



# BRAME

*Blue Ribbon for the Awareness of Myalgic Encephalomyelitis*

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### **PERSONAL INDEPENDENCE PAYMENT:**

### **SECOND DRAFT OF ASSESSMENT CRITERIA**

### **RESPONSE TO PIP: ASSESSMENT THRESHOLDS AND CONSULTATION**

#### **General**

PIP must learn from past experiences, and be a benefit, which has a claim, assessment, and decision process, which is fair and accurate, looking at all the evidence, including personal medical and supportive evidence, which should be given at least equal weighting, to enable a correct and fair decision to be made and awarded the first time.

Not everyone can, or will ever be able to lead '*a full, active and independent life*', a phrase I have seen in some PIP documents. This is a very insensitive statement, for those with chronic illness/disability, with an incurable condition, and poor prognosis/terminal condition, as '*a full, active and independent life*' will never be achievable. People living with chronic illness/disability, do try to stay positive, and try to think of what they can achieve, for their own dignity, but they have to also accept the reality of their condition(s), which the DWP must also accept.

You are still not asking the right questions, or allowing a person to inform you of the full extent of the problems, and difficulties, which they have to face, and endure, during their 24/7 existence of living with long term chronic illness/disability. Living with complex long term conditions (LTC), for most, has an overwhelming impact on their daily lives, and asking people to tick just one box in each category is extremely difficult for them to do, especially when most of the questions do not encapsulate many of their disability problems – many will not fit in a single tick box – it also does not allow DWP to capture the overwhelming illness impact on a person's daily life.

Those living with the neurological condition Myalgic Encephalomyelitis (ME), 25% of the estimated 250,000 people with ME, are severely or very severely affected. This group can have a prognosis of less than 2% improvement, when they have been severely affected for more than 5 years (CMO Report on ME/CFS Jan 2002) – this needs to be recognised by the DWP, and their assessors and decision makers, when they are making decisions, not only on the level of the awards, but also the length of the award eg indefinite/long term. If cases like this are to be reviewed in the future, then rather than putting a chronically ill person through a full assessment, a report from their specialist/GP should be accepted by DWP, if their situation has not improved. This is relevant for all chronic long term conditions.

Within each section there needs to be an ‘extra information box’ where people can give extra explanation to how their condition impacts on their daily lives, or explain that 2 answers are equally valid for them. This information must then be taken into consideration in the assessment, and be valid for being awarded points towards their total.

In all the questions you need an extra box to state ‘cannot do any of the tasks **without assistance**’ as it goes directly from doing some tasks with assistance, to ‘cannot do any of the tasks’, and you can only tick one box. Many living with chronic illness/disability would rather the dignity of saying they can do the tasks with assistance, than say they can do nothing, and this should score equally.

The DWP must insure that the assessor provides the claimant, at the beginning of the assessment, with a hard copy of the assessment questions and options (this could be without their relevant assessment valuation scores) so that the claimant has a written copy to refer to, throughout their assessment, of the questions and their options, and the extra information such as the 50% rule, and clear explanation of interpretations and meaning of phrases, which at present are hidden within the regulation document eg reliably; in a timely fashion; repeatedly and safely (annex A 7.4) – these descriptors need to be highlighted and handed out to the person before the assessment, similarly the descriptors for simple meal, grooming, bathing etc, as not everyone would go searching for them. This would allow the claimant to understand, and identify, more accurately the category that applies to them. By having these to refer to, would also enable those with cognitive, or communication difficulties, to understand and follow the assessment more clearly – of course alternative formats should always be made available eg large print, Braille etc. Certainly people with ME, who suffer from cognitive dysfunction, chronic pain throughout their body, as well as a multitude of symptoms, and of course overwhelming fatigue, would find the process very hard to follow, and would find such handouts of descriptors helpful to refer to.

It is also possible that some assessors, given past experience by claimants, may not give all the options, when asking a question, nor adequately or fully explain them, thereby leading to misvaluation and subsequent appeals. Whilst we appreciate assessors have limited time, it is important that claimants be allowed adequate time, for that individual, to read and fully understand the questions. The erroneous practice, which does still go on today, of assessors making people sign the forms, without allowing the claimant to read them, or saying they will fill in some sections later, must end, including the threat of assessors/visiting officers saying ‘if you do not sign now, we will not process your claim’. People already do not trust the DWP, or the assessors, because of this practice.

There is still no questions to identify those who need 24/7 care, sleep dysfunction/reversal, night time needs/support. Those most chronically ill/disabled are often the most vulnerable group of people, and often need 24/7 care and support, this includes those who have a poor prognosis, and/or are terminally ill. Their needs are not always about giving therapies, but just providing personal care, support, reassurance and comfort, as well as medication and monitoring – nowhere do the questions try to identify, or address, the needs of these most vulnerable and chronically ill/disabled individuals. Each individual illness journey is just that – individualistic – and whilst we appreciate the DWP’s difficulties – people do not always fit in a single tick box! Many of these points are valid for people with ME

It must also be noted that night time care is much more expensive than day time care, and if being provided by a relative, or friend, has a great impact on the carer and their health.

Need to explain clearly, at the beginning of each question, the 50% or more days of being affected for each 'activity' for those living with fluctuating conditions, and what supportive evidence those with fluctuating conditions need to produce.

It needs to be clearly explained that the claimants have to be able to manage to do the task for more than 50% of the time. We need reassurance that assessors will clearly explain the guidance and criteria they have, and we assume that 'an activity descriptor is generally deemed to apply if the disabling effect applies, at some stage of the day, on more than 50 per cent of days' and '...the one (descriptor) applying for the greatest proportion of the time should be chosen', will be clearly explained to the individual – and at every question throughout the assessment.

### **Q1 – What are your views on the latest draft Daily Living activities?**

Please also refer to comments/feedback made in the general section at the start of this document.

The 3 new activities included: Communicating; Engaging Socially; and Making Financial Decisions, each of these groups of questions will certainly give information on different aspects of difficulties that people with disabilities face, and impact on their daily activities.

However under Communicating 'd' and 'e' can have **equal weighting** for someone, and also are indicative separately of **both a physical difficulty, and cognitive dysfunction**. How can someone be asked to choose just one? It is also unhelpful to provide/give an accurate assessment of the impact of a person's condition on their daily living activities. Cognitive and physical difficulties are both relevant for people with ME

What happens if a person's aid/equipment, which enables them to perhaps be awarded a '2' rating breaks, and they cannot afford to replace it, are they going to have to go through the whole assessment process again, or would there be a fast-tracked brief reassessment? This is equally relevant for other categories, where a low rating relies on a person being able to afford to keep/repair a piece of equipment/aid.

