Employment and Support Allowance
Work Capability Assessment review

Making it work for fluctuating conditions

April 2011

About the members of the group

MS Society
Multiple sclerosis (MS) is one of the most common disabling neurological conditions affecting young adults in the UK. Around 100,000 people in the UK have MS. The MS Society is the UK's largest charity dedicated to supporting everyone whose life is touched by MS. We provide a freephone MS Helpline; grants for home adaptations, respite care and mobility aids; education and training; support for specialist MS nurses and a wide range of information. Local branches cater for people of all ages and interests and are run by people with direct experience of MS. The MS Society is the UK's largest funder of research into MS.

www.mssociety.org.uk

Arthritis Care
Arthritis Care is the UK's leading organisation working with and for people with all forms of arthritis. People with arthritis are at the heart of our work: they form our membership, are involved in all of our activities and direct what we do. We believe that people with arthritis are entitled to receive the best possible treatment and support, and to have their voice heard in decisions affecting their health and well-being.

www.arthritiscare.org.uk

Parkinson's UK
Every hour, someone in the UK is told they have Parkinson's. Because we're here, no one has to face Parkinson's alone. We bring people with Parkinson's, their carers and families together via our network of local groups, our website and free confidential helpline. Specialist nurses, our supporters and staff provide information and training on every aspect of Parkinson's. As the UK's Parkinson's support and research charity we're leading the work to find a cure, and we're closer than ever. We also campaign to change attitudes and demand better services.

www.parkinsons.org.uk

Forward-ME Group
Forward-ME consists of a fairly broad spectrum of charities and voluntary organisations invited by the Countess of Mar to meet from time to time. The Aim of Forward-ME is to promote effective joint working by ME and CFS organisations to maximise impact on behalf of *all* people with ME and CFS in the UK. Forward-ME has no formal constitution. It exists to improve recognition, understanding, research, management, support and information for everyone whose life is affected by ME and CFS.

Membership comprises of Action for ME, Association of Young People with ME, Blue Ribbon for awareness of ME, CFS Research Foundation, ME Association, ME Research UK, reMEmberCFS, and The Young ME Sufferers Trust.

http://www.forward-me.org.uk

NAT (National AIDS Trust)
NAT is the UK's leading charity dedicated to transforming society's response to HIV. We provide fresh thinking, expert advice and practical resources. We campaign for change.

Shaping attitudes. Challenging injustice. Changing lives.

www.nat.org.uk

Crohn's and Colitis UK
Crohn's and Colitis UK is the working name for the National Association for Colitis and Crohn's Disease (NACC). NACC is a voluntary Association, established in 1979, which has 30,000 members and 70 Groups throughout the United Kingdom arranging educational and support meetings, publicity and fundraising. Each Group is supported by a Medical Adviser.

www.nacc.org.uk

Foreword

Ensuring that people with a fluctuating condition are dealt with fairly and consistently in assessing their capability to work is a vital task. It has therefore been extremely rewarding to bring together a disparate group of charities to formulate recommendations to Professor Harrington for improvements to the Work Capability Assessment (WCA) for those with fluctuating conditions. I would like to thank colleagues in the MS Society, the National AIDS Trust, Parkinson's UK, Arthritis Care, the Forward ME Group, and Crohn's and Colitis UK for the commitment, energy and skill with which they have approached this important work in a challengingly short timescale. I would also like to thank Hayley Jordan of the MS Society for her adept coordination of the group's work that has resulted in this report.

The recommendations that we make in this report are designed to ensure that the processes of the WCA more accurately reflect the experiences and capabilities of many millions of people in the UK with fluctuating conditions that may affect their capability to work. We hope, therefore, that these recommendations are taken forward, and the group is ready and willing to assist further in their development. Employers' attitudes to people with fluctuating conditions remain unclear and we would welcome more systematic research to determine whether, in reality, someone whose condition means intermittent and unpredictable working would be considered for employment in the real world although they might be considered 'employable'. There is therefore further work to be done to ensure the outcomes of the WCA match the behaviours of employers.

It also became apparent in our work that our organisations have a significant amount of experience and knowledge that can continue to be applied to assist in ensuring that WCA is fair, transparent, and effective in identifying those who need support because they cannot work or have reduced capability to do so. We would welcome further opportunities to work alongside the Department of Work and Pensions, and Atos, as partners in supporting improvements to processes and knowledge of assessors and decision-makers in conducting the WCA for people with fluctuating conditions.

Simon Gillespie
Chief Executive, MS Society
Chair of the group

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1. Executive summary

The MS Society, Parkinson's UK, NAT (National AIDS Trust), Arthritis Care and the Forward ME Group were invited at the end of January 2011, as representatives of people with fluctuating conditions, to:

- provide for consideration by Professor Malcolm Harrington, recommendations for further refining and improving the WCA descriptors that relate to fluctuating conditions so that they will more effectively identify the right people for the Limited Capability for Work and Limited Capability for Work Related Activity groups;
- ensure recommendations take account of the refinements proposed to the descriptors published in the Internal Review of the WCA;
- offer evidence to support recommendations and the effects they will have;
- ensure recommendations are fully supported by all organisations involved; and
- deliver recommendations by the end of April 2011.

Crohn's and Colitis UK joined the group at the beginning of March to share their expertise.

Capability for work is not a clear-cut issue. Although some people with long-term conditions or disabilities can be considered to be either completely 'fit for work' or completely incapable of work, many people will not fit neatly into either of these categories. Those whose conditions fluctuate may move between the two extremes, but more often will find themselves somewhere in the middle. We feel that the Work Related Activity Group is an important step towards recognising this, and giving people the support they need to get back to work, where possible.

However, it is clear that the current assessment does not cater for such nuances – some descriptors incorporate a time dimension, some don't; some descriptors cover a range of severity through allocating 6, 9 or 15 points, others don't. In the new WCA particularly, descriptors have been reduced down so that points will only be allocated to those with the very highest and most serious barriers. We share the concerns of many other disability organisations that the boundary between 'capability for work' and *'limited* capability for work' has been blurred.

We make a number of recommendations to improve the descriptors generally, and where possible we have made some recommendations to improve the wording of specific descriptors. In many cases we have highlighted examples of what they should be measuring and how they could better capture fluctuation without going into detail on precise wording. Instead we have highlighted where further research or discussion with experts is needed.

We hope that this work is simply a first step in the process of improving the ESA assessment process for everyone, and particularly those with complex and fluctuating conditions. The descriptors are just one small part of the assessment process. We have also made some initial suggestions and supporting recommendations as to how the process of assessment as a whole can be improved, we hope to work closely with the DWP to build on this work and support the implementation of any recommendations.

a) Key recommendations

1. At the start of every WCA, claimants should be invited to comment on how their condition affects them, whether it is relatively stable, improving, deteriorating or fluctuating. If it is fluctuating, they should be asked how frequent and severe fluctuations are, and what factors may cause or exacerbate them.

2. We strongly encourage the DWP to develop a definition of ‘work’ for the purposes of the Work Capability Assessment, based on the Australian system’s definition (see Section 3b).

3. Further research should be done with employers to develop a better understanding of ‘capability for work’ (see Section 4).

4. Descriptors should be multi-dimensional – they should take into account both severity and frequency of the symptom or symptoms. Where possible and appropriate, a time dimension should therefore be brought onto the face of all descriptors. We recommend that this be done by assessing the percentage of time that someone is affected by the relevant symptom or symptoms in a three to six month period.

5. To more accurately assess the impact of multiple symptoms or conditions, and to recognise their cumulative impact, the WCA should include descriptors worth 3 and 6 points (see Section 4b).

6. All descriptors should expressly assess whether someone can perform an activity ‘reliably, repeatedly and safely’ and, as appropriate, ‘within a reasonable amount of time’, without significant discomfort, breathlessness or fatigue.

7. The descriptors cannot be dealt with in isolation – we make a number of supporting recommendations regarding the implementation of the descriptors as part of the assessment process as a whole in Section 5b, including guidance and training for assessors and decision-makers, the general approach to the assessment, timing of assessments, and gathering additional medical evidence[1].

[1] This should include not only evidence from healthcare practitioners who know the claimant best, but also existing score systems, such as the Barthel and Health Assessment Questionnaire (HAQ) scales. Condition-specific scales that should also be signposted to include the Expanded Disability Status Scale (EDSS), a commonly used measure of disability in multiple sclerosis, or the Disease Activity Score (DAS) in the case of rheumatoid arthritis. Other useful scales may include those referred to in section 6 where we consider the assessment of fatigue and pain.

8. The descriptors need to be amended to reflect more accurately working activities. More research needs to be done, particularly with employers, to establish what these activities are.

9. Further work should be undertaken with impairment-specific groups to develop exact wording and scoring of descriptors, and consideration must be given to re-establishing a descriptor regarding moving between standing and sitting.

10. The recommendations of the group regarding mental, cognitive and intellectual function should be seriously considered and implemented. In particular, a descriptor which covers this sort of cognitive dysfunction in both physical and mental conditions is a crucial addition which should be made to the WCA. It is extremely important that the time taken to complete activities is taken into account.

11. An additional descriptor should be added which addresses the impact of generalised fatigue and/or pain.

12. The 'non functional descriptor' should be used more actively and consistently. It should be included on the face of the WCA alongside the functional descriptors to encourage this.

b) Next steps

- We have outlined some key points for scrutiny at the end of this report: we look forward to working with Professor Harrington's scrutiny group to develop our recommendations into practical and workable solutions that can be taken forwards and implemented by the DWP.

- Functional capability alone may not be a sufficient proxy for someone's ability to work. Professor Harrington highlighted in his recommendations for the second year of his review that there should be consideration of whether it would be possible to bring in a supplementary 'real-world' test to consider a wider range of issues which impact on an individual's capability for work. Our work supports further consideration of this.

- There is a need to engage with employers on what they expect from an employee, and therefore what they think makes someone 'capable for work'. We recommend that further research is done with employers and JobCentre Plus to establish whether those found 'fit for work' as a result of the assessment process are considered to be so by employers.

- User testing should be carried out on the finalised descriptors, using Atos assessors applying the descriptors to real claimants, and feedback should be gathered from disabled people on the descriptors.

- In the meantime, results of Incapacity Benefit reassessments should be carefully monitored, including the number of appeals and complaints, to scrutinise the impact of the new WCA on the number of people placed in different groups. These results should be broken down as far as possible to monitor the impact on people with different impairments, disabilities and conditions.

2. Introduction - our remit

The MS Society, Parkinson's UK, NAT (National AIDS Trust), Arthritis Care and the Forward ME Group were invited at the end of January 2011, as representatives of people with fluctuating conditions, to:

- provide for consideration by Professor Malcolm Harrington, recommendations for further refining and improving the WCA descriptors that relate to fluctuating conditions so that they will more effectively identify the right people for the Limited Capability for Work and Limited Capability for Work Related Activity groups;
- ensure recommendations take account of the refinements proposed to the descriptors published in the Internal Review of the WCA;
- offer evidence to support recommendations and the effects they will have;
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- deliver recommendations by the end of April 2011.

Crohn's and Colitis UK joined the group at the beginning of March to share their expertise.

Below is our response to this brief. However, like our colleagues who developed recommendations on the descriptors relating to mental, cognitive and intellectual function, we wish to prefix our recommendations with a caveat on the terms of undertaking this work.

a) Our involvement

We welcome the express recognition by Professor Harrington and the Department for Work and Pensions that the current assessment has serious flaws when it comes to assessing people with complex and fluctuating conditions.[2] We are therefore delighted to take this important opportunity to offer recommendations to reform the WCA descriptors to improve the fairness and effectiveness of the WCA.

Our work, however, must be understood in the context of the limited time and resources available for the development of these recommendations. The time and resource restraints on our work have limited our ability to support our recommendations with as comprehensive and extensive research and evidence as we would like. We have, where possible, identified where we feel further research would be required.

Likewise, we have attempted to engage relevant stakeholders in our work, asking for specific evidence and recommendations on how the existing descriptors may be improved to better assess the impact of fluctuation. We have also sought expertise of other disability organisations when considering

[2] Professor Malcolm Harrington, *An Independent Review of the Work Capability Assessment*, November 2010, at 5:31

descriptors with which we have limited experience - for example, those concerning sensory impairment. However, we urge that additional input be sought from appropriate stakeholders before any modifications to descriptors are finalised.

A number of disability organisations have experienced some difficulties engaging productively with the Department for Work and Pensions on issues of welfare reform in the past. This has been particularly highlighted in the confusion over organisations' involvement in the WCA 'internal review'. We therefore follow our colleagues at Mencap, the National Autistic Society and Mind in premising this contribution to the Independent Review process on the understanding that:

- The recommendations relating to the descriptors should be seen as just one of a large number of reforms that are required for improving the fairness and effectiveness of the WCA, many of which we have highlighted in section 5 of this report.

- These recommendations should be consulted on, including with disabled people, and piloted before being put into effect.

- The Atos handbook and training should reflect the shift of emphasis that we have recommended, and that our comments regarding the content of any guidance accompanying the descriptors are taken onboard. Should our proposals be accepted, we would welcome involvement in the process of revising the handbook,.

- Any amendments to the scoring mechanism for the descriptors should not be used to tighten eligibility to ESA and disability organisations should be involved in the process of finalising the scoring.

- The operation of the WCA and its outcomes should continue to be reviewed regularly by an independent evaluator and the outcomes of appeals should be reviewed to improve the operation of the system.

We hope that these parameters make clear the intent behind our involvement in this piece of work. We are pleased to note that the outcomes of the Independent Review and our discussions with Professor Harrington are conducive to these terms.

We welcome the iterative approach being suggested by Professor Harrington going forward in scrutinising the recommendations made in this paper. An open and continuing dialogue with the scrutiny group is a welcome and appropriate way forward and acknowledges the need for further analysis of the proposals (e.g. scoring thresholds) given the relatively short time-scale for the completion of our work. At the end of this paper, we highlight some specific aspects of our proposals, where we consider that some further focused discussion would be useful.

b) How we carried out our work

- We established a policy group consisting of a representative from each of the charities involved. The policy group met at regular intervals.

- The policy group also met with chief executives from the charities involved – who acted as a steering group, chaired by the chief executive of the MS Society.

- We produced a timetable and project plan for achieving key aims and objectives – which was agreed by the members of the group at the outset. The timetable was met and the output (this report) was delivered.

- The timeframe assigned to us was three months. The work was conducted using the resources of the members of the group, and without additional external funding or resourcing.

- The introduction of legislation bringing new descriptors into operation on 28 March meant that we had to examine two sets of descriptors, which added to the group's workload.

- We consulted with representatives from other charities covering the same and similar fluctuating conditions.

- We consulted with representatives from other charities and organisations in relation to descriptors where we did not have all the necessary expertise to produce recommendations. This included the RNIB, RNID, Epilepsy Action and the Royal College for Speech and Language Therapy.

- We invited other charities and organisations to submit evidence to the group.

- Regrettably, we did not have time or resources to consult more widely with potential stakeholders. We would, for example, have liked to have held a workshop where our recommendations could have been discussed by people with a range of fluctuating conditions.

- We would have also liked to have consulted with employer representatives in order to obtain a better idea of how employers view the problem of people with fluctuating conditions returning to work – especially where this will involve adjustments to hours and duties and the fact that there may be unpredictable periods of sick leave.

- A meeting was also held with Professor Harrington mid-way through to review progress.

