

Pathways

Price £ 2.50 (Free to members)

The newsletter of Leger ME/CFS Supporting Myalgic Encephalopathy or Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Post Viral Fatigue Syndrome (PVFS), Fibromyalgia Syndrome (FMS), Patients & Carers.

The Welfare Reform Act 2012 Becomes Law

The Welfare Reform Act 2012 received Royal Assent and is now law as of 8th March 2012, and this Bill will affect almost everyone within Leger ME as follows:

- Universal Credit will replace ESA(IR), Income Support and other benefits
- Personal Independence Payments will replace the current Disability Living Allowance
- Housing Benefit entitlement will change for social housing tenants whose accommodation is larger than they need
- It up-rates Local Housing Allowance rates by the Consumer Price Index
- It amends the forthcoming statutory child maintenance scheme
- It limits the payment of contributory Employment and Support Allowance to a 12-month period
- It caps the total amount of benefit that can be claimed.
- It enables changes to the Appeal process.

It is not possible to cover everything within the act, so In the following pages we give an overview of the Welfare Reform Act, then list a number of common questions and issues raised concerning ESA. Finally we give details of PIP issues which will shortly be undergoing trials to see how the system works before a pilot study in the Merseyside/Bootle area starts next year. Most of the information has been lifted from DWP websites and 'Benefits and Work'.

Many of the issues concerning ESA are of a financial nature, there being no big change to the way the ESA 50 assessment works. Where PIP is concerned, it is intended to replace DLA, purely as a cost saving exercise, and is a major rethink. In essence, the low rate of personal care goes, and there will be a tougher mobility assessment.

As this point in time, there are several pieces of advice I would give to members.

- 1) Do not take on any new big financial commitments if you rely on state benefits, because really there is no guarantee that your current level of benefit will be maintained in the coming years.
- 2) If you have high rate mobility, do not take on a new Motability contract without serious consideration, because there is no guarantee that the DLA will continue to be paid after 2013.
- 3) If you have had an ESA medical and have 9 or 15 points in section 1(mobilizing), it is worth applying for DLA while you can. Leger ME members have access to the 'Benefit and Work' guides.

Finally I've included some of the usual Pathways features, and the secret of Annes' carrot cake is finally revealed in recipe corner. *Mike*

You Write

Pearl writes: Thank you for your Newsletter, Very Good Stuff. Also, your card; is that your dog, how cute! I enjoyed the cartoon very much; every doctor's surgery should have it on display, but of course, there's always the same aspect by most doctors – No such thing as ME/CFS. Some refuse to even know what it is. You get some medicine i.e. paracetamol or diazepam and away you go.

You start off (as a woman) at menopause, before that menstrual tension, then commences to age, and then next is consulting a good Funeral Plan.

How much longer will people have to wait to be taken seriously?

Over tired- doing too much. Aches and pains –old age (at 20?). Muscle pain – try Deep Heat. Fever – something is going about! Headache – cut down on drink.....WHAT, water and tea? How about a dose of S.S.R.I's.....on and on and on it goes. Try the Gym; Absail, Rock Climb, Roller Blade, Exercise, Voluntary Work. Feel sick? Try Phenergan. Oh, well, round and round we go. It's all in the mind. Never mind, a chemical cosh will solve it all and don't visit the local chip shop. Reaction to perfume etc.? Try a different brand – how about the latest Dior at only 94 quid a bottle. Soap reaction? – don't bathe or shower, try to go around the water! Keep up the good work—Mike. Of course being 74½ years, I fall into the 'lived too long category' so the answer now is at my age, "I've had a good innings." PHEW!

Wendy writes: I couldn't get to the W.F.I. (Health Related Work Focused Interview) today. When I rang to tell them to rearrange app the advisor told me I had to get to the next interview in two weeks or I may have my benefit taken away. I explained my health condition; she said it's the rules. I'm so frustrated; I've been totally wiped of energy now for 2 weeks. I haven't been able to do anything but rest and sleep. I have tried to do things, but end up in bed straight after.

For the benefit of Pathways reader Wendy has recently gone through and won a tribunal for ESA (Limited Capability for Work). She is now required to attend a series of six Health Related Work Focused Interviews a month apart.

! NO EXCUSES PLEASE!