As with all the questions there needs to be an added 'extra information box' where people can give extra explanation to how their condition impacts on their daily lives, or explain that 2 answers are equally valid for them. This information must then be valid for being awarded points towards their total.

### **Q2 – What are your views on the weightings and entitlement thresholds for the Daily Living activities?**

Please also refer to comments/feedback made in the general section at the start of this document.

One assumes this 'activity' includes the majority of the time/50% of days, and will be included at the beginning of the question, and clearly explained before asking the questions, as again chronically ill/disabled people cling on to any fragment of independence they have, however small or brief it is.

### **1 – Preparing food and drink:**

Appreciate this section is about preparing food and drink, but nowhere do you ask how the person purchase the food and drink, how do they manage to get their food/drink/groceries? If they are unable

to shop, or have no-one to do it for them, they would have nothing to eat or drink. Not everyone has a computer, (it has been stated that 48% of disabled people do not have a computer – and even if they did many would not be able to afford the cost of broadband), so are unable to do their shopping on-line, whilst many disabled people do not have a bank account or credit card they actively use, and some do not have one at all.

There can be physical fatigue and cognitive dysfunction not only in preparing meals, but in planning and budgeting, accessing cash - ie from bank/post office - to do shopping – again many who are house/bedbound, and have multiple carers, prefer giros. There is also the need and extra cost of special dietary requirements, food intolerances, planning and cost of managing a balanced and healthy diet. Some people may need assistance in managing a healthy diet eg too many fatty/sugary foods, portion size etc.

You cannot prepare a meal if you have empty cupboards and fridge/freezer, as you have no supplies in the home. Nowhere in the assessment does it ask:

- if you can prepare a shopping list
- are you able to go shopping for food and basic groceries
- are you able to select healthy foods
- do you need help and assistance to get provisions
- do you need help and assistance to store provisions appropriately eg fridge/freezer – raw meat from cooked - monitor food not out of date etc
- do you depend on someone else to go and buy your basic food and provisions
- do you depend on official carers to come in, which includes providing meals - which again official carers are only able to make sandwiches or microwave a ready meal, as they no longer prepare meals for people.

This information is about basic human needs and the reality, and yet they are not identified, or addressed, in this assessment, and yet it can impact on their quality of life and nutrition, which will then impact on their general health and well-being.

Whilst there are some chronically ill/disabled people who will clearly never be able to do a task for themselves, there are some who may be able to get themselves a drink, or heat a microwave meal, if it was got in for them, on perhaps a handful of days a year, but reading the last assessment criteria – ‘g’ – ‘Cannot prepare and cook food and drink at all’ would be honest and say that they could on occasions. This is a problem you have with those living with long term conditions (LTC) who are so disabled, that they cling on to any fragment of ability, or however rare the ability to do a task is. The reality is that they may never know when that odd hour may come, or may still need supervision in case they get in difficulty.

It needs to be clearly explained that they have to be able to manage to do the task for more than 50% of the time. We need reassurance that assessors will clearly explain the guidance and criteria they have, and we assume that ‘an activity descriptor is generally deemed to apply if the disabling effect applies, at some stage of the day, on more than 50 per cent of days’ and ‘...the one (descriptor) applying for the greatest proportion of the time should be chosen’, will be clearly explained to the individual – and at every question throughout the assessment.

People applying for the benefits need to be clearly informed, by both the DWP and the assessor, and to be handed a copy in writing, what is meant by the 50% rule, and what the DWP classes as a simple meal (Interpretations page 11 of PIP 2<sup>nd</sup> Draft Assessment Regulations 2011) in which you state that a simple meal is “a cooked, one course meal for one using fresh ingredients”. Does one assume therefore, that this is only one meal per day for the claimant, prepared and cooked from fresh

ingredients – this is not one course per meal sitting ie breakfast, lunch, dinner, - this is not a ready meal bought in, or a meal prepared by another person, for the claimant to heat up in the oven/microwave – as it is not a simple meal prepared/cooked by the claimant themselves from fresh ingredients. If our assumptions are correct, and how the regulations at present interpret themselves as, then this needs to be made very clear, so that a person can accurately answer the questions you are asking.

Feel **there needs a further question, valued at 6**, to identify those who may be able to heat/microwave a ready meal, or meal, which may have been prepared and left for them eg for lunch, but needs to have breakfast and evening meal prepared and cooked for them. This again would be the reality for many, who have a partner caring for them, who also had to go to work to keep a roof over their heads, whilst the person who is unwell is left in bed, or on the sofa, managing just to get themselves to the toilet when needed, and make/heat their meal when able.

Others have no family or formal carers. People are expected to have breakfast, lunch and evening meal a day, as well as drinks, whether hot or cold. Nowhere do you ask, if you can manage to prepare one meal, would you be too exhausted, or the impact of the effort would mean the person is unable to prepare a second meal that day, even if a sandwich, or heat a tin of soup, for tea, or the cumulative effect of the activity would be incapacitating. One assumes if this is the impact on a person, for more than 50% of the time, the answer would be ‘g’ cannot prepare food and drink at all.

So much depends on the assessors explaining the questions clearly when they are asked. Assessors need to ask further questions about ability to repeat the task every day, and number of times in the day, and whether assistance is needed all of the time, or some of the time – ie reliably; in a timely fashion; repeatedly and safely (annex A 7.4) – these descriptors need to be highlighted and handed out to the person before the assessment.

Nowhere does it acknowledge those who are chronically ill, disturbed sleep pattern, sleep dysfunction, sleep reversal, where they may want their meal during the night at 3 or 4 am, as that is the time they are awake and hungry/thirsty, or some may only be able to eat small amounts, ie little and often, and may also need nourishment/drinks during the night. Others with eg constant nausea, or other symptoms, may need food and drink provided for them at any time within the 24/7 period, when they feel they can tolerate it. Again the complexity of living with chronic conditions, especially where full 24/7 care is needed, does not seem to be acknowledged or addressed, and will lead to the most chronically ill/disabled not scoring accurately in relation to their needs.