There are, therefore, a number of important 'loose ends' that require further attention. We refer to these in the body of the report.

Case studies

All cases studies that are featured in this report are genuine quotations or experiences of real people. Some names have however been changed to preserve the anonymity of the individuals.

c) Our rationale

Capability for work is not a clear-cut issue. Although some people with long-term conditions or disabilities can be considered to be either completely ‘fit for work’ or completely incapable of work, many people will not fit neatly into either of these categories. Those whose conditions fluctuate may move between the two extremes, but more often will find themselves somewhere in the middle.

We strongly support the principle of supporting all those who are able to, to work. Indeed, the MS Society has recently completed a project funded by the DWP, in partnership with a large number of other disability organisations, to set up a website to support people with chronic and fluctuating health conditions to remain in work.[3] We hope to build on this work at a later date to consider how further information and support can be provided to help people to return to the workplace following a debilitating relapse or deterioration in condition.

We therefore support the existence of a ‘Work Related Activity Group’ (WRAG) in ESA. The WRAG is designed specifically to identify those who have a ‘limited capability for work’, i.e. those who face significant barriers in returning to the workplace, and will require extra time and support to move back into the workplace. This will therefore be a particularly important group for people whose conditions and capability for work fluctuate. Far from leaving too many people ‘languishing on benefit’, the WRAG is designed specifically to be a benefit which actively involves people to support them back towards the workplace by asking them to undertake ‘work related activity’ that is personalised and appropriate to their needs and abilities.

We feel that there is some level of consensus on what constitutes someone who faces such substantial barriers that they can be considered to have no capability for work – i.e. those who will qualify for the Support Group, and should not be expected to make any efforts to move back into the workplace (although this could perhaps be refined and we will make comments on this where appropriate).

However, we believe that the new WCA sets too high a bar for the test of ‘limited capability for work’, which admits people to the Work Related Activity Group. Many applicants who should be included in this group (i.e. individuals who could work provided they received the right support), or who had previously qualified for this group, are effectively falling at the first hurdle, and being denied entry into this group on the basis that they are not obviously, or entirely, *unfit* to work. This is a wrongful application of the initial assessment, as it rests on assumptions about fitness to work and about the availability or accessibility of existing support which are not reflected or borne out in practice. Individuals whose ability to work rests on their ability to receive the right support should not be turned down for ESA at the initial assessment but placed in the WRAG,

[3] www.yourworkhealth.com

which exists precisely to ensure that such individuals are neither placed on indefinite benefits nor expected to find work on their own and without any kind of assistance.

We have therefore focused on refining the descriptors regarding this group. Under the new WCA, we are concerned that large numbers of people with 'limited capability for work' will be inappropriately found 'fit for work', and placed (if they qualify) on Jobseeker's Allowance (JSA) – as indeed has already been the case, with many individuals effectively finding themselves in limbo between ESA and JSA.

We believe that JSA, in contrast to the WRAG of ESA, is not an appropriate benefit for people with disabilities or long-term conditions who face significant barriers to work, for the following reasons:

- Disabled people will find it more difficult to comply with JSA conditionality requirements, such as attending regular jobsearch reviews at their local Jobcentre Plus.

- Disabled people may be unable to attend job interviews and be 'ready and available' for work at short notice, for example because of their health condition, or the need to arrange suitable transport and support.

> ***Case study: Karen has MS***
> *"After I was found 'fit for work' I was told to attend a work related interview at the Job centre plus at Kettering. This Job centre plus have no disabled parking. So I had to park at the back of the mobility shop, so I would be able to use a scooter. I asked if there were disabled toilets I would be able to use as I have a bladder problem: and I was informed to use toilets at Morrisons which is 5 minutes away. DOWN the hill. How can I be expected to find an employer who'll have me when even the Job centre plus is not accessible to me?"*

We recognise that there are attempts to make back-to-work support on JSA more personalised, and that individual advisors have the discretion not to apply sanctions if someone has a legitimate (e.g. health-related) reason for not complying with JSA requirements. However, even JSA staff themselves have commented on the inappropriateness of ill and disabled people being subject to the JSA regime, relying on the discretion of their advisor to avoid sanctions and penalties for lack of compliance with requirements that they are simply not able to meet.

> ***Case study: Job Centre Plus (JCP) staff***
> *A DWP research report in 2010[4] found that many JCP staff believed that large numbers of customers who were not well enough to go onto JSA*

[4] Department for Work and Pensions. Research Report No 631. Employment and Support Allowance: Early implementation experiences of customers and staff. London, 2010.

were being found fit for work at the WCA, and many even supported individuals to appeal. One JCP advisor commented:

"You've got some people who will say "Oh I'm just going to go onto JSA, it is more trouble than it's worth to appeal". And if I feel that they have some sort of case, I'll try and persuade them to appeal. Because if they went on to JSA, didn't fulfil the conditions, lose the benefit, they can't go back onto ESA within a limited length of time and they end up just disappearing down the plughole. So it's to try to stop that."

The additional stress of being put through this system can also be detrimental to the individual's health and wellbeing – undermining the policy intention to move people closer to the workplace.

In particular, in relation to fluctuating conditions, we believe that the current WCA assesses people at the peak of their abilities (the relatively 'good days') and wrongly finds them 'fit for work' without recognising the significant barriers that are experienced through the 'bad days'.

Case study: Rebecca has MS

"I have relapsing and remitting MS. I'm suicidal. I'm tired, I can't feed myself, pay for bills, or anything and rely on my partner solely. I do receive DLA high rate mobility and middle rate care.

I am mobile, and have applied for jobs, but the requirement is 15 hours a week minimum and truly I don't have it in me to commit to that because of fatigue and pain and bladder issues and getting virus after virus after virus leading to relapse after relapse after relapse...Why should I risk the MS hospitalising me if I'm forced back into work? What would happen if I ever did get as far as a medical for DWP, and I was doing well? They'd see someone fit enough to work... and then I get an infection or virus... and I won't be well enough to work."

Case study: Paul has arthritis

"I was made to remove the splints from both wrists that I wear 24hrs a day and am not supposed to do ANYTHING without them on. I had to do the assessment without them and was in great pain all through…Despite this the result was a full list of '0's in every box and they said I was fit for work."

Case study: Steve has Parkinson's:

"I took medical retirement from my job… which was quite a physical job and was becoming very difficult for me to maintain, about 18 months ago. Now when I see people, especially ex- colleagues, they say, virtually without exception, 'you look so fit and well'. The energy or concentration reserves needed to do simple physical or mental tasks are quite low so any difficulty encountered quickly drains those reserves and I get into a sort of "closing down state". My thoughts slow down. My movements slow down. My breathing gets laboured. I want to sleep. I find it hard to swallow properly. I get headaches and experience a

feeling of desperation as I worry if it will be worse this time or what the future holds. Even when I'm well, I live with certain physical reminders of the condition such as my dragging left foot and my lack of dexterity in my left hand and general fatigue".

The descriptors therefore need to be revised to encourage assessors to take into account the frequency and severity of the 'bad days' in order to truly assess an individual's average level of capability. We suggest that three to six months would be a generally appropriate timescale over which to judge someone's capability. However, there may need to be further flexibility in some cases depending on the individual's condition. For example, someone with MS may have periods of remission lasting many months, but their relapses may be so severe as to significantly impact on their overall capability for work. Similarly, in the case of rheumatoid arthritis, it is important to take account of individuals' treatment cycles – it can take three months for people to feel the effects of some biologics.

The system should be as transparent as possible, and easily understood by claimants. However, this does not mean that the assessment should be simplified to the point where it cannot take into account the nuances and complexities of people's conditions.

Finally, functional capability alone is not a sufficient proxy for someone's ability to work. We strongly support the development of a supplementary 'real-world' test to consider a wider range of issues which impact on an individual's capability for work.

3. Definitions

a) Fluctuating conditions

The group has been asked to examine the WCA descriptors that apply to what are termed ‘fluctuating conditions’ and recommend changes that would improve their effectives and fairness.

This follows on from a key conclusion in Professor Harrington's review which states that:

“Some conditions are more difficult to assess than others - this appears to be the case with more subjective conditions such as mental health or other fluctuating conditions. As a result some of the descriptors used in the assessment may not adequately measure or reflect the full impact of such conditions on the individual's capacity for work.”[5]

What do we mean by ‘fluctuating conditions’?
The DWP has not identified what they would consider a ‘fluctuating condition’. Neither is there an agreed medical definition or list of what constitutes a fluctuating condition.

We have therefore taken this to mean the following:

> Any chronic condition - physical or mental (or a combination of the two) - where a characteristic clinical feature is significant variation in the overall pattern of ill health and/or disability, which may be combined with variations in the type and severity of the symptoms being experienced. So while certain aspects of a person's disability may remain relatively stable, the level of ill health, specific symptoms, or parts of the body and functions affected, may vary considerably.

The time variation may be quite narrow and occur throughout the day - as for example in the case of rheumatoid arthritis where pain and stiffness may be more prominent in the early part of the day. Or the variation may be on a day to day basis ("good days and bad days"), a week to week basis, or on much wider basis. This can be the case in relapsing remitting multiple sclerosis, where the overall condition follows a pattern of relative remission and relapse. Relapses can be mild or severe and can last for a matter of days, or for as long as several months, and remission can last for many months or many years. Similarly with Parkinson’s, people can undergo changes of functionality from hour to hour, during the course of the day and over the course of a week.

Symptoms that fluctuate may be the result of an underlying health condition, or the result of essential (life-preserving) medical treatment - this is common in the case of HIV, where symptoms such as severe diarrhoea or nausea may be

[5] Professor Malcolm Harrington, *An Independent Review of the Work Capability Assessment*, November 2010, at 5:31

experienced for some hours after taking treatment. An NAT survey of people living with HIV found that HIV treatment was a cause of gastro-intestinal problems in over 70% of people who experienced the system.[6] For people with Parkinson's, the effect of treatment may lead to "on-off" periods as the impact of medication changes. The symptoms in the "off" period can be sudden and unexpected and last for hours. The pattern of fluctuation may be relatively predictable or completely unpredictable.

> ***Case study: Jesse has HIV***
> *"On my current medication it takes four or five visits of the course of each morning and early afternoon (at least) to adequately clear my bowels. If something interferes with my very solitary routine or with my digestive tract (which it often does), then I get IBS [irritable bowel syndrome], sometimes agonisingly so."*

> **Case *study: Brian has Parkinson's***
> *"Aspects of the condition that cause the greatest problems vary on the length and the intensity of the disease and, indeed, it can vary depending on the level of drugs in my system at any one time*".

Conditions that would meet our criteria cover a wide spectrum. Examples of physical conditions include chronic infections such as hepatitis and HIV; inflammatory bowel diseases such as Crohn's and ulcerative colitis; neurological conditions such as multiple sclerosis (MS), myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and Parkinson's; rheumatological disorders such as fibromyalgia, repetitive strain injury (RSI), rheumatoid arthritis and systemic lupus (SLE); and hormonal disorders such as diabetes. A number of mental health conditions also fluctuate in severity - often in an unpredictable manner. Examples include depression, bipolar disorder and schizophrenia.

There is also another group of chronic conditions which may be more periodic or seasonal in nature with significant periods of good health, or relatively good health, in between. During periods of good health the condition does not normally affect a person's ability to work but when symptoms occur they can produce significant periods of sick leave. Examples include some cases of allergic disease, asthma, migraine, sickle cell disease. Although we have attempted to cover a range of chronic conditions that are generally accepted as fluctuating, these examples may require further separate consideration in relation to work capability assessment.

It is important to note that treatment with drugs, and sometimes other interventions, can also cause a fluctuation in both range and severity of symptoms. Specific examples include the use of antiretroviral therapy in HIV/AIDs and certain Parkinson's treatments.

Fluctuation in relation to employment

[6] Forthcoming NAT report on fluctuation in HIV.

The fact that a person's level of ill health and/or disability is fluctuating in severity will obviously cause significant problems in forward planning and commitment in relation to employment. While some employers are sympathetic to the problems this creates, the vast majority are not and do not find it an attractive proposition to employ someone who is likely to be taking erratic and potentially extensive periods of sick leave, or having to change working hours/duties, sometimes significantly and at short notice, due to the fluctuating nature of their illness.

Case study: Calvin has arthritis and has had to give up work
"Colleagues do not understand your needs and you feel alienated because there are tasks you cannot do. I had to give up a job because compulsory overtime made it impossible for me to continue work. I was working 25 hours per week and was expected to do as much overtime as other people in the office. This caused me so much pain and so I resigned from the job."

Case study: comments from people with Crohn's Disease and Colitis:
"Due to having Crohn's Disease I have different symptoms everyday so I find it hard waking up in the morning expecting one symptom when something totally different comes on. Wish I had a disease that every day I had the same symptoms so I could possibly be able to work round them a little."

"My Ulcerative Colitis makes it so that I cannot consistently give a good day's work. Some days I am fine and can work as well as anyone. Other days, I spend half the day on the toilet."

Recommendation 1: At the start of every WCA, claimants should be invited to comment on how their condition affects them, whether it is relatively stable, improving, deteriorating or fluctuating. If it is fluctuating, they should be asked how frequent and severe fluctuations are, and what factors may cause or exacerbate them.

At the start of every WCA, individuals should be given the opportunity to state how their condition affects them and indicate if their condition is relatively stable, improving, deteriorating, or if it fluctuates/ changes over time. If the claimant indicates that their condition fluctuates, they should be given the opportunity to state how frequent and severe fluctuations are. This should then set the tone for the approach to the rest of the assessment.

If the claimant indicates that their condition is relatively stable, there should be less need to ask questions relating to how much of the time they are affected; but if the condition fluctuates, more effort should be focused on establishing the frequency and duration of problems that the claimant faces, as well as the severity. The claimant should also be asked about factors that may cause or exacerbate the condition or symptoms. This could be particularly important if work activities, work environment, or work related factors cause further pain or disablement. For instance, an RSI sufferer able to complete a limited activity carefully at home, where he won't be under pressure, can pace himself, and has the autonomy to decide not to complete it if it is causing increasing problems, a work situation may be very different. In a work situation, particularly with a disability which is not readily visible, the worker will be under pressure to undertake the task, which could result in further pain and disability which could last days, weeks, months or even years.

> ***Case study: Elisabeth has RSI***
> *Elizabeth was a PA in a hospital, she was very fast and efficient. She presented with RSI symptoms, the treatment prescribed was exercises which resulted in the loss of use of her right arm, the trauma of which has set in reflex sympathetic dystrophy resulting in the further loss of use of her lower limbs, and now is reliant on an electric wheelchair and carers.*

b) What do we mean by 'capability for work'

The Work Capability Assessment is designed to assess whether a claimant has 'limited capability for work' or 'limited capability for work-related activity'. Under the Welfare Reform Act 2007, a person has limited capability for work if:
"(a) his capability for work is limited by his physical or mental condition, and
(b) the limitation is such that it is not reasonable to require him to work."

However, no definition is offered on the face of the statute, nor in the regulations, as to what we understand 'work' to mean. We believe that this is a significant omission. Individuals must not only be capable of some very limited work, they must be capable of obtaining realistic and sustainable employment.

We broadly endorse the Australian Social Security Act (1991) definition of meaningful work, and the Australian Assessment of Work-Related Impairment for Disability Support Pension criteria that relate to the capability to carry it out.