YOU MUST ATTEND WHEN SUMMONED IRRESPECTIVE OF HOW ILL YOU ARE

However the DWP have to take into account that you are chronically ill. Their first requirement is that you should be doing something about it. Threats to withdraw money are counterproductive. The bit about 'had to get to the next interview in two weeks or I may have my benefit taken away'. It is totally wrong in this context, and if it happens can be taken to appeal and tribunal just like a benefits refusal. In any case they can't withdraw DLA or pay you less than the assessment rate of ESA. So, yes, it can be done but not in that context. I take the view that such threats are counterproductive to ME/CFS recovery, and as such we as a group need to do something about it. I need to know names of staff, telephone number and fax numbers and the address of the office where this threat came from. I have no hesitation in taking up these issues directly with the office manager concerned and copies will be also directly sent to your MP.

Vicki Writes: Just to let you know if you do not answer their calls they make a note of time and dates and put it as evidence against you if you go to a tribunal - in my case they have said "not being able to get hold of the client" - it's a crafty way of saying you're out of the house.

Further to this I am receiving reports from members that the DWP are contacting members by telephone regarding the transfer from Incap to ESA. I'm also hearing this from other ME groups as well around the country. The 'phone calls are as early as 8 am or as late as 10 pm and on a weekend. They are getting to the point of harassment in some cases. Repeating my advice - do not discuss anything over the 'phone with DWP. Tell them to put it in writing and hang up. Usually a standard letter will follow anyway, so nothing is lost. This letter usually talks about arrival of an ESA 50 to fill out, which is of course not a problem for us.

Julie Writes I just wanted to say thank you for letting me know about the electricity grant worth £120. I applied and met the criteria and recently had the money credited to my British Gas account.

Tom Writes: I am the information Officer Irish ME/CFS Association. I have written a paper called Reporting of Harms Associated with GET & CBT which was published in the Bulletin of the IACFS/ME. 2011;19(2): 59-111. The paper took a lot of effort. I began writing it in August 2010 and submitted the last draft 15 months later.

Of course I wasn't working on it for all that time but did spend a lot of that time writing and rewriting it, along with researching it and dealing with comments from the peer reviewers. I have had ME 22 years and have been severely affected 17 years and in some ways have been thinking about the points for those 17 years. So I bring up some issues that people who don't have the illness, or don't live with someone with illness, might not consider - for example in Section 5.6. "Measure non-physical harms / patient-oriented outcomes pertaining to quality of life". I am copying the abstract below. It is a little dense but then one can only use 250 words in an abstract so they tend to be relatively dense. The full paper is less dense so should be easier to read and understand. The feedback I have had has been almost exclusively positive. The only criticisms I can recall seeing are from a few people who claimed that CBT couldn't harm people. However, the paper explicitly says it is about the form of CBT that involves scheduling increasing activity and/or exercise. Here is an example of one such program for "relative passive" patients: "So, for example, the first day the patient has six 1-minute walks, the second day six 2-minute walks, the third day six 3-minute walks, and so on. The aim is a total build-up of 5 minutes a week for each walk a day." I think most people with knowledge of ME/CFS could imagine that such a program has the potential to cause problems for some patients. Section 6 is specifically about the reporting of harms (which is a technical term for "adverse events" or "side effects") in the PACE Trial, which might be of particular interest to some people. I used data from patients surveys from four different countries. I'm attaching a table (Table 2) from the paper which gives a summary of the results.

Table 2. Pooled Data of Harms from GET, CBT and Pacing reported in Surveys

Therapy	Sample Size	Harms ^a (N)	Mean rate of harms (%)	Range
Graded Exercise Therapy (GET) (or similar terms) ^b	4338	2223	51.24%	28.1 - 82%
Cognitive Behavioural Therapy (CBT) ^c	1808	360	19.91%	7.1 - 38%
Pacing (or similar terms) ^d	5894	152	2.58%	0.2 - 9.3%

^aThis includes any degree of harm e.g. both "somewhat worse" and "a lot worse" from the ME Association survey [85].

^bTaken from [75,78-80,82-85]; ^cTaken from [80,81,83-85]; ^dTaken from [79,80,83-85]

Thanks for the interest. Pathways readers can access the paper on:
<http://www.iacfsme.org/LinkClick.aspx?fileticket=Rd2tIJOoHqk%3D&tabid=501>.