Of course there is also the need to buy other essentials like toiletries, sanitary wear etc, plus clothing and footwear which is not being taken into consideration.

All of the points raised here are particularly relevant for people with neurological ME, especially those who are moderately and severely affected with sleep dysfunction, pain, overwhelming fatigue and the characteristic delayed impact, cognitive dysfunction, orthostatic intolerance, special dietary needs and food intolerances, and would need help of a carer to do all the tasks for purchasing and preparing food and drink for them, at any time 24/7.

## **2 – Taking nutrition**

Please also refer to comments/feedback made in the general section at the start of this document.

Again one assumes this ‘activity’ includes the majority of the time/50% of days, and will be included at the beginning of the question, and clearly explained before asking the questions, as again chronically ill/disabled people cling on to any fragment of independence they have, however small or brief it is.

Again there is no acknowledgement or recognition of those who may need nutrition during the night, need 24/7 care, as highlighted under preparing food and drink

In the past I have personally experienced having to feed and administer medication, using syringes through a PEG system – directly into the stomach – and then flushing through, it takes time, needs training and care, and I would have thought that this level of responsibility, and time, of someone having to administer nourishment in this way, should score 10.

Is ‘e’ just connecting a food bag for eg overnight feeding and making sure the equipment is working OK, or having to fully feed in the way I have just described by using syringes through a PEG.

It has to be taken into consideration motivating someone to eat and drink, especially those with chronic health problems eg neurological conditions, especially where swallowing and choking become problematic, and apart from the fear factor, food and drink can go into the lungs, leading to chest infections and pneumonia – this is equally true for those who have respiratory and cardiac conditions where breathing is very difficult, and can cause the same problems.

Many conditions also result in chronic pain and/or constant nausea, which also leads to a lack of appetite, and the need for carer(s) to tempt/motivate them to eat and drink. Many conditions also result in people only being able/needing to eat and drink little and often, as that is all they are able to tolerate.

All of these points are relevant for people living with ME, including problems with tolerating food and drink, and some will lose the ability to swallow, or are so exhausted, they have no strength left to manage to eat, and so are tube fed.

Motivating and tempting people to eat and drink is equally relevant for those with mental health conditions, dementia, and of course those with eating disorders. It is also important to encourage healthy food choices and appropriate portion size.

### **3 – Managing therapy or monitoring a health condition**

Please also refer to comments/feedback made in the general section at the start of this document.

Again one assumes this ‘activity’ includes the majority of the time/50% of days, and will be included at the beginning of the question, and clearly explained before asking the questions, as again chronically ill/disabled people cling on to any fragment of independence they have, however small or brief it is.

Feel very strongly there is a category of patients omitted here, as in no way do the criteria grading allow for the many people with severe and chronic health conditions, many of which are incurable, and the only mention of monitoring is in an almost derogatory way and given 0 or 1 point. Often it is essential that these people are not left alone, or need assistance/supervision for the majority of the time to monitor their health and well-being. This is certainly true for those severely affected with ME

There is still nothing about constant/on-going monitoring of a person’s health or needs, or making sure they are safe, cared for, and supported. For chronically ill/disabled, and/or terminally ill – some may have only very basic medication – some may not have any treatment/therapy, and for some conditions there are none – some may have difficulty with breathing and/or choking - these most vulnerable individuals still need their health condition monitored and symptoms managed, or just need to have TLC, support, reassurance and understanding to help them cope from hour to hour, day to day, 24/7.

There is still nothing included about night time care, or sleep dysfunction, which is common for many with chronic health conditions – including ME. This is not being acknowledged or identified for this vulnerable group. Many people will have to pay extra for night time care, which again is not being taken into account.

All of these points are equally true for those suffering from dementia/alzheimer's, and can also be true for those with chronic mental health conditions, severe epilepsy, and autism, there is so much more to a person's care, monitoring, and needs, than being given medication/therapy for their condition.

Only 'a' and 'b' asks about monitoring a health condition – this should be included in all sections, and so should be added to 'c, d, e, f'. Those with the most chronic conditions need constant monitoring and /or 24/7 care.

**24/7 care, of someone chronically ill/disabled, is just that. There must be another box added in this section 'g' to identify this most vulnerable/complex/disabled group and should score the maximum 8 points – if they did not get this amount of monitoring and care, then their health would deteriorate, it could be a danger for them, or others, or may well be life-threatening.**

In its current form these questions and grading would actually ignore these most vulnerable, chronically ill, and possibly terminally ill people, and the care and monitoring they need. This needs to be **urgently addressed, and a new point 'g' added and given the highest grading**, as these people would need the highest level of monitoring of their care and health condition.

Having cared for someone with severe ME, and needs full 24/7 care, for almost 30 years, and having given end of life care to relatives and friends with various cancers, and family with heart disease and COPD, and more recently dementia, I feel very strongly that DWP are failing in not acknowledging and identifying the level of monitoring and care such chronically ill/disabled people need 24/7, to make sure they are cared for, their condition monitored, and they are kept safe and reassured.

#### **4 - Bathing and Grooming**

Please also refer to comments/feedback made in the general section at the start of this document.

Again one assumes this 'activity' includes the majority of the time/50% of days, and will be included at the beginning of the question, and clearly explained before asking the questions, as again chronically ill/disabled people cling on to any fragment of independence they have, however small or brief it is.

The interpretation of *'bathe' (p10) means clean one's torso, face, hands and underarms* obviously to bathe or wash oneself – as far as DWP is concerned - the lower body does not exist once again! The lower body is often the most difficult part of the body for anyone with a disability to wash/care for and probably most needed for hygiene – trying to reach their extremities, they need more assistance, or there is a risk of over-balancing and falling - this must be added, and taken into consideration and weighted accordingly.

How do you grade grooming if someone can manage 2 out of 3 of the tasks eg can brush hair, clean teeth, but not wash their hair? Again questions are not asked, to identify how often they are able to achieve this, or have difficulty managing to do these tasks – for anyone struggling to live with chronic illness/disability, in reality these may well not be daily activities as many may suppose, as they find it far too difficult and/or exhausting to do them, or are unable to tolerate it, due to pain/discomfort, to bathe or groom, or the impact it has on them. Or is it going to be very clear in writing, as well as verbally in a face-to-face assessment, at the beginning of every question, that these tasks have to be achievable for a person on more than 50% of days?

