2. Contracted assessors should be obliged to seek further evidence to clinically justify their recommendations on likely return to work before being able to place anyone with a progressive condition in the WRAG, whether a new claimant or those being reassessed under Incapacity Benefit.**
- 3. There must be more comprehensive training and guidance issued to assessors and decision makers about progressive conditions so that people with these conditions are dealt with appropriately.**
- 4. All letters placing people in the WRAG should state clearly what the expectation is of this group, and contain a prognosis statement that sets out the expected return to work date.**
- 5. If the prognosis statement selected by a contracted assessor is that someone is “unlikely to return to work in the longer term” then these individuals should be placed into the Support Group, rather than the WRAG.**
- 6. The DWP should adopt a list of progressive and other incurable conditions which signal to assessors that the Support Group is likely to be suitable, and that they should justify placement in the WRAG with further evidence. For this group who are placed in the Support Group only light touch reviews at the longest possible interval should be carried out. This list should include those with severe and degenerative brain disorders such as MND, MS and Parkinson’s but also complex physical conditions such as Cystic Fibrosis and autoimmune diseases such as Rheumatoid Arthritis.**

7. **The DWP should operate a comprehensive quality assurance process of both assessor recommendations and the decision making process to improve the consistency of decisions. This should focus on why people with a progressive condition have been assessed as improved and whether there was any supporting clinical evidence to justify why. Particular focus should be on reassessments of those on Incapacity Benefit as this cohort will have progressed in disability over many years. Incapacity benefit claimants with progressive conditions should not be placed in the WRAG on the basis of a paper based assessment.**
8. **The DWP should adopt the recommendation of the Year 4 Review swiftly to reduce the frequency of reassessments. Tribunals should be allowed to take into account deterioration of someone's condition.**
9. **The end of time limiting of contributory ESA for those in the WRAG with a progressive condition as a matter of principle, with immediate attention given to those whose return to work prognosis is more than 12 months according to the contracted assessor.**

#### **More information about the charities involved in this submission**

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#### **Description of conditions**

- **Cystic Fibrosis**

There are over 10,000 people with cystic fibrosis living in the UK. Cystic fibrosis is a progressive, life-shortening inherited disease caused by a faulty gene. The lungs and digestive system become clogged with mucus, making breathing and digestion something which requires daily intervention with treatment and medications.

New treatments and better clinical care are helping people with cystic fibrosis live longer, but the irreparable decline in lung function caused by cystic fibrosis means those with the condition will struggle on a daily basis, with moving around being a particular issue.

The latest data shows that the median survival rate for people with cystic fibrosis is 37 years old. The condition continues to take the lives of younger adults, teenagers and children.

- **Motor Neurone Disease**

Few conditions are as devastating as motor neurone disease (MND). It is rapidly progressive in the majority of cases, and is always fatal. People with MND will, in varying sequences and combinations, lose the ability to speak, swallow and use their limbs; the most common cause of



death is respiratory failure. Most commonly the individual will remain mentally alert as they become trapped within a failing body, although some experience dementia or cognitive change. There are about 5,000 people living with MND in the UK. Half of people with the disease die within 14 months of diagnosis. There is no cure.

- **Multiple Sclerosis**

Multiple sclerosis (MS) is one of the most common disabling neurological conditions affecting young adults. Around 100,000 people in the UK have MS. For most people, MS is characterised by relapses followed by periods of remission while for others it follows a more immediately progressive pattern.

The causes of MS are unknown, there is no cure and the treatments that are available are effective in only certain cases and for some of the time. MS symptoms include loss of mobility, pain, fatigue, visual impairment, numbness, loss of balance, depression and cognitive problems.

MS can lead to severe and permanent disability.

- **Parkinson's**

Parkinson's affects 127,000 people in the UK, and onset commonly occurs aged 50 or over, although one in 20 people are aged under 40.

Although Parkinson's can be well-managed with medication and treatment, the condition is progressive. Everyone with Parkinson's is different but symptoms include sudden freezing, tremor, muscle rigidity and slowness of movement, or less visible issues such as pain, fatigue and anxiety. Fluctuations can mean people have better days, or better hours. Treatment can also cause side effects and fluctuation. Everyone with Parkinson's is individual and so statements on "average" progression are unhelpful.

However as the condition progresses the majority of people with Parkinson's in work report that work does become more difficult for them. A small scale study found that respondents with Parkinson's worked for an average of 4.7 years after diagnosis, with another study putting mean retirement age at 55.8 years compared to the then UK average of 62 years.

- **Rheumatoid Arthritis (RA)**

RA is a chronic, progressive and disabling autoimmune disease affecting 580,000 people in England and over 690,000 adults in the UK. It is a disease in which the immune system attacks the tissue within the joint, leaving it painful and inflamed. If the disease is left untreated, joints can lose their shape and alignment, and can eventually become unstable or ultimately, destroyed leading to severe disability.

It is a painful disease that varies significantly between individuals. It can progress very rapidly, or more slowly. Any joint may be affected but it is commonly the hands, feet and wrists.

RA is a systemic disease which means that it can also affect other organs such as the lungs, heart and eyes.