Reporting of Harms Associated with Graded Exercise Therapy and Cognitive Behavioural Therapy in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

From Bulletin of the IACFS/ME. 2011;19(2): 59-111 by Tom Kindlon

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ABSTRACT*

Across different medical fields, authors have placed a greater emphasis on the reporting of efficacy measures than harms in randomised controlled trials (RCTs), particularly of non pharmacologic interventions. To rectify this situation, the Consolidated Standards of Reporting Trials (CONSORT) group and other researchers have issued guidance to improve the reporting of harms. Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT) based on increasing activity levels are often recommended for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). However, exercise-related physiological abnormalities have been documented in recent studies and high rates of adverse reactions to exercise have been recorded in a number of patient surveys.

51% of survey respondents (range 28-82%, n=4338, 8 surveys) reported that GET worsened their health while 20% of respondents (range 7-38%, n=1808, 5 surveys) reported similar results for CBT. Using the CONSORT guidelines as a starting point, this paper identifies problems with the reporting of harms in previous RCTs and suggests potential strategies for improvement in the future. Issues involving the heterogeneity of subjects and interventions, tracking of adverse events, trial participants compliance to therapies, and measurement of harms using patient oriented and objective outcome measures are discussed.

The recently-published PACE (Pacing, graded activity, and cognitive behaviour therapy: a randomised evaluation) trial which explicitly aimed to assess safety, as well as effectiveness, is also analysed in detail. Healthcare professionals, researchers and patients need high quality data on harms to appropriately assess the risks versus benefits of CBT and GET.

ME/CFS - Treatments which are not worth trying from Doctor Myhill's website

Graded Exercise (GET). This is positively harmful when ME/CFS is active. I find it quite extraordinary that so many doctors seem to advocate this as a treatment. It is as if they are unable to distinguish between CFS and lack of fitness! Let's face it, if graded exercise worked then the diagnosis could not possibly be CFS. The only possible explanation I can think of as to why this has stuck in the medical folklore is that after a physician has recommended this to the CFS patient, the latter never bothers to attend again for useless advice. The doctor then believes he has cured the patient because they don't come back. Has anybody else got any better explanation?

Cognitive behaviour therapy (CBT). The idea behind this is that the ME/CFS patient does not exercise because he is afraid to because it makes him ill. CBT is all about getting round this fear. The trouble is that the patient is right - he is fearful of exercise because it really does make him ill! Trials of CBT show it is far more likely to make patients worse. ME/CFS initially can tolerate so much CBT because they do the exercises at the expense of other activities, not in addition to and this distorts the results of such trials. I have seen a great many ME/CFS made much worse by CBT!

There is a place for CBT, but only when as many of the underlying physical issues have been identified. The point here is that the brain is constantly monitoring how much petrol there is in the tank. If it perceives little reserve, then that alone is enough to make one feel tired. It is the way that the brain protects the body from over-doing things. This was beautifully illustrated by an account in *New Scientist* of a Sports Psychologist marathon runner who was competing in South Africa. He had been told that the marathon was all on the flat and at 18 miles was running comfortably knowing he could complete easily. Turning a corner, suddenly he realised the end of the race was at the top of Table Mountain. Within a millisecond of appreciating this fact he felt the most profound and overwhelming fatigue so he was forced to slow right down. His brain had told him "Not enough petrol in the tank"! My guess is this partly explains why many ME/CFS are owls - once one nears bedtime the brain does not have to pace so rigidly - it knows it has a get out of jail free card just round the corner i.e. a night's sleep. So it "allows" the body to do a little extra!

Cold water therapy. This was advocated as a treatment for fatigue by Kakkar. It probably works because it gives the adrenal glands a huge "kick". However, if the adrenal glands are not working properly, as in CFS, then the patient feels awful. I don't recommend cold baths.

Amino acids. I tried these after reading a paper about amino acid deficiencies in CFS. The tests are expensive, the amino acids expensive and the results very disappointing.

Enada. This is the activated version of niacinamide or NAD. NAD is an essential part of the mitochondrial package and considerably less expensive. Although the trials look promising I have not been that impressed with the clinical response. It is the old story - single interventions are highly unlikely to result in worthwhile improvements because CFS is a complex problem - it is the combined approach that gets the results.

Cocktails of Low Dose Antidepressants and Treatment of CFS. At the British Society for Allergy, Environmental and Nutritional Medicine meeting in April 1998, Dr David Smith presented his views on the treatment of CFS using cocktails of low dose antidepressants. His theory is that CFS patients have low levels of neurotransmitters across the board, namely acetylcholine, noradrenaline, adrenaline, dopamine, GABA, serotonin and probably others. It is this which causes the multiplicity of symptoms including fatigue. He has concluded from his studies and his experience with patients that the fatigue in CFS is central - that is to say the cause is within the brain. These abnormalities are within the mid-brain, thalamus and hypothalamus and are neurological in origin. I tried these cocktails for several patients, but they just developed the side effects that I see in most of my patients with any one antidepressant. I was not impressed by this approach and would not particularly recommend this line.