Grooming should also include cutting of finger/toe nails. Why is shaving not included in this section, as this is part of daily/regular grooming for men and should be included? It must be added, as this can be a real problem for men who are chronically ill/disabled, including neurological conditions such as MND, MS, Parkinson's, ME, and many other conditions.

People with ME find it very difficult to manage washing, cleaning their teeth, brushing their hair, with those who are severely affected unable to do these tasks, and many find they are unable to tolerate a carer doing this for them either, as the constant intense pain, and extreme sensitivity to touch, makes it intolerable.

## **5 - Managing Toilet Needs or Incontinence**

Please also refer to comments/feedback made in the general section at the start of this document.

Again one assumes this 'activity' includes the majority of the time/50% of days, and will be included at the beginning of the question, and clearly explained before asking the questions, as again chronically ill/disabled people cling on to any fragment of independence they have, however small or brief it is.

Constantly raise the issue that menstruation is never included here, as this is equally difficult for menstruating females, they need help and assistance to toilet and clean themselves for their bleeding, help to get clean clothes and underwear, and dispose of soiled sanitary wear. Menstruation should be included in this section – are people writing this document who are too embarrassed to mention it?

Menstruation results in having to clean the person, or assist them with this, get new sanitary wear, clean underwear, clean night clothes, and change soiled bedding. Once the person has been cleaned and had clean clothes, the bed has to be remade with clean bedding, the person settled back in bed, and soiled clothes and bedding put in to soak. The need to strip and remake the bed could happen 3 or 4 times in a 24 hour period. The need to help and assist with toileting and changing sanitary wear, cleaning/freshening themselves, and clean underwear would be on-going day and night for days, weeks, or months in some cases, where they have menstrual problems.

As a PIP IDG member, I made this point very strongly to the Policy Team on 6 December 2011, and again on 25 April 2012, at PIP IDG meetings. It is essential that another grading is added here for menstruation, or it is added to point 'e' and 'f'. Menstruation can require equally as much help and support, especially for those chronically ill young women/ladies who suffer from heavy menstruation, and/or continual heavy bleeding for weeks/months at a time.

In fact there is nothing to mention the practical help that is also needed, whether for incontinence and/or menstruation, to deal with soiled clothing/bedding – changing/soaking and washing bedding etc – this is the reality – it does not do itself. Are we to assume this is all supposedly embraced under 'needs assistance, or cannot manage'? How do you assess the amount, and extent, of the help and assistance someone needs? It is all down to interpretation!

Again there is no acknowledgement or recognition of those chronically ill/disabled people who need help/assistance to do these tasks in the night and need 24/7 care, and/or have greater frequency in the night, this needs to be addressed.

Nowhere do you ask about the help needed to actually get to the toilet. 'b' only talks about 'aids' for some chronically ill people, however they may not be able to support their own bodies, and so often they are physically supported, by their carer, not only to get to the toilet/commode, but also whilst on the toilet/commode. Again this is not acknowledged or addressed, and needs to be added.



Obviously there can be more problems if out, in finding a disabled toilet, that is working and clean, as well as having the aids that are needed. The number of disabled toilets that we have tried to get in, which are actually not big enough to accommodate a wheelchair, or have been used and abused by others, and are therefore unusable.

Again all of these points are relevant for people with ME, especially the severely affected.

## **6 - Dressing and Undressing**

Please also refer to comments/feedback made in the general section at the start of this document.

Again one assumes this 'activity' includes the majority of the time/50% of days, and will be included at the beginning of the question, and clearly explained before asking the questions, as again chronically ill/disabled people cling on to any fragment of independence they have, however small or brief it is.

Again there is no acknowledgement or recognition of those chronically ill/disabled people, and those with sleep dysfunction, who need help/assistance to do these tasks in the night, and need 24/7 care, this needs to be addressed.

The dressing of **upper and lower body should at least be equal weighting**, although we believe that there is more difficulty in trying to dress/undress the lower body, and trying to reach their extremities, they need more assistance, or there is a risk of over-balancing and falls/injury etc, and yet you have weighted this less than the upper body - this must be weighted accordingly, and at least be a 4.

**Need an extra box 'g' 'Cannot dress or undress upper and lower body without assistance' and should be weighted the same as 'f' and score 8.**

In all the questions you need an extra box to state 'cannot do any of the tasks without assistance' as it goes directly to 'cannot do any of the tasks' – eg again with dressing can only tick one box, whereas if a carer gave assistance to help dress upper and lower body eg could hold a blouse or shirt for an arm to go in, and do buttons up, or put trousers on so far, and enable the person to pull them up, but they could not manage any of it alone. Again chronically ill/disabled people cling on to any fragment of independence they have, however small or brief it is, and will try and feel they still have some dignity, and will not admit how much help they need. This answer would be more acceptable/reflective for some people with LTC, and should then be weighted the same as not able to do it at all – as this would be the situation if they did not have any assistance/help/care/support. Whereas, some people, may be eg paraplegic and unable to do anything at all.

Dressing/undressing should also include socks and shoes, and also to tie shoe laces.

Assistance or prompting to select appropriate clothing (c-ii) one assumes could include appropriate for the weather, or circumstances eg if going out, but also if clothes are clean, or in need of repair.

Nowhere is there a question to ask if the person is able to launder their clothes, as well as ability to dry them, as they may not have, or are unable to use a washing line - whether they have, or able to use a tumble dryer – impact of wet washing hanging in their home on their health – or the ability and safety of using an iron. All of these points are difficult, and a reality, for chronically ill/disabled people.

All of these points are again valid for people with ME, and those who are severely affected often have a heightened sensitivity to touch, and so find clothes on the body can cause pain, or have to wear clothes that are very soft on the body, but most who are severely affected are bedbound for the vast majority of the time.

There is also the need for all the above and prompting and assistance for those with mental health conditions, and those with dementia/alzheimer's

## **7 - Communicating**

Please also refer to comments/feedback made in the general section at the start of this document.

Again one assumes this 'activity' includes the majority of the time/50% of days, and will be included at the beginning of the question, and clearly explained before asking the questions, as again chronically ill/disabled people cling on to any fragment of independence they have, however small or brief it is.

There needs to be a real acknowledgment or recognition of those with cognitive dysfunction, who find it difficult to understand complex/simple information without assistance, and have difficulty in remembering what has been said.