This means that in order to be 'capable of work', the claimant should be able to:
- Work for at least 15/16 hours each week in meaningful work that pays the national minimum wage or above.
- *Reliably perform* their work on a *sustainable basis* without requiring excessive leave or absences. The Australian system takes this to be at least 26 weeks.
- Work in *open unsupported employment* without requiring excessive support to perform their work.[7]

In addition, the claimant must be able to prepare themselves for work and safely travel to and from work, without these factors having an adverse effect on their health or disability.

> **Case *study: Andy has Parkinson's***
> *"Trying to use the disabled parking bays… can be a nightmare, they are often taken by non-disabled drivers, and times when I need to use a*

[7] http://www.fahcsia.gov.au/guides_acts/ssguide_images/guide%20to%20the%20impairment%20tables.pdf Chapter 1 section (B)

wheelchair means that I often can't use the Underground. If I'm travelling on the tube on foot, I can rarely get to the special seats, people don't give them up and as I'm a slow walker I get shoved and knocked about getting to platforms." [8]

The Australian system also specifies that the 'work' that the individual is expected to do must exist in the country, *even if not within the person's locally accessible labour market*. We support the inclusion of the former criterion, but we believe that further consideration must be given to the second part, as part of the consideration of a 'real-world' test.

Consideration should also be given to any factors directly related to health or disability that impact on their ability to carry out work. For example, disqualification from driving as a result of a health condition can significantly impact on someone's ability to travel to and from work.

Recommendation 2: We strongly encourage the DWP to develop a definition of 'work' for the purposes of the Work Capability Assessment, based on the Australian system's definition.

It is important to note also that there is a difference between capability for work and employability. As stated above, it is clear from anecdotal evidence that many employers find it difficult to employ someone whose capability for work varies dramatically and unpredictably. It is important to work with employers to understand what they expect from an employee, and therefore what they think makes someone 'capable for work'.

Recommendation 3: Further research should be done with employers to develop a better understanding of 'capability for work'.

[8] Parkinson's UK, *Life with Parkinson's today – room for improvement*, 2008.

4. Current problems with the WCA for fluctuating conditions

a) Assessing work capability

The fluctuating nature of symptoms related to conditions such as arthritis, Crohn's and colitis, HIV, ME/CFS, MS and Parkinson's is not merely a complicating factor in assessing health-related barriers to work - this variation in health is itself one of the main barriers people living with these conditions will have in finding and retaining employment. Employers expect reliability from their staff. Even when someone can predict when their symptoms will fluctuate, there is no guarantee that an employer can and will accommodate for them. We are also aware that for people living with fluctuating conditions, there is a big difference between staying on in a job and finding a new one.

The fluctuating nature of an illness means that any assessment of work capability has to accurately capture how a person's ill health and disability have been behaving in the recent past and whether it is possible to predict how this is likely to occur in the future. A one-off assessment of the 'here and now' situation is not therefore appropriate to people with fluctuating conditions and the group believes that this is one of the main reasons why people with fluctuating conditions are frequently finding it so difficult to meet the current WCA point scoring criteria.

> ***Case study: Dylan has HIV***
> *Dylan is not currently in work, and does not see how he will find an employer who can accommodate for the impact of his symptoms, which include gastro-intestinal problems as well as depression:*
> *"Gastro Intestinal problems can also be unpredictable- although they have been a constant theme the severity can be unpredictable. Loose stools and vomiting are the most distressing. Vomiting nearly always happens in the mornings and then leaves me feeling bad all day, without appetite and without energy. I can go weeks without vomiting but then it can happen 5 times in a week and may happen on a weekly basis for a number of weeks. Planning how well I can be is almost impossible and this is the issue with work. Employers cannot reasonably be expected to employ someone who has an unpredictable attendance and health record. The stress that then builds when you feel you are putting your workload on fellow colleagues increases, this can build to resentment amongst other staff and adds to stress for all concerned."*

The DWP guide to the WCA states that the Healthcare Professional (HCP) will take "full account of factors such as pain, fatigue, stress and the possible variability of the condition". We welcome the very clear support given to this by Lord Freud during the House of Lords debate[9] into changes to the WCA descriptors that were brought in on 28 March that in relation to fluctuating conditions:

[9] Employment and Support Allowance (Limited Capability for Work and Limited Capability for Work-Related Activity) (Amendment) Regulations 2011, Motion to Annul, Moved By Lord Kirkwood of Kirkhope, debated at 7.32 pm on 16th March in the House of Lords. Available at http://services.parliament.uk/hansard/Lords/ByDate/20110316/mainchamberdebates/part013.html

"It must be possible for all the descriptors to be completed reliably, repeatedly and safely, otherwise the individual is considered unable to complete the activity."

However, this is not reflected in the existing descriptors, which assess functionality in a static way. The updated set of descriptors, which came into effect on 28 March 2011, make reference to whether someone can 'repeatedly' carry out the action without 'significant discomfort of exhaustion' (Descriptor 1-Mobilisation), but this distinction has not been brought onto the face of the descriptors across the board. This fails to capture the real impact of pain, fatigue and variability of health among claimants with fluctuating conditions.

The guidance given to HCPs on how to consider variability is also simplistic. The ESA Handbook given to HCPs states that the HCP should consider how the illness or disability would impact upon the claimant's ability to work "the majority of the time". However, even if someone's ability to work is significantly affected a minority of the time, this will still seriously impact upon their ability to find and stay in employment for a period of time without unreasonable sickness absence (see our discussion on a definition of 'work', including the sustainability of work, at section 2b). It is also unclear what period of time is taken into account: a typical day, week, month or period of several months.

b) Multiple impairment

Claimants with fluctuating conditions often experience a range of symptoms, which will affect them differently at different times. Many of these symptoms are 'hidden' and not easily picked up in a short assessment: for example, intense fatigue, pain, problems with memory and concentration and gastro-intestinal problems. Where these symptoms are picked up by the WCA, they are unlikely to attract sufficient points to demonstrate limited capability for work.

DWP have expressed concern that the previous personal capability assessment (PCA) for incapacity benefit (IB) allowed some "double-counting", where multiple descriptors appeared to measure the same activity (in particular some around mental health). The points system introduced in response to this through the WCA, however, has the opposite problem: it is possible to be considered to have real problems with two (or more) completely distinct types of activity and still not pass the WCA. For example, under the new WCA, each of the following descriptors attracts 6 points:

- *"At risk of loss of control leading to extensive evacuation of the bowel and/or voiding of the bladder, sufficient to require cleaning and a change of clothing, if not able tor each a toilet quickly."*

- *"Cannot repeatedly mobilise 200 metres within a reasonable timescale because of significant discomfort or exhaustion."*

If these two descriptors both applied, the claimant would be found 'fit for work', despite having two significant barriers to finding work.

In the above example, two impairments interact directly so that one exacerbates the impact of the other: the presence of barriers to mobilising will undoubtedly reduce the individual's ability to manage their risk of experiencing continence problems. More broadly, though, simply experiencing two conditions that limit capability for work simultaneously means that the sum of their impact will be greater than suggested by the cumulative score under the WCA. For example, someone living with a fluctuating condition who also experienced depression would find this creates an additional burden even if there isn't a direct interaction between the conditions. The impact in limiting their chances of entering employment is more than the simple sum total of points would suggest. Yet this is not recognised by the current system.

> ***Case study: Diana has Parkinson's:***
> *"I highlighted difficulties in writing, balance, simple tasks taking much more time e.g. putting letters in envelopes, using paper fasteners, aspects of dressing, stress, stiffness causing some difficulty in walking, getting up from kneeling, difficulty in locating objects from pockets. My voice at times is croaky and I have become more softly spoken. I do not sleep well and I do get very tired at times. I was told I needed 15 points to qualify and I was given none."*

Recommendation 4: Descriptors should be multi-dimensional – they should take into account both severity and frequency of the symptom or symptoms. Where possible and appropriate, a time dimension should therefore be brought onto the face of all descriptors. We recommend that this be done by assessing the percentage of time that someone is affected by the relevant symptom or symptoms in a three to six month period.

Recommendation 5: To more accurately assess the impact of multiple symptoms and/or conditions and their cumulative impact, the WCA should include descriptors worth 3 and 6 points.

> ***Case study: Charles has MS***
> *"I have IBS (irritable bowel syndrome), leg spasticity, optical neuritis in my right eye, cognitive difficulties, heat intolerance and an intermittent tremor in my right hand. In April I had an MS relapse which: severely impaired my balance (making walking very difficult), left half my tongue without taste, caused bladder problems, further affected my eyesight, caused tremor in my right arm and leg, increased my fatigue so that I was virtually useless after 2pm and further exacerbated the spasticity in my legs. My assessment was at 8:30am so my apparent MS symptoms were at their lowest. I was given 0 in the points."*
>
> ***Case study: Stuart has HIV***
> *Stuart experiences fatigue, insomnia, neuropathy, anxiety, blepharitis (inflammation of the eyelid) and a range of skin and hair problems related to his HIV. He finds that these fluctuate, but tend to vary according to how much he has been doing:*

"Some of my symptoms (e.g. skin and hair stuff, fatigue, blepharitis) begin when I've been doing anything for more than an hour, sometimes longer - in short, I have no stamina."

He also has fairly constant gastro-intestinal problems which mean he needs to stay near a toilet for much of the day. Stuart manages to keep his symptoms under control, by leading what he describes as a very quiet, mostly solitary life, without a regular job or much social interaction.

Case study: Person with Parkinson's[10]
A Citizens Advice Bureau client "had both physical and cognitive difficulties. He went for a WCA for ESA and was awarded no points despite the following problems: difficulty in standing longer than 10 minutes and tendency to fall; difficulty in open spaces in the dark or dull light, which led to his panicking and falling; inability to negotiate steps safely; panic in a crowded room if he had to get from A to B without support; deteriorating speech – he slurred his words and could not control saliva; very poor short term memory, with inability to recall conversations that happened a few hours previously; difficulty with concentration and inability to do anything in a systematic or ordered way. His mental health had suffered because of his difficulties".

c) The role of the appeal service
All of our recommendations are obviously aimed at trying to ensure that people with fluctuating conditions are given an assessment of their ability to work that is as fair and accurate as possible. Making the correct decision first time round, at the application stage, means that far fewer people with fluctuating conditions will need to go to appeal - where the current high level of success in overturning initial decisions again emphasises the need to reconsider the way in which the descriptors apply to people with fluctuating conditions.

Making the correct decision first time round will help to reduce the steadily increasing burden on the appeal system. Getting the WCA right is crucial to this, but we make a number of other recommendations later in this report which must also be addressed.

Whilst acknowledging that the work of the appeal system is somewhat outside our remit, the group noted a number of important observations about the way in which the appeal system is working, and how doctors are being trained, that were given to a recent meeting of the Forward ME Group at the House of Lords by Dr Jane Rayner, Chief Medical Member of social security tribunals.

Extracts from her presentation are relevant to points and recommendations that we make throughout our report, and are contained at Annex A.

[10] Source: *Not Working – Citizens Advice Bureau evidence on the ESA work capability assessment*, Citizens Advice Bureau 2010

5. The descriptors and guidance: proposed refinements

a) Our approach

In this section we will outline our recommendations for refinements to the descriptors. Given that the Work Capability Assessment is currently in a state of flux, with a new set of descriptors that were brought in by Regulations on 28th March, we have considered both the old and new WCA descriptors in developing our recommendations.

However, we share the view of many charities representing people with both physical and mental health conditions, as well as Parliamentarians who have pressed to annul this legislation, that these changes will make it even harder for some people who we believe should qualify for ESA to be recognised as having limited capability for work. Combined with the major changeover from Incapacity Benefit (IB) to ESA, through which over one million IB claimants will be reassessed over the next couple of years, this has created a significant amount of uncertainty and concern amongst people with disabilities and long-term health conditions.

Rather than considering each individual descriptor in turn, we have attempted to group descriptors together to outline what barriers to work we think these descriptors are trying to address. We have then made recommendations for the range of dimensions that we feel that the descriptors should be addressing. Where possible, we have offered some suggested wording of and points scores for descriptors, as an example of how our recommendations could be put into practice. However, given the short time-span of this work, and our remit to focus on how the descriptors can take better account of fluctuating conditions, we have been limited in our ability to conduct the detailed research we feel is needed to look in detail at each individual descriptor. Instead, we have highlighted factors for consideration, and where we feel further research and consultation with occupational health experts may be necessary.

We have carefully considered the work done by Mencap, NAS and Mind for Professor Harrington on the mental, intellectual and cognitive function descriptors. We think that these recommendations take excellent steps towards improving the way that descriptors take into consideration how people's conditions and impairments fluctuate. We therefore broadly follow their approach to broadening the dimensions of the descriptors to take into account not just the severity of a condition, but also considerations such as duration, frequency and predictability of impairment. We have also considered foreign models, and in particular the Australian approach to assessing 'intermittent conditions'. Our recommendations aim to highlight ways in which the descriptors could more accurately assess functional abilities related to the workplace, and assess people's ability to do activities reliably, repeatedly and safely.

Like the recommendations regarding mental and cognitive descriptors, each descriptor should therefore include dimensions of fluctuations relating to:

- **Severity**: we have suggested a range of measures which may be considered by each descriptor for this – based on activities/ function that we feel could be expected in a reasonable workplace.

- **Duration/ frequency:** we suggest that a percentage measure of how much of the time someone faces barriers would be more appropriate for most task-based descriptors. This would help to capture both those whose conditions fluctuate over the course of a day or week, as well as those who experience more severe relapses or fluctuations that can last longer. We recommend that three to six months would normally be a reasonable time-span over which to calculate percentages. The assessment should consider the evidence from the previous three months, along with medical evidence and evidence from the claimant in order to assess this.

Recommendation 6: All descriptors, on the face of them, should assess whether someone can perform an activity 'reliably, repeatedly and safely' and, as appropriate, 'within a reasonable amount of time', without significant discomfort, breathlessness or fatigue.

b) Implementing the descriptors

The assessment process
The group has considered a number of ways in which the assessment procedure must be improved to meet the needs of people who have a fluctuating condition.

Although we have aimed to focus in particular at refining the descriptors that are particularly relevant to fluctuating conditions, the descriptors cannot be successfully implemented and will not produce an accurate and fair result without some changes to the assessment process as a whole. It is of vital importance that the following recommendations are taken forwards in tandem with any work to change the descriptors.