Fludrocortisone The idea here (Dr David Bell) was that the fatigue in CFS is caused by low circulating blood volume and low blood pressure. He certainly demonstrated that this was the case and is probably due to autonomic disturbance. The question is what can one do about it? In theory by using a mineralocorticoid blood volume could be increased. In practice I found that the fludrocortisone simply caused swollen ankles and the blood pressure was unchanged.

OUT AND ABOUT with ME/CFS by Ann Fisher

Almost four year ago I had a bad relapse in my ME. Having to stop work, walking, dancing and most other social activities was extremely frustrating leaving me feeling isolated and trapped. After about a year we decided that I should have an electric scooter so that we would be able to go out into the much loved countryside. I was so excited about my first trip that I wrote about it for Pathways. Three years on we are still going out and I am using the scooter with more confidence and feel less conspicuous. I find using the scooter tiring and sometimes have rebound reactions to our 'time out' but the pleasure of seeing the hills, rivers and trees with their accompanying birds does wonders for my state of mind. So I would like to share with you some of the places we have visited and what the disabled facilities are like and encourage you to get 'out and about' and give some of them a try.

OPEN COUNTRYSIDE. Ladybower Reservoir – Parking on A47 near Ashopton Bridge, along the side of the reservoir and Fairholmes. Toilets, picnic site and refreshments are available at Fairholmes. There are two scooters for hire from the cycle hire at Fairholmes for £3 an hour (01433 651261). The paths are part tarmac and part compacted stone and can be rough in places. It is possible to ride completely round Ladybower but the Derwent and Howdon reservoirs are not as accessible. Food is also available at The Yorkshire Bridge Inn on the A6013 to Bamford and The Ladybower Inn on the A57. Information about other disabled access paths in Derbyshire is available in the "You're welcome" booklet from the Peak District National Park Authority on 01629 816310 or 01629 816581.



NATURE RESERVES. Potteric Carr Nature reserve – Mallard Way Doncaster, 01302 570077. (Opposite Doncaster B&Q). This is a lovely local reserve that is very disabled-friendly. Most of the paths are accessible to wheelchairs also the hides are easy to get into. The site is open from 9am to 5pm and the café 10am to 4pm, 7 days a week. There is ample parking and spaces for blue badge holders. Toilets are available at the entrance shop and the field centre/café.



COUNTRY PARK. Rufford Abbey

Country Park – Ollerton, Newark, Notts. 01623 821338,
 Parking off A614 with free parking for the disabled. Toilets are available at both the Abbey and Mill entrance. A restaurant and café are available at the Abbey and café only at the mill. The whole site is free to roam around, with woodland, lakeside paths, gardens and open grassland. The paths are of varying standard but most are wheelchair-accessible. There are mobility scooters and wheelchairs on free loan, bookable in advance. Collect a guide from the visitor information office.



STATELY HOMES. Nostell Priory – Nostell, Wakefield, W Yorkshire 01924 863892.

Disabled parking, toilets and café. The grounds and parkland are accessible but there are some rough areas and gradients. The Priory's interior is worth visiting as it was designed by Adam and contains Chippendale furniture. There are wheelchairs and a scooter available but must be booked in advance.

COASTAL WALKS. Cleethorpes–Lincolnshire. Drive via M18 and M180.or go by train from Doncaster. Parking available along the promenade, at the leisure centre and close to the lake. Toilets available near the pier, leisure centre, and lakeside café. The promenade is in excellent condition, you can also visit without a chair if you are able to walk short distances, then use the Land Train and miniature railway to travel the sea front. Try 11-13, High St, Cleethorpes, DN35 8LA Tel: 01472 600055 for wheelchair hire.



If you don't have your own scooter or wheelchair then try some of the places that loan or hire them. Build up slowly the amount you can do in a day; try somewhere close and only for a short time at first. You may need to rest before you go and be prepared to rest afterwards until you know how much you can do. I also recommend that you take hat, gloves, scarf, blanket and dress warmly as the wind seems to be very chilling even on mild days. My hands suffer the most from holding on to the handles of the scooter. The blanket is also useful for an afternoon nap if needed. I hope you have as much fun as I have being able to go 'out and about' again. I hope to post more ideas in the next issue.