These problems are certainly the overwhelming experience of people with ME, if and when they do try to communicate, and they need to be constantly monitored, as their bodies will suddenly become overwhelmed by the illness impact, and will need to be got back to bed as quickly as possible, and the communication stopped. Many with ME find even the briefest of conversations on the phone, or face to face, again overwhelming on their body, and it is physically and cognitively exhausting for them, and will take them some time/days to recover again.

The parts of the brain which deal with communication will be different for writing, as it will be for speech, so again, by asking for one box to be ticked, it is not acknowledging the breadth of cognitive/communication impairment. This is not enabling a full and holistic picture of someone's abilities, by asking them to choose between different things, and to tick one box, when both are different, and equally, applicable eg 'd'- *'needs assistance to access written information'* and 'e' – *'needs communication support to express or understand complex verbal information'*.

**Again need an extra box to say 'need help and assistance with both written and verbal information' – to score eg 6 to 8.**

There are many conditions which could lead to needing communication support eg many neurological conditions, stroke, dementia/alzheimer's, mental health problems etc. with many of these conditions it is just not understanding, but the cognitive ability of processing and remembering information. This support will mostly be given, for the majority of the time, and/or 24/7, by a family member, friend, carer.

## **8 - Engaging Socially**

Please also refer to comments/feedback made in the general section at the start of this document.

Again one assumes this 'activity' includes the majority of the time/50% of days, and will be included at the beginning of the question, and clearly explained before asking the questions, as again chronically ill/disabled people cling on to any fragment of independence they have, however small or brief it is.

There is a physical and social overlap here for those who are chronically ill/disabled, who are bed/housebound, and so have little or no social contact. They will need much assistance if this occurred, as well as physical, and practical support to manage to leave the home and the journey, they will probably need help, and emotional support, to engage socially. They will probably also have

cognitive dysfunction which would cause difficulty in them understanding exactly what is being said/explained to them, and also for them to make themselves clearly understood. If there is a lot of noise, many people talking at the same time, would make it difficult for them to cope, and to comprehend what is being said to them, due to their impaired cognitive function. It is explained as being like an overload of information, and the brain just closes down, and they are unable to comprehend or understand what is being said to them, and feel unable to formulate a response, and just need complete quiet.

These problems are certainly the overwhelming experience of people with ME, if and when they do try to communicate, they need to be constantly monitored, as their bodies will suddenly become overwhelmed by the illness impact, and will need to be got back to bed as quickly as possible, and the communication stopped. Many with ME find even the briefest of conversations on the phone, or face to face, again overwhelming on their body, and it is physically and cognitively exhausting for them, and will take some time/days to recover again. The impact of this is felt by the whole family, as it often leads to being unable to have family or friends to visit, as the person who is ill, even if in bed, cannot tolerate the sound of people in the home.

There is also the concern where chronically ill/disabled, who are bed/housebound, and so have little or no social contact, try to go out and interact with people, especially in a social situation, as they often do not have the ability, or experience, to judge people's intentions, or read body language. They can be extremely vulnerable to abusive attitudes and comments, which may be blatant, or subtle, and they would find it very difficult to cope with, or know how to react, other than wanting to leave – that is if their carer has stayed with them. They are also vulnerable to people who may be very nice to them, and as they have no, or no recent, life experience, they become trusting, and can then be open to abuse in a different way.

It is not only those with mental health problems that can have difficulties in engaging socially.

Many with chronic illness/disability will need constant support, and indeed monitoring of their condition, and assistance if and when necessary, to even attempt any social interaction, this is not picked up in 'd', and should be included. Eg **'overwhelming impact/exacerbation of symptoms/condition'** and should **score 8**.

## **9 - Making Financial Decisions**

Please also refer to comments/feedback made in the general section at the start of this document.

Again one assumes this 'activity' includes the majority of the time/50% of days, and will be included at the beginning of the question, and clearly explained before asking the questions, as again chronically ill/disabled people cling on to any fragment of independence they have, however small or brief it is.

Again there is no acknowledgement or recognition of those chronically ill/disabled people who need help/assistance to do these tasks, and this needs to be addressed.

There are many chronically ill/disabled people who are very ill, in chronic pain, and experience cognitive dysfunction, who will find it very difficult to deal with their financial affairs, but for their own peace of mind, and dignity, would still wish to do so – or have no-one else they can trust to do so – but will need help and assistance to achieve this. This is different to those who have no physical or mental capacity to deal with financial affairs.

There is an enormous difference between 'prompting' someone to make a financial decision in 'b' and 'c', and 'd' 'cannot make any financial decision at all'. There certainly needs to be another box added here eg **'cannot make financial decisions without help/assistance' – and should score 6**.

Many people will need more than prompting to make financial decisions, they will need actual assistance to help them make a decision, and then assistance to carry that decision out. So whilst they have been assisted/helped, and involved in the process, and made the final decision, they may well be unable to carry it out, eg paying the bills, contacting companies, phone calls, writing letters etc.

Therefore there needs to be extra criteria added here, between prompting and not able to do it at all, eg:

- **Need assistance to make/carry out simple financial decisions/transactions**
- **Need assistance to make/carry out complex financial decisions/transactions**

There is another group here, which has not been acknowledged or recognised, and that is chronically ill and disabled adults who are cared for within the family home, so they will probably not have to make simple, or complex financial decisions about the home, but would find it very difficult to do so, and would need a lot of help and assistance, if it became necessary for them to deal with financial decisions and transactions eg carer/family member becoming ill or dying.

The points made here are again relevant for people with ME, where physical and cognitive problems would make this process difficult, and would need someone to help them deal with financial matters.

### **Q3 – What are your views on the latest draft Mobility activities?**

#### **1 – Planning and following a journey**

Please also refer to comments/feedback made in the general section at the start of this document.

Again one assumes this ‘activity’ includes the majority of the time/50% of days, and will be included at the beginning of the question, and clearly explained before asking the questions, as again chronically ill/disabled people cling on to any fragment of independence they have, however small or brief it is.

At **c(i)** and **e(i)** need to add ‘assistance’, so it reads ‘supervision, assistance, prompting ...’ as many people with chronic illness/disability actually need assistance to move around, access places, ask questions etc, not just being supervised or prompted.

Appreciate the difficulties encountered by those with mental health problems have been addressed, but again there is no acknowledgement or recognition of those chronically ill/disabled people who need help/assistance to do these tasks, and this needs to be addressed. Supervision is hardly the same as needing the help and physical support necessary.