Recommendation 7: The descriptors cannot be dealt with in isolation – the following recommendations must be implemented in tandem with any work to change the descriptors:

a) Where appropriate, there should be **a list of specific questions for the claimant to answer relating to the way in which a condition fluctuates.** In particular, the 'typical day' history taken by Atos assessors should be amended to reflect that there is no one 'typical day' for someone whose condition fluctuates, and should take into account relatively 'good' and 'bad' days.

b) Claimants should be strongly encouraged to **gather information on their current state of health and disability from health professionals who know them best** - doctors, specialist nurses, occupational therapists, physiotherapists, psychologists etc. DWP decision-makers should afford particular weight to this evidence where a claimant has indicated that their condition fluctuates. We support this recommendation in Professor Harrington's review,[11] but were concerned to note that evaluation of the pilot migration sites highlighted that the message that additional evidence was welcomed has not been clearly received by claimants.

c) The WCA process as a whole should be **more personalised and co-produced**[12]: claimants should be encouraged to provide additional information in relation to each descriptor, and should be able to add information about additional work-related symptoms or disabilities that are not captured in any of the current descriptors. In this respect, we welcome Professor Harrington's recommendations to include a personalised justification on both the claim form and the Atos report.[13]

d) We welcome the recognition by the DWP that claimants must be able to perform a descriptor task **'reliably, repeatedly and safely'.** This wording should be placed **on the face of each descriptor**, and **a clear description** of what is meant by these three terms should be clearly placed in the form that claimants have to fill in.

e) Letters inviting people to a WCA, and any other documentation or advice for claimants should specify that if an individual feels that their condition or disability changes/ fluctuates over time, they may like to keep **a diary recording how their condition or disability affects them over time** to help them to answer questions in the assessment as to how their condition affects them over time. Decision-makers should be encouraged to ask for such information to support their decision-making in difficult cases.

f) Professor Harrington's review noted that DWP Decision Makers had 'a pivotal role in gathering evidence'[14] but were often just rubber stamping Atos decisions on fitness for work and not reviewing all the evidence that was, and should have been available to them. In addition, Professor Harrington concluded that many Decisions Makers lacked the confidence to make a decision that deviates from Atos advice.[15] We agree with Professor Harrington's recommendation that **Decision Makers need to be more proactive and confident** in making their decisions but in order to do so they require **information and training about fluctuating conditions**. Charities working with people who have fluctuating conditions could play a useful role here, and this training should also involve contact with people who have fluctuating conditions. Our organisations would be very happy to support such training.

[11] Professor Malcolm Harrington, *An Independent Review of the Work Capability Assessment*, November 2010, Recommendation 12
[12] As recommended by Demos in their report, *Destination Unkown*, C. Wood and E. Grant, 2010.
[13] Professor M. Harrington, *Op cit*, Recommendations 2 and 5
[14] *Ibid*, 6:27
[15] *Ibid,* 6:7

g) DWP Decision Makers and Atos assessors should have **access to medical experts** with an understanding of fluctuating conditions (such as a healthcare professional with experience with neurological or musculoskeletal conditions) who can provide ongoing support and training on these conditions, and the problems they create in relation to WCA.

h) **The special circumstance rules and the non-functional descriptor should be used more actively and consistently**, particularly where a claimant shows that a range of impairments or symptoms sum together to present a significant barrier to work, but this is not clearly represented in their scoring under the WCA. (See section 5e of this report for further information on this recommendation.)

i) The problems associated with fluctuating conditions, along with their unpredictability, must be taken into account when claimants are being requested to attend medical examinations – especially where a significant amount of travel is involved. **There should be flexibility** and a willingness to arrange an appointment at the time of day when the person is normally feeling at their best – something that will be of benefit to both the claimant and the assessor. Alternatively, home visits should be more readily offered: it is clear that this adjustment is not adequately offered currently. As one person with MS stated: *"I was made significantly worse by the whole ESA application process. Even getting a home visit was a trauma."*

Identifying fluctuation
As stated above, while some conditions do have inherent fluctuation, everyone experiences their condition or disability in a different way. We recognise that it would not be appropriate to add additional complexity to every assessment, particularly those with a relatively stable and unchanging condition. In order to identify those individuals whose conditions do fluctuate, and whose assessment will therefore need to be more thorough and complex, there is a need to give people an opportunity at the beginning of each assessment to express how their condition affects them.

As per our recommendation 1, the assessment guidance must clearly instruct assessors to consider if the particular condition(s) presented by individual applicants are static/ chronic, improving, deteriorating or fluctuating/ changeable/ variable. If the condition or symptoms do fluctuate, how bad are fluctuations, and are they relatively regular and predictable or irregular and unpredictable? This should be established early on in the assessment through open questions, to help the healthcare professional to know whether it would be relevant to ask probing questions related to frequency and duration of impairment, as well as severity.

If the claimant states that their condition fluctuates, it should also be established early on whether the day on which the assessment is taking place represents a relatively 'typical', relatively 'good', or relatively 'bad' day. The training and guidance for Atos assessors places a significant amount of emphasis on using observations during the assessment to inform their judgements. However, without further exploration, this observational evidence can be highly misleading for someone whose condition fluctuates. The assessment is highly likely to be carried out on a relatively ‘good’ day – as claimants may not feel well enough to attend on a ‘bad’ day. In addition, claimants often make an effort to attend the assessment centre, and prepare themselves for the stress and exertion of the day – so the assessment cannot necessarily reflect a typical working day, in which such preparations may not be possible.

Guidance should therefore expressly highlight to assessors and decision-makers that where someone says that their condition fluctuates, observational evidence should be given less weight then medical evidence or self-reported evidence. Any observational evidence that is going to be relied upon should be queried to ensure that it is properly representative of the claimant over time, rather than simply a snapshot of their abilities on the particular date, time and environment of the assessment.

Case study: Seema has MS
“When I have an early start (like going to the assessment), I do everything I can to prepare myself and cut down the time I’ll need in the morning. I know I’m not going to have the energy to get ready quickly. I laid out my clothes and had a shower the night before, and tried to get as much rest as possible the day before. I even got my son to do up the buttons on my shirt the night before so that I could just slip it on in the morning.”

Interpreting the descriptors: supporting guidance
While the wording of the descriptors is important, it is the interpretation that is key. We therefore have a number of recommendations as to how the guidance to support the descriptors could be improved. We would welcome the opportunity to work with the DWP to improve the WCA Handbook to take these recommendations into account.

The guidance should:

- Define ‘reliably, repeatedly and safely’. ‘Reliably’ should mean completing a task to a satisfactory standard each time it is undertaken, within a reasonable amount of time – examples could be given to support this judgement.

Case study: Rose has MS
Her MS nurse told us:
“When she went to the assessment, they asked her: ‘Do you get ready and dress yourself?’ ‘Yes I do’, she said, and so they think she’s fit for work. But what they don’t know (because they didn’t ask) is that this woman is like a wobbly weeble in the mornings: she tries to put her top on and up come her legs and she falls over, she bends down to put on her trousers and falls over again. It actually takes her up to two hours to get ready in the mornings – it’s just her sheer determination that gets her through and it leaves her exhausted.”

‘Repeatedly’ should mean being able to complete the task at a rate/frequency that is relevant to a workplace situation, without experiencing fatigue and/or pain, in line with what would be necessary for work. Guidance on how to define this should be given for each descriptor. For example, ‘repeatedly’ in terms of manual dexterity tasks, such as picking up a pound coin, may mean every few minutes or picking up several coins in a row, whereas ‘repeatedly’ mobilising 200m would mean the ability to do this several times in a day. ‘Safely’ means that the task can be completed without risk to either the claimant, another employee, or someone else that the claimant comes in contact with.

The guidance should also:

- Be more detailed, and should make specific reference to how someone whose condition fluctuates can be assessed under each descriptor, rather than simply having one separate page referring to variable and fluctuating conditions.[16]

- Provide specific examples of who may score under the different descriptors.

- Be clear about how percentages/ duration/ frequency should be established (see above and notes on our individual descriptor recommendations) for each descriptor.

- Encourage assessors to probe answers for clarification, and in particular should explore the ‘typical day’ discussion to establish the severity and frequency of ‘bad days’, and to take into account a typical *working* day. It must be acknowledged that work itself can impact on an individual’s functional abilities (this is particularly the case for claimants with a condition such as RSI, or conditions which can be exacerbated by fatigue).

- Refer the decision maker to further evidence where this may be helpful. This should include in particular medically recognised scales and evidence, such as the Barthel and Health Assessment Questionnaire (HAQ) scales, or condition specific scales, [17] and other specific evidence highlighted within the guidance on individual descriptors.

- Make specific reference to the predictability of impairment when giving guidance as to how to assess whether someone has adapted to their disability – some specific examples are given below.

[16] The current Training and Development Handbook on the WCA contains less than two pages of guidance related to variable and fluctuating conditions, of a 175 page document.

[17] Examples of condition-specific scales that should be signposted to include the Expanded Disability Status Scale (EDSS), a commonly used measure of disability in multiple sclerosis, or the Disease Activity Score (DAS) in the case of rheumatoid arthritis. Other useful scales may include those referred to in section 6 where we consider the assessment of fatigue and pain.

c) Descriptor refinements

In order to recommend refinements to the descriptors to better reflect the impact of fluctuations, we have had to also suggest improvements that are not limited to capturing fluctuation. We considered that in many cases the existing descriptors would not adequately address the severity or impact of some impairments, even if fluctuation was measured in line with our recommendations. For this reason our refinements attempt to address the descriptor as a whole, including but not limited to how to capture the time dimension in assessment. We also urge DWP to undertake further development of the descriptors in collaboration with stakeholders including employers and people with disabilities and long-term conditions.

Recommendation 8: The descriptors need to be amended to reflect more accurately working activities. More research needs to be done, particularly with employers, to establish what these activities are.

Recommendation 9: Further work should be undertaken with impairment-specific groups to develop exact wording and scoring of descriptors, and consideration must be given to re-establishing a descriptor regarding moving between standing and sitting.

1. Mobilising

To address fluctuation in mobilising, we recommend consideration of what proportion of the time the claimant experiences difficulty getting around, as well as the severity of the difficulty.

We recognise that inability to walk is too simplistic a measure to assess whether someone is adequately able to mobilise in order to work. We therefore support the efforts to re-focus this descriptor on whether the individual is able to 'mobilise unaided by another person, with or without a walking stick, manual wheelchair or other aid if such an aid can reasonably be used'. We also welcome the move to take into account some form of aids and adaptation, and to address the issue of repeatability to some extent.

However, we feel that the descriptor, as it is currently phrased, fails to take into account the full range of mobility that an individual needs to be fit for work. Accessibility of workplaces and transport has improved in recent years, so it may no longer be appropriate to treat someone who has adapted to their limited ability to walk through use of a wheelchair or other aids as automatically having limited capability for work. However, it must be recognised that this continues to present a significant barrier to work for many people.

Recommended descriptor
We believe that this descriptor should aim to assess whether the claimant can *reliably, repeatedly and safely, within a reasonable amount of time* mobilise:

- Over at least 100m [or suitable alternative distances to attract lower points]

- On a variety of terrain, including steps and uneven as well as level ground
- Through a variety of working spaces, including negotiating doors and other entrances and exits
- To and from the workplace, and work-related commitments including external meetings, with some prior planning and adjustments
- Without significant discomfort, breathlessness or fatigue

Individual's ability to walk can very considerably over time. The descriptor should therefore contain a second dimension which asks whether this is the case:

a. More than 75% of the time
b. Between 50% and 75% of the time
c. Between 25% and 50% of the time

Case study: Graham has ME/CFS
"My ability to walk is extremely variable within a week, a day, or even within an hour. If I'm rested and feeling reasonably OK, I can walk fairly well for a short distance. On my rare good days I can sometimes walk for nearly half a mile but within an hour I can hardly move. On the bad days, it can take me 5 minutes to walk 100 metres, or I might not get that far.

If I am having a bad day or a bad period within a day I cannot stand up due to balance problems. Some days I can stand if I have to but have severe consequences. For example, I had a christening to go to. I managed to stand at appropriate times during the service and the party afterwards and even walked around a bit. The next day I had to have help to get out of bed, going to the loo and then had to find a wheelchair to help me get home. "

We are concerned that the current handbook states *'If the person does not actually have a wheelchair, they should be considered in terms of whether they could use one if provided, as manual wheelchairs are widely available.'* It is concerning that someone who may have trouble walking should be expected to use a wheelchair in order to access work, rather than be judged on the basis that they may want to continue to walk as best they can, although they may have difficulties walking. People whose mobility fluctuates, or is static, are often encouraged to maintain their activity levels within their limitations in order to maintain muscle strength, and individual activity management programmes play an important role in conditions such as arthritis, ME/CFS, MS and Parkinson's. Such individuals should therefore be judged on the basis of how they *actually* mobilise, not on the assumption that *if* they were to resort to a wheelchair they may be able to mobilise more easily, or further distances. It must also be taken into account that those whose need for walking aids and adaptations fluctuates will be less able to adapt to the use of such aids and adaptations, and this in itself can limit someone's ability to mobilise.

Only adaptations actually used by the individual, or those that they could reasonably be expected to use *without* it impacting negatively on their health or wellbeing (including mental health) should be taken into account. It is important, therefore, to cross-reference with other descriptors to consider for example whether someone has the upper body strength and coordination to propel themselves in a manual wheelchair.

In order to establish someone's mobility, questions should be posed around a typical *working* day to understand how working commitments would impact on someone's mobility, and assumptions should not be made based on the individual's mobility during the test.

2. Standing and sitting

This descriptor aims to assess whether someone has the functionality to transfer from one seat to another (such as moving from a wheelchair to a vehicle or toilet seat) without assistance, and to remain in one place (at a 'work-station') without discomfort such as to carry out work. As with the mobilising descriptor, it is important that even if this is not the case the majority of the time, real difficulty with standing or sitting for any period of time should attract some points.

We support the focus on being able to stand or sit for long enough to remain at a work station, but a clearer definition of what is meant by a 'work station' should be furnished in the guidance alongside this descriptor.

Recommended descriptor
A. Cannot reliably, repeatedly and safely, using any aid that it is reasonable to expect them to use:

a. Move between one seated position and another seated position located next to one another without receiving physical assistance from another person. *(4)*

b. Remain at a work station, either:
   i. Standing unassisted by another person (even if free to move around) or;
   ii. Sitting (even in an adjustable chair)

   for more than 30 minutes without significant discomfort, loss of balance or exhaustion *(3)*

c. Remain at a work station; either:
   i. Standing unassisted by another person (even if free to move around) or;
   ii. Sitting (even in an adjustable chair)

   for more than an hour without significant discomfort, loss of balance or exhaustion. *(2)*

B. This is the case
a) More than 75% of the time *(3)*
b) Between 50% and 75% of the time *(2)*
c) Between 25% and 50% of the time *(1)*

Descriptor scoring:
If A*B is less than 3 = 0 points
If A*B is 3 = 3 points
If A*B is between 4 and 7 = 9 points
If A*B is more than 7 = 15 points

NB: If the DWP does not agree with our recommendation that someone who cannot remain at a workstation either standing or sitting for more than 30 minutes should attract 15 points, a 10 minute level descriptor should be inserted to ensure that it is possible to attract the full 15 points under this descriptor.

The current guidance alongside this descriptor states:

"The person does not have to stand or sit for the whole 30 or 60 minutes. They can alternate between the two."

However, we believe that alternating between sitting and standing throughout the space of even 30 minutes is not a reasonable expectation in the large majority of workplaces. Someone in a meeting situation could not alternate every 15 minutes between sitting and standing; nor could someone in any desk-based job. There may also be health and safety issues involved with needing to alternate between standing and sitting: in certain working environments, such as a lab, sitting down can be a safety hazard.

Furthermore, if someone needs to alternate in such a way to avoid pain, fatigue or dizziness, it would be important to consider whether they are able to repeatedly rise from sitting to standing – a descriptor which has been removed from the new WCA. We therefore strongly recommend that consideration is given to re-establishing a descriptor to measure the ability to move between sitting and standing.

We recognise the concern not to 'double score' wheelchair-users, but this is an important and necessary functional capability for those who do not routinely mobilise using a wheelchair.

If this descriptor is not re-established, consideration of the ability to rise from sitting to standing must be given to inform the allocation of points for the 'remaining at a work-station' descriptor. Thus someone who can only remain at a work-station for an hour by alternating standing and sitting should not be taken to be able to do so unless they are able to repeatedly, reliably and safely move between sitting and standing without experiencing significant discomfort, fatigue or dizziness.