Also for those chronically ill/disabled people trying to make a journey, it will often have enormous and overwhelming impact on their health, and symptoms may well become exacerbated, and they will need to be accompanied, constantly monitored, and appropriate action taken, and/or medication given if necessary. They may suffer with chronic pain, find it difficult to sit, even in their wheelchair, suffer with nausea, dizziness etc. Once again this vulnerable group is not being identified and included here.

The PIP criteria continues to assume, albeit falsely, for many of those who are chronically ill/disabled, that it is all orientated around independence, but often fails to acknowledge, identify, and address the level of support and assistance that this vulnerable group of people need, and that for many they are never going to have the ability to do things independently, or only with a substantial level of assistance, and monitoring of their condition, to make sure they are safe and cared for.

Nowhere does this section cover whether a person is able to actually do a journey alone, know how to get around, nor take into account impaired spatial orientation for those using/confined to a wheelchair – ability to make turns/gaps, while judging distances. Also to be aware of dangers, eg traffic.

If using an electric wheelchair, not a ‘buggy’, extra awareness, care and supervision is needed, as if they hit an uneven surface, or slightly raised dropped kerb the wheelchair can tip backwards. Also they may well still need assistance/support to get in or out of the wheelchair, and to transfer to a seat or toilet, ask for ramps to access a building etc.

Also it does not address how often they are able to do a journey eg whether a person has the ability to do this day after day, once a week, only occasionally, or what impact doing such a journey has on them.

It is not just about planning a journey ie how you get from A to B, but how do they navigate the problems associated with your disability, and overcoming any physical eg steps, and/or emotional barriers, they may encounter. Nowhere does it ask about a person’s ability to book a journey and assistance, seat or wheelchair space, ramps etc. They also need to hear, and comprehend, any public announcements, and be able to find their way around, read and understand a bus/railway board etc.

This group is also more vulnerable, or certainly feel more vulnerable, to negative attitudes towards them, being approached by strangers, or fear of being taken advantage of, or attacked – also anxious of whether a journey will go ahead without mishaps – all of this can be helped by being accompanied by a carer/supporter they can trust.

Nowhere does it take account of if a journey is more complex, and the need to change buses, or train and bus journey, and finding your way around, and finding the correct next mode of transport. This is important both physically and cognitively. Understand you have been asked to change complex to unfamiliar journey, but we disagree as a complex journey may be familiar to you. May we suggest you put **‘unfamiliar and/or complex journey’** similarly **‘familiar and/or simple journey’**

It must be recognised that most rural areas have no accessible public transport to make a journey, and would need to take a taxi, which is a much greater expense, and if you have a wheelchair are immediately charged a surplus for the wheelchair. This should be taken into account with mobility awards.

All of the points raised here are relevant for people with ME, and those who are moderately affected would need help and assistance, but for those who are severely affected, if and when they ventured out, would need total help and assistance in every way, as physically and cognitively they would be unable to manage at all, and they would need a trusted carer to constantly monitor them, and be able to identify when the impact of the effort becomes overwhelming on their body, and make sure they are cared for, and got home safely. The severely affected would not be able to plan or follow a journey and would need constant help, monitoring, and supervision.

## **2 – Moving around**

Please also refer to comments/feedback made in the general section at the start of this document.

Again one assumes this ‘activity’ includes the majority of the time/50% of days, and will be included at the beginning of the question, and clearly explained before asking the questions, as again chronically ill/disabled people cling on to any fragment of independence they have, however small or brief it is.

Nowhere in this section does it ask if any of these mobility tasks, whether walking or in a wheelchair, can be achieved, without pain and/or discomfort, or has impact, or exacerbation of symptoms, due to

their efforts, or a delayed or cumulative effect. This is extremely important as it may mean, by struggling with mobility, that the impact on them means that they are not then able/well enough to cope with daily living activities, let alone if they could manage to repeat the 50 metres, 200 metres, or a journey, again for several days. This is certainly true for people with ME, with the characteristic delayed fatigue, and exacerbation of symptoms.

What is the length of time that DWP accepts as being able to walk 50 or 200 metres? Someone may be able to walk 50 metres, with or without an aid, but it takes a very long time, and is achieved with great discomfort, and has an impact on their health, and/or a cumulative effect, which would mean they could not repeat the task. This could include those with respiratory and heart disease who would be very breathless, as well as those with other physical impact/fatigue eg ME. How will this be graded?

Nowhere does it try to identify if the person is at risk of falls, or may fall occasionally or quite frequently, and are the falls indoors as well as outdoors – are they at risk of harm/danger? This is important and was always included in DLA. Many people may need the physical support of a carer or family member as the person may be at risk of falling, are dizzy, or have poor balance.

Identifying the difficulties people have with moving around indoors is equally as important as outdoors, and cannot be picked up completely, unless very incapacitated, in the daily living components.

The terrain can also cause problems, if there is a steep incline it will prove difficult for the person, and the carer if pushing a wheelchair, and also if trying to walk independently. The ground could be cobbles, uneven, or soft ground, all of which will cause problems, as do barriers such as steps, or lack of dropped kerbs.

Nowhere does it mention ‘danger awareness (such as traffic)’ or in fact spatial awareness. Spatial orientation is also applicable here– ability to make turns/gaps, while judging distances, as is the ability to recognise the dangers around them – this can be relevant both indoors and outdoors.

If using an electric wheelchair, not a ‘buggy’, extra awareness, care and supervision is needed, as if they hit an uneven surface, or slightly raised dropped kerb the wheelchair can tip backwards.

Nowhere are carers input/needs assessed eg has the person had to get an electric wheelchair, as the carer’s own health problems means they are no longer able to push them in a manual wheelchair. This is different to the person choosing to have an electric wheelchair.

Once again, as in daily living activities, also need extra boxes, to enable the person to give full information of a person’s abilities, limitations, and illness impact. People do not fit in your single choice boxes – these are individuals with an individual illness/disability impact on their lives.

All of these points are relevant for people with neurological ME due to the cognitive and physical impact of the condition.

#### **Q4 – What are your views on the weightings and entitlement thresholds for the Mobility activities**

Please also refer to comments/feedback made in the general section at the start of this document.

If the points/revisions we have made above at Q3, and in our general points, are included, then the weightings and thresholds seem to be OK, on the provision that people are not penalised, or weighted, as being more able, because they use an aid or wheelchair to enable them to get around.

There also needs to be a fast track reassessment safeguard put in place, so that if eg someone's wheelchair is broken, and they cannot afford to repair/replace it, this would have enormous implications on their mobility, and would probably mean they would then be house/bedbound, and have a greater impact on both their mobility and daily living activities, which would mean the points they would then be awarded would be higher.

#### **Q5 – What are your views on how the regulations work regarding benefit entitlement**

Please also refer to comments/feedback made in the general section at the start of this document.

Where do you start on this question? People do not fit in a single tick box. How can you truly assess the overall impact of chronic illness/disability when you are only allowed to tick one box with the 'descriptor' that applies most? People with chronic illness/disability often have very complex needs and their condition(s), and often multiple symptoms, will have enormous impact on their daily lives.

There are no questions about those needing night time care and/or 24/7 care, and the implications of this, their care and support needs, or indeed the extra cost of night care. Caring for someone with illness/disability is not just about giving medication/therapy, or putting a meal in front of them, at what DWP deem as set times. This is not the reality for most people, their care and support needs are at any time in a 24 hour period. The questions do not reflect this, or allow for the 24/7 overall care and support they need to be identified.

There are no extra information boxes with any questions to enable this information to be given – if these are included then it also needs to be included in the assessment, and points be awarded.

How these regulations will work is also so very dependent on the independent assessor, how they relate to the person, and their carer, their understanding of the person's condition(s), and whether they try to ask the right questions to ascertain the real impact of the person's condition.

As myself, and others in the PIP IDG continue to repeatedly feedback, the independent assessors should go through very thorough education and training, and at least some of these assessors should be trained to specialise more with eg neurological conditions, mental health, autistic, deaf and blind. These are the main conditions where assessors so often fail in completing an accurate assessment and/or leave the person traumatised by the whole process, due to their misunderstanding of their condition and/or insensitivity to its impact on their lives. This has to stop. Appropriate education and training should be introduced urgently for assessors and decision makers.

The information then goes to the Decision Maker (DM) who historically has always taken the independent assessors report as the main source to make their decision. Medical evidence from the person's consultant/GP/HCP and/or carer(s) who have known and cared for the person, often for many years/decades should be given at least equal weighting – not just lip-service that this will be the case.

The regulations must include these guidelines and safeguards, to enable a fairer and more accurate assessment and decision process.

Historically people with neurological ME have often been met with scepticism and disbelief of their condition by assessors for the DWP, who have often erroneously filled in the DWP forms and made people sign them without reading them, or say they will fill in sections later. People with ME are historically the largest, if not one of the largest groups of claimants, who are declined benefits, but the majority are successful on appeal.

A survey by the 25% ME group, a group representing those who severely affected by ME, ie those who are primarily house/bedbound, found that 59% of people severely affected with ME were

unsuccessful on their first attempt of claiming DLA, but 86% of those 59% of people with ME appealed, and 85% of this 86% were successful on appeal, usually with no extra evidence.

It also has to be recognised that there are very few specialists in neurological ME, and so the majority of people with ME have no specialist care, and this can also prove difficult for them to get specialist medical evidence to support their claim. This is not their fault, and people with ME should not end up being penalised for this. Assessors sometimes have a preconception/misunderstanding of a condition, such as ME, before they have even met a claimant, and this is often reflected in an inaccurate assessment report. This practice must stop and appropriate information, education and training should be given to assessors, and decision makers.

Myalgic Encephalomyelitis (ME) is classified by WHO ICD10 G93.3 as a neurological condition, as is the similar condition Chronic Fatigue Syndrome (CFS). Whilst there is no specific diagnostic test for ME and CFS, these conditions can be more accurately diagnosed by using the Canadian Consensus Guidelines and Clinical Criteria (2003) and the new ME International Consensus Criteria (July 2011). The assessors should be made aware of this in their education and training, and DWP guidelines also need to be reviewed urgently to reflect this.

#### **Q6 – What are your views on how we are dealing with fluctuating conditions**

Please also refer to comments/feedback made in the general section at the start of this document.

It is imperative that Professor Harrington's recommendations to ESA, and especially his report and recommendations for fluctuating conditions, are adopted and included. Any independent review of PIP needs to particularly look at the assessment of people with fluctuating conditions to make sure that PIP is being interpreted, used and assessed correctly, as PIP is a new introduction for DWP.

This is a good step forward to acknowledging those living with fluctuating conditions. It needs to be clearly explained to the person that it is relative to what affects them for more than 50% of the time.

4 (c) (iii) – pleased to see this included - that if, 2 or more descriptors are satisfied for periods, which when added together, satisfy over 50% of the days in the required period – the descriptor greater portion of time will be included.

However there can be problems, for those with fluctuating conditions, if someone has a relapse or crisis, and is severely incapacitated for 45% of the time and needs total support/assistance, and then is relatively well for 55% of the time, they would not be eligible under the proposed 50% rule – whereas someone else may be mildly to moderately affected for 55% of the time, needing some/occasional support, and is well for 45% of the time, and they would be eligible. There needs to be some understanding and flexibility in the system, for those who have more illness impact.

As with our response to other questions, once again for the majority, people do not fit into a single box, an extra information box would be helpful and should be part of the assessment, and awarding of points.

In any reassessment in the future if one symptom has become more prominent, and another box is ticked, DWP has no idea of whether the original symptom is still causing problems, or what overall symptoms/illness impact there is.

Again there is a need to ask about pain and impact of symptoms, can you repeat tasks, is there a cumulative effect? This would be the case for most living with ME.

All of these points are equally relevant for people with ME, which can be a fluctuating condition for many, although for the long term severely affected it usually fluctuates between being severely and



very severely affected, and who have a prognosis of less than 2% improvement, when they have been severely affected for more than 5 years (CMO Report Jan 2002) – this needs to be recognised by the DWP, and their assessors and decision makers, when they are making decisions not only on level of the awards, but also the length of the award eg indefinite/long term. If cases like this are to be reviewed in the future, then rather than putting a chronically ill person through a full assessment, a report from their specialist/GP should be accepted by DWP.