Case study: Mike has ME/CFS
"One of the complications of having ME/CFS is what's called autonomic dysfunction. This means that the nerve messages from my brain which control my heart rate and blood pressure get mixed up. Overactivity of this part of my nervous system can also cause diarrhoea and a frequent need to pass urine.

The heart and blood pressure problems mean that I always feel light-headed when I stand up and find it very difficult to do anything that involves standing still for more than ten minutes – especially if it's hot.

My occupation for the past twenty years has been teaching – which involves a lot of standing – and there is no way that I could return to working in a school in my current state of health."

As someone who routinely mobilises through walking, an inability to rise from sitting to standing repeatedly without feeling light-headed represents a significant barrier to work for Mike.

3. Reaching, picking up and moving

With musculoskeletal pain and stiffness, such as that caused by arthritis, difficulty with reaching, picking up and moving can be significant for some activities, and not for others, and present all of the time, some of the time or occasionally. As with other descriptors, we therefore recommend the introduction of a time dimension, as well as the inclusion of 'repeatedly, reliably and safely, without significant discomfort or exhaustion' on the face of the descriptor.

The current descriptors assess simply whether an individual is able to lift their arms *or* if they are able to lean, bend, kneel or squat, separately to whether someone is able to pick up and transfer objects. However, the reality of the large majority of working tasks is that they involve a combination of the ability to move one's body to reach for something, and the manual dexterity to pick something up and use it. We therefore feel that a descriptor under this section should measure the ability undertake one complete action of leaning and reaching (involving movement of upper body and lower body, including bending, kneeling and/or squatting when reaching down), picking up and transferring an object. Simple examples that could be used include picking an object up from a low shelf in a supermarket, putting shoes on, hanging a coat on a hook, or moving a hard-back book or file on a shelf at head height.

Case study: Karen, an MS nurse told the MS Society:
"Many of my patients with MS wouldn't have a problem just lifting their arms in the assessment, and so probably wouldn't score any points on this section. But the reality is that they often have falls when reaching to try to pick things up – making something as simple as hanging washing up or putting a book on a shelf impossible.

Likewise, a patient might be able to pick up a pound coin, but ask them to do anything with it – like put it into a vending machine – and they won't be able to; tremors and lack of coordination can set in due to the sheer effort of the activity."

Recommended descriptor

Although the exact wording of the descriptor needs consideration, we recommend that the descriptor should measure whether the claimant:

A. Due to difficulties with or restricted movement of upper body (arms, shoulders, back, neck) and/or lower body (hips, knees, ankles), cannot *repeatedly, reliably and safely, without significant discomfort or exhaustion*, from standing or sitting:

a. Reach up, down (i.e. through bending, kneeling or squatting) and sideways a reasonable distance
b. Pick up and move a range of differently-sized objects up to 1kg
c. Reach up, down or sideways a reasonable distance; *or* reach and pick up and move a range of differently-sized objects up to 1kg

B.

a. with either hand *(highest points)*
b. with dominant hand *(medium points)*
c. with both hands *(low points)*

The descriptor should also measure whether this is the case
a) More than 75% of the time
b) Between 50% and 75% of the time
c) Between 25% and 50% of the time

Examples should be given in the guidance as to what constitutes a 'reasonable distance' – along the lines of our above examples.

4. Manual dexterity/ hand movement

As with the descriptors relating to reaching, picking up and moving, pain and stiffness in the hands or wrists caused by a condition such as arthritis, MS, Parkinson's or RSI can cause significant problems with manual dexterity for some activities, and not for others. This difficulty can also be present most of the time, some of the time or less frequently. For example, most people with rheumatoid arthritis have times – known as flare-ups – when the inflammation suddenly becomes more active, and pain, swelling and stiffness get worse. Similarly, people with MS can find their manual dexterity significantly decreases during relapses.

Case study: Person with arthritis
"I do remember having to fill in the questionnaire about whether you could put a hat on your head and carry a bag of potatoes…That wasn't very relevant, because it was asking can you do this activity once, it wasn't saying could you do this 5 days a week, 52 weeks a year. So yes you may be able to do that activity once, but it wasn't appropriate because it wasn't asking if you can do it over and over again."[18]

[18] Kristina Staley and Bec Hanley, *Incapacity Benefit and employment – the experiences of people with MS or arthritis*, Arthritis Care and the MS Society, April 2006.

Importantly, working activities can often have an impact on this functional ability. This is particularly the case for conditions such as RSI, where problems can often be significantly exacerbated by working activities such as use of a computer keyboard or mouse, turning pages of a book, cutting food, or other repeated or awkward movements. Similarly, many people with MS and ME/CFS find that their symptoms are aggravated by environmental factors, particularly heat. Heat induced weakness can in fact present safety concerns for people with MS because the impact of the weakness can be quick and dramatic. A snapshot asking someone to undertake a simple manual dexterity task within the assessment therefore cannot give a complete picture of someone's true abilities. It is extremely important to explore how the individual's manual dexterity varies over time, as well as the impact of environment and carrying out working tasks on this.

As with other descriptors, we therefore recommend that a time dimension is brought in. We also recommend that more consideration is given to developing a descriptor that more accurately reflects real working tasks. For example, the current descriptor, *"Can make a meaningful mark with a pen and pencil"* does not reflect the reality of a working situation: that individuals are expected to do far more than make a meaningful mark: they need to be able to write legibly at a reasonable speed.

Conditions such as rheumatoid arthritis can, among other things, also result in deformity of the hands, which clearly reduces manual dexterity and makes it difficult for people with this condition to use their hands for work-related purposes without the use of specific adaptations.

Consideration should also be given to the strength of an individual's grip, and assessors should be encouraged to use recognised medical measures and tools[19] to assess this, such as hand dynamometers.

Recommended descriptor

We feel that this descriptor should assess whether the claimant:

Cannot reliably, repeatedly and safely, within a reasonable amount of time and without significant discomfort:

- Grip and turn a door handle, tap and/or piece of equipment (such as a dial on a radio)
- Create a legible message through the use of a pen or pencil
- Use a suitable keyboard or mouse
- Repeatedly press buttons, such as to dial a number on a telephone keypad
- Twist a lid or cap so as to open a jar or bottle.
- Turn the pages of a book
- Pick up and move a £1 coin (so as to put it into a slot in a machine/ box)
- Carry out fine motor/ finger movement, such as to do up a button or tie shoelaces.

[19] An example of scales used to determine the "quality" of grip strength can be found at http://www.complete-strength-training.com/grip-strength-test.html

This is the case:
a) More than 75% of the time
b) Between 50% and 75% of the time
c) Between 25% and 50% of the time

Consideration should also be given to whether the claimant is able to undertake these activities with either hand, or their dominant hand. Although it is possible over time to adapt to not being able to use one's dominant hand, someone who intermittently loses functionality in their dominant hand will find it harder to adapt in such a way, and this should therefore be recognised as a barrier to work.

5. Communicating/ making self understood/ speech

In a similar vein to concerns outlined earlier regarding adaptation, we believe that it is important only to consider ability to communicate using the means normally used *by the claimant*. The current descriptor only addresses the ability to communicate a *simple* message to strangers. However, the reality in most working situations is that people need to communicate not only short, simple messages, but to take part in a conversation, which may involve longer, more complex messages.

The descriptor also fails to capture fluctuating speech problems. For example, speech difficulties of some kind affect between 40 and 50 per cent of people with multiple sclerosis (MS). They can come and go throughout the day, perhaps lasting only a few minutes at a time, or may be a symptom that appears during a relapse. Problems can include slurred or weak speech, or dysphasia – an inability to recall the vocabulary to speak. Similar problems can be experienced by people with Parkinson's. The difficulties can therefore be dependent not only on the complexity of a message, but also the length – while short messages or conversations may be possible, fatigue could make a longer conversation impossible.

We have therefore amended the descriptor to take into account intermittent problems with speech and communication (through the addition of a time dimension, as in other descriptors), as well as recognising the barrier presented by difficulties taking part in a conversation, rather than only the barrier presented by the total inability to communicate a short message.

We have consulted with the Royal College of Speech and Language Therapy, and they support the following recommendations for revision of the descriptor. We would encourage the DWP to engage with similar professional bodies to further refine the language and scoring of the descriptor:

Recommended descriptor
A. Through speaking, writing, typing or other means normally used by the individual, the claimant has difficulty repeatedly, reliably and understandably:
a) communicating a simple/ brief message *(3)*
b) a complex/ lengthy message *(2)*
c) taking part in normal conversation (2)

B. to the extent that this is:
a) impossible *(3)*
b) very difficult *(2)*
c) difficult *(1)*

C. This is the case:
a) More than 75% of the time *(3)*
b) Between 50% and 75% of the time *(2)*
c) Between 25% and 50% of the time *(1)*

<u>Descriptor scoring:</u>
If A*B*C is less than 4 = 0 points
If A*B*C is between 4 and 8 = 6 points
If A*B*C is between 9 and 12 = 9 points
If A*B*C is more than 12 = 15 points

6. Understanding communication/ hearing
This descriptor originally focussed on the ability of the claimant to hear a message that was conveyed to them. In the revised descriptors, it is broadened to encompass a wider notion of understanding communication by both verbal and non-verbal means. However, this new descriptor is highly confusing. It could be easily read that if the claimant could not hear, but could read 16 point font print, they would not face difficulties with communication at work.

Although we do not have expertise in hearing loss, consultation with RNID leads us to recommend that, to avoid this confusion, communication by verbal and non-verbal means are treated separately, and that this descriptor focus solely on barriers to work associated with limited hearing.

Where an individual has indicated some fluctuation in their hearing impairment (e.g. hearing loss can be experienced as a symptom of MS relapses for some people), the additional time dimension should be brought in to ensure that the barrier presented by fluctuating hearing impairment is adequately recognised.

> ***Case study: Shoshana has MS***
> *"Hearing wise, I have massive fluctuations in what I can hear due to 'fluttering' in my ears... it drives me insane!!!! Very hard to hear over. I also get sound sensitivity. I have had relapses where I haven't been able to bear sound: during the past week when I have had trigeminal neuralgia, I haven't even been able to stand the radio or TV on quietly. I've needed real quiet."*
>
> *Shoshana is highly unlikely to attract any points under the current descriptors for her hearing problems, despite the fact that her total intolerance to sound during relapses, and regular difficulties with hearing can certainly present a major barrier to working.*

Recommended descriptor
Using hearing aids or cochlear implants if normally worn:

A.
a) In a working environment without significant ambient noise (including speech, traffic, music or noise from machinery electronic devices) (3)
b) In a working environment with some ambient noise (2)

B.
a) Cannot hear at all (3)
b) Cannot hear well enough to understand a brief (or simple) message from a stranger (2)
c) Cannot hear well enough to understand a lengthy (or complicated) message from a stranger (1)

C. This is the case:
a) More than 75% of the time (3)
b) Between 50% and 75% of the time (2)
c) Between 25% and 50% of the time (1)

Descriptor scoring:
If A*B*C is more than 17 = 15 points
If A*B*C is between 12 and 17 = 9 points
If A*B*C is between 9 and 11 = 6 points
If A*B*C is between 6 and 8 = 3 points
If A*B*C is less than 6 = 0 points

We recommend that further work is undertaken with the relevant organisations representing deaf and hearing impaired people to further refine this descriptor and allocate appropriate points.

An area which has not previously been addressed in this descriptor is tinnitus, where people hear a variety of abnormal and annoying sounds - eg buzzing, hissing, ringing - in the ears, which can be associated with hearing loss. Tinnitus can fluctuate in severity and may also affect concentration and mood. We recommend that when this descriptors is further refined, severe tinnitus should be considered in conjunction with hearing loss as a serious barrier to work.

7. Navigation/ sight
In terms of addressing how the descriptor could be improved purely in terms of recognising the fluctuating aspect of sight loss for some people, we recommend, as with other descriptors, that an additional time dimension should be brought into the descriptor.

However, consultation with sight loss organisations such as the RNIB group has identified a large amount of discomfort with the new descriptors which address sight loss. They largely favour the previous WCA 'Vision' activity as being broadly appropriate, as they are simple, measurable, objective and correlate broadly with certification criteria (for registration as sight impaired or severely sight impaired).

The new descriptors now only address the impact of visual impairment in terms of its impact on ability to navigate safely. Consultation with RNIB makes clear that this is far too narrow. The descriptor must measure the three areas in which sight loss and visual impairment can impact on an individual's capability for working activities:

- visual acuity (reading & communication)
- field of vision (navigation, orientation & safety)
- ability to recognise people/workmates (expressive and receptive communication).

> ***Case study: Shoshana has MS***
> *"I completely lost the sight in one eye before during a relapse. It was like looking through a thick misty cloud. And my whole horizon went diagonal. It took about 2 months for my vision to come back to functional use.*
>
> *I am unable to judge distance and speed of moving objects, but sometimes this is much worse than others. Thus I cannot drive. In various relapses I have had blurred vision, or double vision or 'trailing vision' where it is as though both eyes are not quite working together and everything trails like a firework.*
>
> *I have also had vertigo, where everything spins round and round...*
> *that's horrible. And I have periods of extreme light sensitivity where I cannot go outside in bright light, or have to wear sunglasses in the house."*
>
> *When combined with her hearing impairment (as highlighted above), it's clear that Shoshana would have major problems finding and sustaining employment. However, Shoshana is unlikely to be awarded any points under the current sensory impairment descriptors. Despite quite extreme fluctuations in her visual impairment which can make life and work extremely difficult, since it does not totally prevent her from navigating safely for the majority of the time, it would not be deemed significant enough to award her points.*

We therefore recommend that further consultation is undertaken with experts and representatives of blind and partially sighted people to further refine this descriptor to reflect the range of barriers that sight loss or visual impairment can cause.

8. Bladder/ bowel continence

The WCA assessment of bladder and gastro-intestinal problems is extremely narrow. Under the existing descriptors, only incontinence is addressed, where the claimant "at least once a month, loses control of the bowels so that the claimant cannot control the full evacuation of the bowel" (15 points). Some points may be gained if this happens 'occasionally' (9 points) or if the claimant “risks losing control of the bowels so that the claimant cannot control the full evacuation of the bowel if not able to reach a toilet quickly” (6 points).

Under the new descriptors, the wording has changed to “at least once a month experiences loss of control leading to extensive evacuation of the bowel sufficient to require cleaning and a change of clothing” (15 points). There is no 9 point option, and 6 points are now scored where there is risk of this happening “if not able to reach a toilet quickly”. The 15 point descriptor mentions frequency, but assumes there is no toilet proximity. Conversely, there is no mention of how often the 6 point scenario may occur. The descriptor is incomplete, and different dimensions are brought in depending on the points available.

There have been some improvements to the new descriptor, namely that the claimant no longer needs to establish “full evacuation of the bowel” to be found to have continence-related barriers to work. However, the overall impact, particularly the removal of a 9 point descriptor, will be to worsen the performance of the WCA in correctly identifying the capability for work of people with conditions such as Crohn’s Disease or Ulcerative Colitis, as well as people living with HIV who experience serious gastro-intestinal problems.

In its consideration of continence the report of the internal department-led review of the WCA document states that on page 33 that:

‘The disability associated with continence is largely one of social acceptability. Whilst the disability itself does not necessarily limit an individual’s capability to work, the loss of dignity resulting from the associated soiling is considered severe enough to make it unreasonable to expect an individual with severe incontinence to work.’