For those who are mildly, or mild to moderately affected by ME, as with other fluctuating conditions, the introduction of this section is welcomed, as it recognises that LTC will fluctuate over time, and to take into account the illness impact on over 50% of days. Also people with ME, if they manage to do a task will have an exacerbation of symptoms and illness impact, including the characteristic delayed fatigue of ME, meaning that the impact will increase over the coming days. So whilst they may be able to achieve a task during the assessment, they may well not be able to repeat it later, or on the following days due to the delayed impact. This needs to be taken into account.

Of course the DWP Guidelines on ME/CFS are very unhelpful and not reflective of neurological ME and CFS. Ever since we worked with DWP to revise these guidelines for 2 years, and then a guideline we could not agree on was published. We have repeatedly asked Ministers, and DWP, including Dr James Bolton, both orally and in writing, for these guidelines on ME/CFS to be urgently revised to truly reflect the reality of the condition, and its impact on people's lives, to no avail. The DWP ME/CFS Guidelines are unhelpful to the claimant, assessors, and the decision makers, and this needs to be urgently addressed.

#### **Q7 – What are your views on the definitions of ‘safely’, ‘timely’ ‘repeatedly’ and ‘in a timely’ manner?**

Please also refer to comments/feedback made in the general section at the start of this document.

These terms should certainly be included within the regulations, with their meanings/descriptions.

But it is imperative that the terms and their definitions should also be a combination of the following:

- within each part of a question
- included at the beginning of each question to say it will relate to each part
- the terms and full definitions should at least be included at the beginning of the document
- a separate sheet of the definitions, to be handed to the person, so they can refer to the definitions, when being assessed, to enable them to accurately answer the question.

Each of these terms will help to reflect the reality of living with ME, as people with ME, if they manage to do a task will have an exacerbation of symptoms and illness impact, including the characteristic delayed fatigue of ME, meaning that the impact will increase over the coming days. So whilst they may be able to achieve a task during the assessment, they may well not be able to repeat it later, or on the following days due to the delayed impact. This illness impact will be taken into account more with the inclusion of safely, timely, repeatedly and in a timely manner.

#### **Q8 – What are your views on the definitions in the regulations?**

Please also refer to comments/feedback made in the general section at the start of this document.

**Part 1** – Find the term ‘negative determination’ a very confusing, and very derogatory term – there could be many legitimate reasons why a person has been unable to contact you. Every effort must be made to contact the person.

**Part 5 (2)** – One month is far too short to get information. Often a person does not receive a letter until one week after the date on the DWP letter, which means one week is already lost. To get help and advocacy support to complete forms will take longer than a month, as most welfare rights officers (or similar advocacy help) have a waiting list of longer than a month to see anyone. Similarly to obtain any personal medical evidence, healthcare professionals will take longer than a month to get any information back to the person. This information needs to be kept together, so it does not get separated or lost. With DWP reassessing everyone at this time, means everyone's workload will also be much greater for the coming years. The time-line must be extended.

**13 – The prescribed date (3)** – Did not agree with the Secretary of State removing the 104 week rule, and reducing it to 52 weeks – a Long Term Condition (LTC) is just that long term, and crises and relapses will happen. Anyone with a LTC trying to return to work – or trying to gradually increase hours - with most never being able to manage full-time or regular part-time work, or those who can, may be fortunate enough to go more than 52 weeks without a major relapse. There needs to be an extra part to the regulation, whereby those trying to return to work, should be allowed the understanding and support that the 52 week rule is extended for a further 52 weeks, and so on. With the Government policy being that they want to support disabled people in/into work, this is very much a backward step reducing the 104 week rule to 52 weeks, and should urgently be reviewed.

#### **Q9 – Do you have any other comments on the draft regulations?**

Please also refer to comments/feedback made in the general section at the start of this document.

Once again there are no questions on night time needs/care, 24/7 care, and sleep dysfunction - this is a real problem for many with chronic illness/disability, including those with ME.

People do not all fit in a single tick box - there needs to be an extra information box at the end of every question to enable people to include the reality of the impact of their condition.

In any reassessment in the future, if a symptom has become more prominent than another, leading to a different box being ticked, the DWP will then have no idea whether the problems causing the original box to be ticked are still causing difficulties/limitations for the person, or indeed what the overall symptoms/illness impact is.

There must be greater consideration, understanding, and inclusion, for those who are most chronically ill/disabled, those with complex conditions, and those who have a very poor prognosis/terminally ill.

End of life is so often associated with cancer, and whilst these people obviously need special consideration, there are other long term conditions which lead to end of life, and degenerative conditions, eg neurological conditions, heart failure, COPD etc. With our own condition neurological ME, research has shown that people can die up to 25 years earlier (Jason et al) and also may be more at risk of developing cancer. Sadly there are well documented cases of young adults dying, some of whom are bedbound and tube fed, and ME has been documented on the death certificates. ME can become, especially for the severely affected, a multi-system, multi-organ illness.

It must be remembered and included in the PIP assessment and decision process that there are many people with conditions which are very misunderstood by the medical profession eg Myalgic Encephalomyelitis (ME), and/or those with medically rare conditions. Often these people have become abandoned in the community, with little or no medical care or support. There are some conditions, including ME, for which there are no definitive diagnostic tests, or any medical treatments that have yet been developed to help these people. They are left, along with their family/carers, if they have any, to manage their condition, to the best of their abilities.

These very sick and vulnerable people, and their carer(s), need a much more understanding, and sensitive, approach from an assessor, and the assessment process. They may also have problems obtaining independent medical evidence if they have no specialist in their condition.

We do not feel this document helps to identify the overall and overwhelming reality, and impact of their condition on their daily lives, for any of these groups, and therefore will not ultimately lead to correct levels of benefit being awarded, nor assessors/decision makers being able to gather all the information necessary, to make an accurate assessment of a person's true level of ability/disability. Having to tick one box is unhelpful.

It must be remembered in the assessment, and decision process, these people are often very sick/disabled, and vulnerable, and it is not their fault they have a condition, which has an enormous impact on their daily lives, for which science and research has not yet identified, or begun to find any answers, or any helpful medication/treatment, to help to manage their condition, and/or begin to improve their quality of life, as is the case in ME, as well as many other conditions, and this illness impact on their lives should be identified by DWP assessments, and the correct and appropriate level of PIP should be awarded.

We hope our feedback will be accepted and included in the final draft.

CHRISTINE AND TANYA HARRISON  
Secretary and Chairperson BRAME