We disagree with this assessment, which effectively dismisses the real physical and mental impacts of incontinence by implying that claimants will suffer only social embarrassment. There is also often discomfort or pain associated with having no effective control over one’s bladder or bowel to defer urination or defecation for more than a few seconds. The need for very frequent and immediate access to a toilet is needed to avoid episodes of incontinence does limit capability for work

Case study: comments from people with Crohn’s and Colitis[20]:
“My symptoms are akin to having food poisoning everyday over the duration of the current flare up, which is two years. It affects your morale to the point that no longer living can sometimes appear a better option”.

“Tendency to remain housebound as anxious about unforeseen urgency of needing to go to the toilet. Impossible to think of a job unless one can work from home.”

[20] Verbatim comments from a Crohn's and Colitis UK research project ‘Crohn’s, Colitis and Employment: from career aspirations to reality’. 2011

> *"I can have diarrhoea every 30 minutes for two or three hours at a time, after this I feel really tired and cannot do much but rest, even too tired to get a shower."*
>
> *"I sometimes can't leave the house until late in the afternoon. Can't wait in line for toilets, when you have to go you really have to go quick, you can't wait."*

Whether or not an episode of incontinence takes place will depend on not only the condition of the individual, but also on practical issues such as proximity to the toilet or whether on reaching a toilet it has always been unoccupied. An individual who has always reached the toilet in time might be assessed as merely at risk. If the same person, the next day, finds the toilet occupied and consequently experiences an episode of incontinence, the regulations suggest that they would be assessed in a different way. Yet neither the individual nor their functioning ability has changed.

It is quite possible that someone who experiences continence problems on a fluctuating basis cannot undertake any travel for work (including to and from home, or to meetings) without the risk described in the 6 point descriptor. Even if this happened a few times a month, and unpredictably, they would only gain 6 points.

> ***Case study: comments from people with Crohn's and Colitis:***
> *"Frequent bowel movements, urgency to use a loo, this all makes travel very difficult. If I have to travel any long distance (20 minutes or more) I have to eat almost nil the day before and use a small amount of laxative to make sure my bowels are empty and a loo won't be needed. This can make life very isolating."*
>
> *"I worry about leaving the house in case of accidents and always need to be somewhere where I know toilets are".*

> ***Case study: Tom has HIV***
> *Tom is in work, but due to diarrhoea related to his HIV treatment, finds it difficult to get to work early in the mornings or travel for meetings. This has also had an effect on his mental and emotional well-being:*
>
> *"I work with a team in a nearby city (40 miles away). I have not been keen to attend meetings there as my stomach has been unpredictable. When I did travel it was a distressing experience for me, to find your stomach was suddenly explosive, then trying to find public toilets in time and generally being flustered and uncomfortable when you finally got to the meeting, while maintaining your outward appearance. As a result a casual invitation to attend a meeting brings on a wider anxiety for me about whether I will be well enough to attend and if I get there will I be in the right frame of mind to contribute effectively."*

We believe that this descriptor should:

- Take into account the presence of only those adaptations or aids that are normally used *without assistance* by the claimant: i.e. factors such as manual dexterity or vision should be taken into account when assessing whether someone is able to manage a stoma or catheter themselves.
- Bring in a time dimension to consider how much of the time someone is affected by urgency, frequency or continence problems, and consider awarding some lower-level points to those who experience problems some of the time (i.e. 25-50% of the time).
- Recognise the barriers that the urgent and/or frequent need for access to toilet can cause (e.g. inability to travel), and the great lengths that some people will go to to avoid episodes of incontinence (e.g. not eating for long periods of time or excessive use of anti-diarroheal medication).
- Recognise the impact of the discomfort that may be felt by those who have some limited control, but can experience significant discomfort through the effort of controlling the bowel until a toilet is reached. These people may be 'at risk' of or fear losing control unless they can reach a toilet quickly.

Case Study: Ron has HIV
"I have had HIV for 26 years and been on meds since 2006. I feel ground down, and that at most I have eight good hours in a day. I thought that "stomach problems", to be polite, were just due to medications, but they seem to have triggered permanent IBS. I can carve out some "better time" by not eating on certain days"

Recommended descriptor
Despite the presence of any adaptations or aids normally used without assistance,

a) At least once a month experiences loss of control leading to voiding of the bladder, extensive evacuation of the bowel or substantial leakage of the contents of a collecting device sufficient to require cleaning and a change of clothing and/or incontinence pads (15 points)

or
A.
b) Without immediate access to a toilet, would experience loss of control leading to voiding of the bladder, extensive evacuation of the bowel or substantial leakage of a collecting device sufficient to require cleaning and a change of clothing and/or incontinence pads; (4)

c) Experiences significant discomfort due to the need to evacuate the bladder or bowel or risks losing control if not able to reach a toilet quickly (1)

B. This is the case:
i) Most of the time (more than 75%) (3)
ii) Some of the time (between 50% and 75%) (2)
iii) Occasionally (between 25% and 50%) (1)

Descriptor scoring:
If A*B is 8 or more = 15 points
If A*B is 3 or 4 = 9 points
If A*B is 2 = 6 points
If A*B is 1 = 3 points

NB. No time dimension is needed for a) – satisfying this criteria at all should automatically award the claimant 15 points.

'Immediate access to a toilet' should be defined as the ability to access a toilet in less than five minutes.

Ability to reach a toilet 'quickly' should be defined as the ability to reach a toilet within 15-20 minutes. This is based on the time taken to navigate a reasonably large building to find a toilet, wait in a queue or undertake a short journey.

The assessment should consider the evidence from the previous three months, along with medical evidence and evidence from the claimant in order to assess the likelihood of this occurring in the next three months.

9. Consciousness
We consider that this descriptor intends to cover the medical triad of fits (i.e. various types of epilepsy), faints (numerous causes), 'funny turns' and absences (which may or may not have a clear diagnosis). It is very difficult to accurately quantify the impact these episodes can have in the same way that has been done for other descriptor areas.

We consulted with Epilepsy Action for advice on improving this descriptor and they told us the following:

"With 30 different epilepsy syndromes and over 40 different types of seizure, it is most important that a person's needs are assessed as an individual, rather than make any attempt to group people based on a shared diagnosis.

In this respect, the current descriptors, although somewhat crude, are good. They allow sufficient scope for a person to stress the impact of a seizure(s) and elaborate on its consequences, and to downplay the impact if they see fit. In theory, the current descriptors allow an episode to be placed in its context, which is all-important in determining potential impact on employment.

To improve the current 'consciousness' descriptors, we would keep the current system which notes frequency, but include reference to recovery time.

We believe variations in recovery time can be just as relevant to a person's work capability as the frequency of seizures. It is possible for a person to have a seizure which "results in significantly disrupted awareness or conception" every week, but for the impact of this seizure to be minimal if their recovery time is short. Equally it is possible for someone to have a seizure on average once every couple of weeks, but require two or three days recovery time. Frequency should not be the sole measure of impact, but neither should recovery time.

Recovery time is not currently a factor in the assessment of this section of the form. We would like it to be. ”

We therefore recommend that the current wording is retained with some minor adjustment to expand the descriptor to cover fluctuating conditions. The assessment should consider evidence of experiences of lost or altered consciousness and recovery times for each experience from the previous six months, along with medical evidence and evidence from the claimant in order to assess the likelihood of these episodes continuing to occur.

Whilst the new WCA descriptor meets with the approval of Epilepsy Action in relation to epileptic seizures we recommend that there should also be some flexibility in the time/frequency factor - currently at least once a week or at least once a month - to cover other types of altered consciousness (e.g. those relating to faints, hypoglycaemic episodes, transient ischaemic attacks or excessive daytime sleepiness in narcolepsy and sleep apnoea) which may occur in a fluctuating, intermittent or unpredictable manner.

The explanation in guidance to assessors needs to be clear about what is meant by involuntary. This term should, for example, include episodes of epilepsy that are precipitated by predictable and possibly avoidable factors (e.g. flashing lights) or faints that result from changes in posture.

e) Comments on mental, cognitive and intellectual descriptors

We have already stated that we support the recommendations contained in the review of mental, cognitive and intellectual descriptors.

Whilst acknowledging that these descriptors are not strictly within our remit we do have some comments to make as some of these descriptors are very relevant to people with fluctuating conditions.

In particular is the issue of cognitive dysfunction (i.e. problems with short-term and working memory, concentration, attention span, ability to monitor and maintain safety of self and others around them, decision-making and information processing) that are often aptly referred to as “brain fog”.

Case study: Graham has ME/CFS   *“Sometimes the brain fog lifts and I can manage for a few hours with a fairly clear mind but then I can be silent for days. I tend to have short periods when I feel able to communicate followed by periods when I can't. I try to make sure that important decisions are made when my mind is reasonably clear because I know that later the same day I will not be able to do this. Sometimes I can 'make' myself speak/do things such as dealing with my children's school and I appear OK, but I can be back in bed and feeling unwell for days.”*

When present, cognitive dysfunction can be a major barrier to employment – especially where this involves being able to sustain even low level mental activity, or where accurate calculations or information processing or retrieval is part of the job description.

The original set of descriptors contained a descriptor (9) that assessed this type of cognitive dysfunction

(9) Memory and concentration
a) On a daily basis, forgets or loses concentration to such an extent that overall day to day life cannot be successfully managed without receiving verbal prompting, given by someone else in the customer's presence (15)
b) For the majority of the time, forgets or loses concentration to such an extent that overall day to day life cannot be successfully managed without receiving verbal prompting, given by someone else in the customer's presence (9)
c) Frequently forgets or loses concentration to such an extent that overall day to day life can only be successfully managed with pre-planning, such as making a daily written list of all tasks forming part of daily life that are to be completed (6)
d) None of the above apply (0)

The mental, cognitive and intellectual descriptor group produced a revised version that we found helpful in relation to both severity and frequency.

(3) Maintaining focus

a. *Due to poor memory or concentration, has difficulty maintaining focus on: all tasks (3); most tasks (2); some tasks (1)*
b. *When working for: an hour or less (3); a few hours (2); most of the day (1)*
c. *This is an issue: the majority of the time (3); frequently (2); occasionally (1)*

Descriptor scoring:
*If a*b* c is less than 4 = 0 points*
*If a*b* c is between 4 and 8 = 6 points*
*If a*b* c is between 9 and 12 = 9 points*
*If a*b* c is more than 12 = 15 points*

However, the new set of descriptors that came into force on 28 March no longer contains a descriptor that attempts to capture this information, and so people with this type of cognitive dysfunction are no longer able to score any points.

Significant levels of cognitive dysfunction are often reported by people with HIV, MS, Parkinson's and ME/CFS – where it forms a key part of the diagnostic criteria.

Case study: Maureen has Parkinson's
"(I was) placed in the Work Related Activity Group and was told with suitable training and rehabilitation and medication will be fit for work in

six months, although I have trouble walking and I am starting to become very forgetful and find it very difficult to finish tasks/jobs (and my) neurologist has mentioned Parkinson's related dementia."

Recommendation 10: We strongly recommend that the recommendations of the group regarding mental, cognitive and intellectual function are seriously considered and implemented. In particular, a descriptor which covers this sort of cognitive dysfunction in both physical and mental conditions is a crucial addition which should be made to the WCA. It is extremely important that the time taken to complete activities is taken into account.

We believe that the current descriptor (13) sets far too high a bar for limited capability to work:

> *(13) Initiating and completing personal action (which means planning, organisation, problem solving, prioritising or switching tasks)*
>
> *a) Cannot, due to impaired mental function, reliably initiate or complete at least 2 sequential personal actions. (15)*
> *b) Cannot, due to impaired mental function, reliably initiate or complete at least 2 personal actions for the majority of the time. (9)*
> *c) Frequently cannot, due to impaired mental function, reliably initiate or complete at least 2 personal actions.(6)*
> *d) None of the above apply (0)*

Once again, maintaining realistic employment requires the ability to complete substantially more than two 'personal actions'. Work involves being able to plan, prioritise and undertake a large number of tasks, and to do so in a range of environments. We believe that this descriptor should be amended to consider:

- A larger number of tasks
- A range of different tasks
- The environment in which the individual is expected to undertake tasks
- How much of the time the individual faces problems completing tasks

Case study: Mary has MS
"I find it really hard to concentrate in busy environments. I used to be a hairdresser, but I gave up work after I found myself one day pins and rollers in one hand, a comb in the other and a client with wet hair in front of me: and I realised I couldn't remember the sequence I had to go through to put the rollers into her hair."

6. Unaddressed barriers

The current set of descriptors aims to produce an objective point-scoring assessment of various aspects of functional ability. In the previous section we have recommended refinements to the descriptors, in order to better measure the impact of fluctuation as well as the severity of impairments.

However, even with these refinements, there is an important gap in WCA. No descriptor adequately captures information about pain and fatigue, which often play a significant or even principle role in deciding whether someone is able to participate in some form of meaningful regular employment.

As symptoms such as fatigue and pain are particularly related to fluctuating conditions we are concentrating on these two in some detail and are recommending that they are assessed as a separate descriptor.

Even if refined descriptors pay attention to the pain and fatigue causes by carrying out the specified activity – for example, reaching, picking up and moving – they will not measure or count the impact of chronic or recurring pain or fatigue which is a feature of daily life, and should be considered as an impairment *per se*. In this way we are confident that there is no risk of 'double counting' to include a descriptor which measures these particular impairments, which are distinct from those already addressed in the WCA.

To help make this distinction clearer to those carrying out the WCA, we recommend that the use of a fatigue scale (such as the example in Annex B) or pain questionnaire (such as the example at Annex C), appropriate to the condition, could be considered as measurement tools where fatigue or pain are the main reasons why someone is claiming that they are unable to work.

Recommendation 11: An additional descriptor should be added which addresses the impact of generalised fatigue and/or pain.

a) Fatigue and fatigability

Fatigue is often reported to be a significant and disabling symptom by people who have a number of chronic health conditions - both physical and mental.

Unfortunately, the presence of fatigue, and the adverse effect it has on functional ability and quality of life, is not always recognised or appreciated by doctors and medical examiners.

Case study: Parkinson's UK Information and Support Worker *"Extreme fatigue doesn't appear to fit into any of the descriptors but is often a major problem for clients."*[21]

[21] Parkinson's Disease Society, *Of little benefit and not working: people with Parkinson's experience of Employment and Support Allowance,* 2009.

Fatigue is particularly common in people with chronic infections (e.g. hepatitis C, HIV, tuberculosis); inflammatory conditions (e.g. rheumatoid arthritis, Sjogren's syndrome and inflammatory bowel diseases); neurological disease (e.g. head injuries, multiple sclerosis, Parkinson's); endocrine and blood diseases (e.g. hypothyroidism, and anaemia); fibromyalgia; heart, liver and kidney disease; and in cancer (both as a result of the underlying disease and as a result of treatment with chemotherapy and radiotherapy). Fatigue that is exercise-induced is a key clinical feature of ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome). Disabling fatigue also occurs in people with mental health disorders - depression in particular - and more severe sleep disorders.

The underlying mechanisms involved in the production of fatigue are complex and often uncertain. They can involve abnormalities in brain, muscle function and cardiovascular function, as well as the immune system response to infection or inflammation.

A considerable amount of high quality research has now been published into the epidemiology,[22] cause[23,24,25,26,27,28,29] and management of disabling fatigue in both medical and psychiatric illnesses.

Case study: Debbie has ME/CFS
"Like most people with ME/CFS my illness followed an acute infection – a nasty attack of chickenpox. Now it feels as though I have a constant dose of flu. The worst part is the fatigue, which affects everything I want to do – work, family life and social life. As soon as I go past my limitations I crash out and have to lay down. And if I do too much on a good day I know I'm going to pay for it on the next day, and several days after that.
I would love to go back to work and did so during a better patch on a part-time basis. This involved sitting at a checkout in a supermarket. But I soon had to stop because I couldn't keep lifting the heavier objects and I was making too many mistakes on the till."

Impact of fatigue

Fatigue can effect both physical and mental/cognitive functioning. It may be

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[22] Jason LA et al. *A community-based study of chronic fatigue syndrome.* Archives of Internal Medicine, 1999, 159, 2129 - 2137.

[23] Breitbart W et al. *Fatigue in ambulatory AIDS patients.* Journal of Pain and Symptom Management, 1998, 15, 159 - 167.

[24] Chaudhuri A and Behan PO. *Fatigue in neurological disorders.* Lancet, 2004, 363, 978-988.

[25] Foster GR et al. *Chronic hepatitis c virus infection causes a significant reduction in quality of life in the absence of cirrhosis.* Hepatology, 1998, 27, 209 - 212.

[26] Krupp LB et al. *Fatigue in multiple sclerosis.* Archives of Neurology, 1988, 45, 435 - 437.

[27] Lou J-s et al. *Exacerbated physical fatigue and mental fatigue in Parkinson's disease.* Movement Disorders, 2001, 16, 190 - 196.

[28] Mayoux-Benhamour MA. *Fatigue and Rheumatoid arthritis.* Annales de Readaptation et de Medecine Physique, 2006, 49, 385 - 388.

[29] Mitchell A et al. *Quality of life in patients with inflammatory bowel disease.* Journal of Clinical Gastroenterology, 1988, 10, 306 - 310.

predominantly activity-induced, as in the case of ME/CFS and some types of muscle disease, or occur as an integral and on-going part of an illness.

Fatigue can come on suddenly and without warning, and significantly disrupt the individual's life. For example, many people with MS describe their fatigue as an overwhelming sense of tiredness with no apparent reason, very different to an ordinary tiredness that people might experience after a hard day's work or strenuous exercise. Some people become tired after very little or no activity, or rarely wake up feeling refreshed in the morning. Fatigue is a symptom that may also fluctuate in severity both throughout the day, and on a day-to-day basis, and in a remitting-relapsing pattern.

> ***Case study: Alex has HIV***
> *"My fatigue does not build gradually - when it happens it's like my whole body is telling me to stop everything, it's like a machine switching itself off but I can't predict when it will happen. When it happens - that's it for the day, I just stop functioning, can't work, can't cook, shop or anything"*

> ***Case study: Liz has MS***
> *"Fatigue is where your body just shuts down. It doesn't make an appointment with you to do so, and you have to just rest immediately. I have to just lie down until it passes. Cannot even talk.*
>
> *I once even fell asleep on my mobility scooter – the fatigue just came at a moments notice. By keeping an eye on it I can make sure it doesn't happen again by not overexerting myself. But it means that holding down a job just isn't an option, although I'd dearly love to work."*

The management of fatigue, where it occurs, is often unsatisfactory because there is only a limited role for the use of stimulant, antidepressant or hormonal drugs - which may help to reduce fatigue in some situations. So management of fatigue tends to concentrate on self-help measures whereby physical or mental activity is not pursued beyond the person's limitations.

> ***Case study:***
> *In 2008/9 Crohn's and Colitis UK undertook, with Kings College London, a series of focus groups looking at the effects of IBD (inflammatory bowel disease) related fatigue. People said:*
> *"I just used to sleep in the lunchtime, have lunch and just sleep in the loo or wherever, if I could find a cupboard or wherever, I would just lie on my desk…and get some sleep, but I had my mobile phone in my pocket, then if I did fall asleep, I had it set every ten minutes to vibrate anyway…just in case I did fall asleep and the boss came back."*
>
> *"Some things –such as putting the kettle in the fridge – do not matter too much, but the problem also extends to making errors at work. I'm very lucky at the university, because I've been there a long time and they do make allowances, but you do get tired and you make mistakes."*

For many people with long-term conditions, fatigue is highlighted as the symptom that affects them the most. In a recent survey of people living with HIV it was the most-cited HIV-related symptom experienced by respondents.[30] Fatigue is a regular topic of discussion on helplines and online discussion forums run by most of the charities represented on this group. Fatigue and fatigability can therefore have a major effect on how someone is able to reliably sustain and repeat a range of physical and mental activities that form part of a normal working day. And this can obviously create difficulties in relation to employment where the need for rest breaks, and modifications to normal duties, may have to be built into a return to work strategy. For example, a number of studies of general MS populations have found fatigue to be the primary symptom responsible for changes in work status and unemployment.[31]

Fatigue can also lead onto other problems with work retention, as well as being an issue in itself. The presence of fatigue is also likely to exacerbate pre-existing ill health and symptoms such as pain and orthostatic intolerance (i.e. difficulty with standing) or orthostatic hypotension (where blood pressure falls on standing). Fatigue can also lead to depression or anxiety, as highlighted by the case-studies below:

Case study: Kay has HIV

Kay has HIV and tries to manage her activity level in order to avoid fatigue:

"Tiredness or fatigue occurs when I do more than normal - this means, for example, spending some time every day doing voluntary work. I am far more tired than I ever used to be. Also anxiety and depression seem to be related to exhaustion, but the exhaustion is not related to the sort of activities that would leave normal people exhausted. You are just more vulnerable if you are HIV positive."

"I do not work full time, so I can pace myself to avoid problems. However, sometimes it is very difficult, even being part time. I know that I am underperforming."

Case study: Lucy has MS

"Fatigue for me is finding every day I think I can do more than I can, being very frustrated, getting shouty at the kids because I can't function after doing the school run, being unable to remember what day it is, what a persons name is because I am so drained, being angry with family/friends because they have no clue what I am talking about, feeling like I have lost all brain matter because I cant spell or talk properly or even think how to get things done. Becoming hysterical because I suddenly find I can't cope and don't know what to do when I am in the middle of town or in the playground. It is without question the

[30] Forthcoming NAT report

[31] Smith MM, Arnett PA. *Factors related to employment status changes in individuals with multiple sclerosis.* Mult Scler 2005 30:137-42; Paltamaa J et al. *Physical functioning in multiple sclerosis: a population-based study in central Finland.* J. Rehabil Med 2006 38:339-45; O'Connor RJ et al. *Factors influencing work retention for people with multiple sclerosis: cross-sectional studies using qualitative and quantitative methods.* J Neurol. 2005 Aug;252(8):892-6.

worst of my MS symptoms, I can manage the pain, loss of sensation, bladder problems etc but there does not seem to be any way to manage the fatigue without giving up some part of your day to day life."

b) Pain

A sensation is 'painful' if it causes mental or physical discomfort. Pain can come and go in short bursts, or may last longer. It can be a daily nuisance, a distressing but occasional shock, or ongoing and severe throbbing, ache or dull pain that makes it hard to think about anything else. Even mild changes in sensations can have an impact on daily life.

Pain has an emotional as well as physical dimension. Pain can sometimes cause distress, fear, anger or frustration and these emotions can, in turn, affect how individuals deal with painful sensations.

Pain can take many forms for people with different conditions and disabilities, experience of pain is unique to each individual, and pain has to be managed to a greater or lesser extent in a variety of different ways. Pain can fluctuate significantly, due to fluctuation of the condition itself, or be caused by other factors such as heat, fatigue or anxiety, which make pain feel a lot worse.

Here we attempt to outline some common forms of pain, and its impact. The UK Pain Proposal report[32], launched in January 2011, highlights the inadequate management of chronic pain, and makes a number of recommendations on the need for a joined-up approach to pain management.

Chronic pain
Chronic pain affects as many as one in five of the European population, causing significant costs to individuals, families and carers but also healthcare systems and economies.[33] However, due to the ambiguities involved in defining chronic pain the true scale of the problem has been difficult to quantify and therefore has not been afforded the same priority as other health concerns.

Chronic pain can be described as 'pain that has persisted beyond normal tissue healing time', which is usually taken, in absence of other criteria, to be around three months. It can be caused by a huge range of common conditions, including arthritis, cancer and diabetes, or by other factors such as injuries or operations. Chronic pain does not fit neatly into one discipline and as a result, the journey of someone with chronic pain through to correct diagnosis and adequate management can be fragmented, difficult and costly.

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[32] The UK Pain Proposal, available at http://www.pfizer.co.uk/sites/PfizerCoUK/Media/Documents/Pain%20Proposal%20-%20European%20Consensus%20Report.pdf
[33] *Pain Proposal UK,* January 2011

Musculoskeletal pain
'Musculoskeletal pain' is pain in bones, muscles and joints. It can be acute or chronic, and can be caused by injury, infection, trauma, overuse, strain or medical procedures such as surgery. In conditions such as Parkinson's and MS it can be due to cramps and spasm caused by muscle stiffness. This can include, for example, difficulties with balance, fatigue or muscle weakness leading to problems with posture which puts a strain on joints, ligaments or other muscles.

Musculoskeletal pain is particularly associated with conditions such as arthritis, fibromyalgia, ME/CFS, MS, Parkinson's, or osteomalacia, and can be felt for a variety of reasons. Inflammation in the joint causes heat, redness, swelling and loss of movement, and can often cause pain. Damaged joints can be painful as well. Both these kinds of pain can lead to a third type – from muscles strained by tensing them and by trying to protect the joints from painful movements. In rheumatoid arthritis, people may feel all these types of pain. With osteoarthritis, most of the pain is felt from damaged joints and aching muscles.

Self-management techniques can be effective at helping some people with musculoskeletal pain keep their pain under control and specialist pain clinics are also able to provide treatment and support for managing pain in many cases. A number of drugs also exist which can help relieve the pain of arthritis, including analgesics, NSAIDS, DMARDS and biologics, but their availability varies significantly and not all people with arthritis are currently able to access the drugs which are most likely to be of benefit to them, meaning that pain is manageable for some people and not for others.

Case study: Caroline has arthritis
"Right now I am in constant pain all of my waking moments and it causes me many sleepless nights. I can't cook a meal, can't wash my own hair and I had it cut short recently due to not being able to brush it myself properly. I can't shop, wash, walk, sit or sleep without severe pain. I take lots of medication and have recently been put on to morphine patches which make me feel ill."

Visceral Pain
Visceral pain[34] is pain that affects internal organs. Most of our visceral pain sensations come from the gut, bladder or uterus, in which relatively minor lesions can produce excruciating pain. Inflammation can be particularly problematic, as organs become highly sensitive to any kind of stimulation, as in inflammatory bowel disease (IBD) and other disorders.[i] In a survey carried out by the National Association for Colitis and Crohn's Disease, 51% of respondents described their abdominal paint as aching, 46% as stabbing, 39% as nauseating, 34% as deep-seated, and 29% as constant. 69% said that their abdominal pain was usually more than 5 on a scale of 1 to 10 and 61% said that their worst experience of abdominal pain had been 9+ on the same scale.

[34] Cervero F and Laird J. *Visceral Pain.* The Lancet, 1999, 353, 2145 - 2148.

There are very few specific painkillers for visceral pain and many commonly used painkillers are not effective and are at times contra-indicated for some conditions. For example NSAID's can trigger a flare of IBD and particular care is required with drugs such as morphine for IDB as these can increase the risk of a dangerous complication.

Neuropathic pain

Neuropathic or neurogenic pain[35] is a different to the type of pain to that which is caused by injury or damage to the tissues. This type of pain is caused by problems with the nerves themselves, and this is a pain which doesn't disappear very easily, if at all. Pain like this without apparent cause can cause a range of sensations, from intense sharp stabbing or burning pains, or 'electrical shock' sensations, to prickling, tingling, numbness or 'pins and needles', and patches or larger areas of skin with heightened sensitivity or altered sensation.

Neuropathic pain can be puzzling and frustrating and is usually chronic rather than acute. This means that it is usually a constant feature, although it may fluctuate in degrees depending on factors such as viral activity in the body, heat, stress or physical over-exertion.

Traditional painkillers are much less effective for neuropathic pain. However, other treatments are available, such as antidepressants (eg amitriptyline) and drugs which are normally used to treat epilepsy (eg gabapentin). They are sometimes very helpful but they can often cause side effects such as drowsiness, dizziness, nausea and blurred vision.

Case study: Imogen has MS

"The hardest thing to manage is the fact that there is no tiny small gap in the pain in my legs, even with my OxyNorm, OxyContin etc. medication. 5 minutes a day/night would be nice. The relentlessness of it."

Case study: Heather has MS

"My legs constantly feel as if they are in a barrel filled with ice - so painful."

Peripheral neuropathy has a number of causes including diabetes, sarcoidosis and vitamin deficiency. It can also be caused by HIV, and is a side-effect associated with certain HIV drugs. Neuropathy can cause significant pain, and affected a third of the respondents to NAT's online survey on HIV-related symptoms. Half of those who experienced fluctuating neuropathy reported that episodes can last up to a week (and longer) – it should be kept in mind that neuropathy is an example of a condition where fluctuation tends to be around severity.

Case study: Chris has HIV

Chris is living with HIV and experiences unpredictable neuropathy, as well as diarrhoea, fatigue and depression. He says:

[35] Dworkin RH et al. *Recommendations for the pharmacological management of neuropathic pain: An overview and literature update.* Mayo Clinic Proceedings, 2010, 85, S3 - S14.

"Nerve pain can be a bummer, it creeps up sometimes when you least expect it - how can you sit in the cinema or theatre and enjoy a performance and at the same time stifle the scream when a red hot poker is stuck in your lower limbs?"

For Chris, this pain is not always directly related to carrying out a function like walking. Nor is the pain directly related to being seated. It simply sometimes hits.

Other neurological conditions where pain is a very disabling feature, and often difficult to control, include Parkinson's, MS, trigeminal neuralgia and complex regional pain syndromes.

Pain as a side effect of drug treatments
Certain drug treatments can have painful side effects. For example, people with MS taking beta interferon often experience headaches and flu-like symptoms such as aching muscles, particularly in the first few months of taking the drug. Likewise, dyskinetic pain can result in result from fluctuations in a person's response to standard anti-Parkinson's drugs. Dyskinetic pain can occur in combination with involuntary movements (dyskinesias) that some people with Parkinson's experience. Other Parkinson's drugs can occasionally cause headaches.

As noted above, neuropathic pain is in some cases a result of HIV treatment, and is long-lasting. Certain HIV treatments have also been associated with lipodystrophy, a disorder of fat distribution, characterised by the loss or gain or fat from specific areas of the body (e.g the face limbs, stomach, buttocks). While this is not painful *per se*, the loss of natural padding can make basic activities painful, as illustrated in the story of Joseph, below.

Case study: Joseph has HIV
"Lipodystophy has removed the fat cushioning on my buttocks and the padding on my feet - so even the slightest degree of unevenness in the floor is painful, and even wearing shoes with 2 pairs of socks and foam pads doesn't prevent this. This is always there. Travel on public transport is awful - the seats are so hard. Even padded seats after a while are no good - taking cushions everywhere is impractical."

Impact of pain
If pain continues, it can be exhausting, often makes fatigue worse, affect mood, or make it harder to continue with everyday activities, and this can therefore particularly impact on people's ability to work. Pain can stop people doing what they like and need to do.

Case study: Steve has Parkinson's
"There are periods every day when my inability to carry out simple tasks and the feeling of my body and mind shutting down, together with pain, weakness and fatigue and breathlessness to mention a few of the

symptoms, give me a feeling of despair as to how something like this could happen to me".

In healthcare, pain is increasingly acknowledged and managed, but it is vital that this is recognised as a distinct symptom that can impact on people's ability to work.

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

c) Recommended descriptor on pain and fatigue

Both fatigue and pain can impact on an individual's ability to carry out individual functional activities, and how this ability fluctuates over time. However, they can also have an ongoing impact on an individual's capability for work per se, which can inhibit an individual's ability to carry out a reasonable working schedule in an average working week. We feel that this latter barrier presented by generalised fatigue and pain is not being addressed by the current assessment.

We therefore recommend that an additional descriptor should cover fatigue and pain where either or both of these symptoms forms the main part of a distinct clinical entity (e.g. ME/CFS in the case of fatigue, or chronic regional pain syndrome in the case of pain), or where fatigue/pain is a prominent and recognised symptom in an existing disorder or condition such as arthritis or MS. We recommend that this new descriptor should relate to the impact that fatigue and/or pain has on the person being able to reliably, repeatedly and safely perform a reasonable daily schedule of physical and mental activities during an average working week. Very clear guidance should be given to accompany this descriptor, including that it is important to consider what factors may contribute to or exacerbate pain and fatigue, particularly where these factors are work-related.

The group would be very willing to give further input the development of a descriptor covering fatigue and pain.

Recommended descriptor
Due to the impact of generalised fatigue and/or pain not adequately managed by treatment or adaptations, reliably and repeatedly performing a reasonable daily schedule of physical and mental activities in an average working week is:
- impossible
- very difficult
- difficult

This affects:
- all tasks

- most tasks
- some tasks

This is the case:
a) More than 75% of the time

b) Between 50% and 75% of the time
c) Between 25% and 50% of the time

Scoring and use of this descriptor
We recognise that this descriptor should not be used as a 'catch-all' descriptor for claimants who are not found eligible under other descriptors. We have recommended it in recognition that fatigue and pain are specific barriers to work which are not currently addressed by the WCA. Therefore, we recommend that the descriptor should be applied only to those whose pain or fatigue is a recognised symptom of a diagnosed condition, which is supported either by a recognised pain or fatigue scale[36], or medical evidence from a healthcare practitioner who knows the claimant.

Consideration needs to be given to whether an individual could score a full 15 points, qualifying them for ESA, under this descriptor alone, or only in conjunction with some points under some other functional descriptor. Very clear guidance would need to be given to support application of this descriptor.

[36] Like those in Annexes B and C

7. Special circumstances rules / the non-functional descriptors

In addition to the functional descriptors that make up the WCA there are additional special circumstances rules that HCPs and decision-makers may take into account. In the DWP's ESA statistics[37], these are referred to as the 'non-functional descriptors'. These describe circumstances in which someone may be found to have limited capability for work or for work-related activity for a medical reason not picked up in the descriptors.

For entry into the Support Group, many of the special circumstances covered by the non-functional descriptors are known, including those who are terminally ill, and claimants who are currently undergoing chemotherapy.

However, the regulations also contain a more general provision for individuals whose health would be at risk if they were found fit for work, to be entered into the Support Group or WRAG as appropriate. These are found in regulation 29 (WRAG) and 35 amend the functional descriptors)

With respect to entry to the WRAG, regulation 29 (b) states that

> *"A claimant who does not have limited capability for work as determined in accordance with the limited capability for work assessment is to be treated as having limited capability for work if...he claimant suffers from some specific disease or bodily or mental disablement and, by reasons of such disease or disablement, there would be a substantial risk to the mental or physical health of any person if the claimant were found not to have limited capability for work."*

This regulation may be used, for example, to show that if someone living with HIV who has a severely compromised immune system and/or is ill with an opportunistic infection went to work, they would place their own health at risk. Regulation 35 is the equivalent rule for the Support Group.

As these rules are exceptional, and not part of the main assessment, ESA claimants are reliant on HCPs and decision-makers to correctly interpret and apply them. The instructions in the ESA handbook to HCPs for applying regulation 35 do note that this regulation may be applicable where someone has, for example "florid psychosis", or a "severely compromised immune function". However, as this is not stated explicitly in the regulations or on the assessment form, it is likely that this exception may be overlooked.

It is far more likely for this rule to be used successfully in appeal after the claimant has been found 'fit for work', such as in the case of Tim, below.

Case study- Tim has HIV
Tim is a young man who applied for ESA with the help of his aunt and an HIV-specialist benefits adviser. At the time of completing his ESA50

[37] DWP, *Employment and Support Allowance: Work Capability Assessment by Health Condition and Functional Impairment: Official Statistics*. January 2011.

form, Tim's CD4 count was 19. Medical evidence from his doctor explained that at the time of diagnosis, Tim had a CD4 count of 0 and pneumocystis pneumonia (PCP), a form of pneumonia associated with a low CD4 count. These are unequivocal indicators that Tim had an extremely compromised immune function, was seriously ill and likely to continue to experience bouts of poor health that would make work impossible in the forseeable future.

Tim was found fit for work. His doctor submitted further medical evidence, but the case still ended up at appeal, where Tim's adviser made a case for Regulation 35 to be considered. Tim's adviser recalled that, "the judge just looked up and said, 'oh - ESA successful, he's in the support group, that's not a problem'."

Up to May 2010, 5% of ESA claims were awarded based on the non-functional descriptors (classed under the heading 'medical reasons'), compared to 24% awarded after appeal or reconsideration. It is likely that some of this latter category could have been resolved at the start of the process, if the non-functional descriptors were routinely considered in cases where insufficient points were scored.

These non-functional descriptors exist for good reason, but do not seem to be used at an appropriate point in the system - before the decision.

Recommendation 12: The 'non functional descriptor' should be used more actively and consistently. It should be included on the face of the WCA alongside the functional descriptors to encourage this.

This should be accompanied by clear examples of the sorts of conditions in which these special rules should apply, and when someone should be found to have limited capability for work or work-related activity. The guidance and examples used should extend beyond the most extreme scenarios to those where the stress or fatigue caused by employment could significantly aggravate someone's condition to the extent that it causes a substantial risk to their health (or the health of others).

The guidance could include reference to the sorts of conditions which previously led to exemption from the Personal Capability Assessment for Incapacity benefit. This list was:

- 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 render the sufferer functionally paraplegic
- Persistent vegetative state
- Severe learning disabilities
- Severe and progressive neurological or muscle-wasting diseases

- 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
- 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.

It may be necessary to update some of these categories.

These rules are just as important as the functional descriptors for assessing work capability, and should be just as prominent.

8. Key points for scrutiny/ key next steps

We are looking forward to working closely with the scrutiny group and the DWP to refine these recommendations and move towards implementing them. We have outlined some particular issues that may need some attention, and some key next steps:

- Work with impairment-specific groups to refine particular descriptors (particularly on sensory impairment)

- Consider scoring for descriptors. We have made suggestions where possible, but further work is needed.

- Reflect on, review and amend support group descriptors through a similar process. We haven't touched on this area as we feel that where the most problems are currently faced by people with fluctuating conditions is the borderline between 'fit for work' and the WRAG, but the guiding principles that we have outlined should also be applied to support group descriptors.

- Consideration of training and guidance, along the lines that we have recommended. We would strongly welcome the opportunity to support this.

- We support consideration of a supplementary 'real-world' test to consider a wider range of issues which impact on an individual's capability for work.

- Research with employers on what they expect from an employee, and therefore what they think makes someone 'capable for work'. We recommend that further research is done with employers and JobCentre Plus looking at people found 'fit for work' to gather a more accurate estimation of their ability to find employment.

- User testing should be carried out on the finalised descriptors, with Atos assessors being involved in applying the descriptors to real claimants, and feedback should be gathered from disabled people on the descriptors.

- In the meantime, results of Incapacity Benefit reassessments should be carefully monitored, including the number of appeals and complaints, to scrutinise the impact of the new WCA on the number of people placed in different groups. These results should be broken down as far as possible to monitor the impact on people with different impairments, disabilities and conditions.

We hope that this work is simply a first step in the process of improving the ESA assessment process for everyone, and particularly those with complex and fluctuating conditions. The descriptors are just one small part of the assessment process. We have also made some initial suggestions and supporting recommendations as to how the process of assessment as a whole can be improved, we hope to work closely with the DWP to build on this work and support the implementation of any recommendations.

ANNEX A: Minutes of meeting with Dr Rayner

Extracts from Dr Rayner's presentation are taken from the minutes of this meeting, which was held on 26 January 2011:

Dr Rayner told the Group that the tribunal service was part of the court service, was neutral and was independent of the Department for Work and Pensions (DWP). As 50% of decisions were overturned, she felt it would be helpful to ascertain why people were deterred from appealing.

Dr Rayner was employed to set up and oversee an appraisal and training system for all the medical members who sit on social security tribunals. Doctors in the Social Entitlement Chamber now have 3-yearly appraisals with a doctor and a judge.

When asked what training was given on difficult conditions such as M.E. Dr Rayner explained that once a year doctors in the chamber were given a self-appraisal questionnaire and asked to identify any training needs. Dr Rayner then devised training taking those needs into account. This year, for example, they were looking at chronic fatigue syndrome and chronic pain.

She was asked whether it was possible for doctors in the chamber to specialise. Dr Rayner said that this was not necessary, as cases were not listed by diagnosis. Assessments were made on the basis of functional loss rather than diagnosis. However, she encouraged doctors to do background research if they were presented with a case involving a diagnosis with which they were not familiar. Dr Rayner confirmed that the service was given feedback on complaints and that they were taken seriously.

Dr Rayner said that she had met Professor Malcolm Harrington and she had told him that sometimes, when she read a report, she had an image of an individual in her mind but when they appeared before her the person bore no resemblance to the person portrayed in the report and that it was as if the report had been written by somebody completely different. She had also encountered cases where examining doctors had insisted that the claimant sign their medical report without having been allowed to see it.

After being told that most people with chronic conditions want to concentrate on the things they are able to do and found it very hard to describe what they could not do, some of which they found embarrassing to describe, Dr Rayner said that people must leave the tribunals procedure with their dignity intact. They were exercising their right to an appeal and the tribunals system should act as a safety net for those who have been incorrectly assessed.

Dr Rayner was asked whether the system was coping with its current workload, and whether it would cope in the future as claimants were migrated from incapacity benefit to employment and support allowance (ESA). Dr Rayner replied they were not currently coping which was why they have just appointed 200 new doctors. Their workload had increased. They used to work at 250,000 appeals a year. That had now risen to 500,000 appeals a year following the introduction of ESA.

Dr Rayner referred to the chamber's president's report, which stated that the most common reason for overturning a decision is additional evidence: most commonly verbal evidence from the claimant.

When asked whether there were any specific concerns about Atos reports Dr Rayner said not, although they did struggle with the standard of some of the medical reports. Some of the recorded information was untrue and claimants denied making some statements.

When asked whether feedback forums could be held between members of the chamber and patient groups, Dr Rayner said that it would be difficult to maintain judicial independence. Doctors were bound by the rules laid down by Parliament and could not use clinical judgement. The DWP had complained that the tribunal service had become part of the benefits culture and needed to be reminded that work is actually beneficial to most people. Her personal view was that it would be helpful for doctors in the Chamber to be allowed to exercise clinical judgement.

Dr Rayner reported that the number of appeals being heard had doubled in recent years from 250,000 to 500,000 and that they were having to take on 200 extra doctors to cope with the increasing workload. Around half of all decisions were overturned and the most common reason was additional evidence, most commonly verbal evidence from a claimant. And sometimes this evidence bore no resemblance to the person portrayed in the medical reports relating to the claim.

Copy of full minutes on the Forward ME Group website: http://www.forward-me.org.uk/26th%20january%202011.htm

ANNEX B: Example of a fatigue scale

The Fatigue Severity Scale

The Fatigue Severity Scale can be used to monitor change in fatigue over time or in response to therapeutic interventions. Patients are asked to respond to each statement on a scale of 1 to 7, with 1 indicating “Strongly Disagree” and 7 indicating “Strongly Agree.”

Statements:

1. My motivation is lower when I am fatigued.
2. Exercise brings on my fatigue.
3. I am easily fatigued.
4. Fatigue interferes with my physical functioning.
5. Fatigue causes frequent problems for me.
6. My fatigue prevents sustained physical functioning.
7. Fatigue interferes with carrying out certain duties and responsibilities.
8. Fatigue is among my three most disabling symptoms.
9. Fatigue interferes with my work, family or social life.
10. Score = Sum of responses divided by 9. Higher score indicates higher fatigue levels.

Krupp LB et al. The Fatigue Severity Scale: Application to patents with multiple sclerosis and systemic Lupus erythematosus. Arch Neurol. 1989; 46:1121-3.

ANNEX C: Example of a pain rating scale

McGill Pain Questionnaire and Pain Diagram

Available at http://www.health-sciences.ubc.ca/whiplash.bc/pdf/mcgill1.pdf

Appendix IV (i)

SHORT FORM McGILL PAIN QUESTIONNAIRE and PAIN DIAGRAM

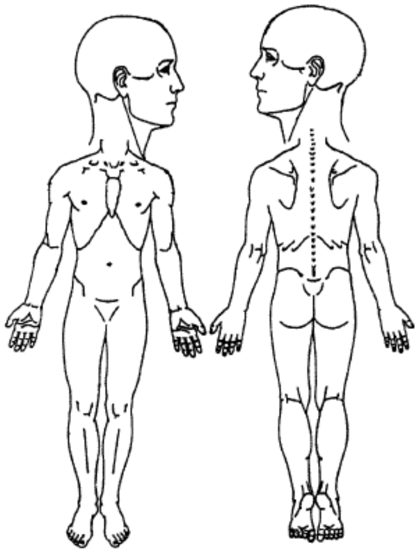
(Reproduced with permission of author © Dr. Ron Melzack, for publication and distribution)

Date: ______________________________________

Name: _____________________________________

Check the column to indicate the level of your pain for each word, or leave blank if it does not apply to you.__

		Mild	Moderate	Severe
1	Throbbing	_____	_____	_____
2	Shooting	_____	_____	_____
3	Stabbing	_____	_____	_____
4	Sharp	_____	_____	_____
5	Cramping	_____	_____	_____
6	Gnawing	_____	_____	_____
7	Hot-burning	_____	_____	_____
8	Aching	_____	_____	_____
9	Heavy	_____	_____	_____
10	Tender	_____	_____	_____
11	Splitting	_____	_____	_____
12	Tiring-Exhausting	_____	_____	_____
13	Sickening	_____	_____	_____
14	Fearful	_____	_____	_____
15	Cruel-Punishing	_____	_____	



Mark or comment on the above figure where you have your pain or problems.

Indicate on this line how bad your pain is—at the left end of line means no pain at all, at right end means worst pain possible.

No Pain	______________________________________	Worst Possible Pain

S	/33	A	/12	VAS	/10

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[i] Visceral Pain by Fernando Cervero. The Wellcome Trust