Welfare Reform Act 2012

The Act consists of five Parts:

- Part 1 - Social security
- Part 2 - Disabled people: right to control provision of services
- Part 3 - Child maintenance
- Part 4 - Birth Registration
- Part 5 - Miscellaneous and supplementary

Part 1 - Social security

Abolition of income support - The Act sets out the framework necessary for the future abolition of income support, and the movement of claimants of that benefit to jobseeker's allowance with differing degrees of conditionality, or to employment and support allowance.

Work-for-your-benefit schemes - These mandatory schemes will be piloted for long-term jobseekers and some jobseekers who are likely to benefit from the scheme at an earlier stage. The scheme aims to give jobseekers the opportunity to develop their work skills through undertaking full time work-experience.

Lone parents and partners of benefit recipients - Parents with younger children (those not required to sign on) and partners of benefit recipients will be placed in a 'Progression to Work' group. Those placed in this group are not expected to immediately return to work but will instead be given a "personalised conditionality regime which is tailored to the individual's circumstances, so that preparation for work becomes a natural progression rather than a sudden step up". Those in the Progression to Work group are required to undertake action planning and work-related activities.

Employment and support allowance (ESA) claimants - Provision is made in the Act to direct and to undertake a specific work-related activity in certain circumstances. This extends the provision in section 13 of the Welfare Reform Act 2007 which requires ESA claimants (with the exception of those in the support group) to undertake a work-related activity of their choice.

Drug users and alcohol abusers - Clause 9 and Schedule 3 of the Act provide for problem drugs users and those who have problems with alcohol to be directed to make, and comply with, a rehabilitation plan. In some circumstances they could also be required to undergo drug testing.

Contribution conditions for Contributory Jobseeker's Allowance and Employment and Support Allowance - These will be amended so that in order to qualify, new claimants will normally need to have paid National Insurance contributions for at least 26 weeks in one of the last two tax years prior to the claim.

Adult dependency increases - There is a provision in the Act to remove adult dependency increase from Maternity Allowance and from Carer's Allowance.

Social Fund - Following the end of the consultation, the social fund: a new approach, the Act allows for the provision of 'external provider social loans' and payment of benefit on account, without the need to apply for a crisis loan.

Part 2 - Disabled people: right to control provision of services

Part 2 confers regulation-making powers that can be used to give adult disabled people greater choice and control over the way in which relevant services (defined in clause 29) are provided by relevant authorities (defined in clause 30). The Government intends that regulations should first introduce pilot schemes having temporary effect, so Part 2 includes provisions allowing this. It also introduces a statutory requirement to consult over specified draft regulations.

Part 3 - Child maintenance

This section deal with the enforcement of child maintenance. Currently the courts have the power to disqualify from driving or commit to prison non-resident parents who have failed to pay child maintenance. The Child Maintenance and Other Payments Act 2008 added to these powers the ability to curfew or to disqualify from holding or obtaining travel authorisation. This Part makes provision to allow the Child Maintenance and Enforcement Commission to make the decision in the case of disqualification for holding or obtaining a driving licence or travel authorisation, with the court dealing with appeals against the Commission's decision.

Part 4 - Birth registration

This section covers the joint register of the birth of children.

Part 5 - Miscellaneous and supplementary

This Part contains clauses dealing with consequential amendments, repeals and revocations of other legislation, financial provisions, the extent of the Act, commencement of provisions of the Act, and the short title.

From April 2012

Abolition of youth ESA for new claimants. Existing claimants at that date will be able to continue claiming, but entitlement will be limited to one year from the time entitlement began, disregarding time in the support group. Time spent on youth ESA prior to April 2012 will count towards the time limit. See Abolition of concessionary Employment and Support Allowance (ESA) 'youth' National Insurance qualification conditions - welfare reform bill impact assessment and clause 52 of the Welfare Reform Act.

Couples with children must work 24 hours a week between them, with one partner working at least 16 hours a week in order to qualify for the Working Tax Credit (WTC).

Contributory ESA time is limited to one year for those in the work related activity group.

The Government contribution to discretionary housing payments will be increased by £40 million in each year from 2012-13.

The family element of the Child Tax Credit will be withdrawn immediately after the child element.

See our emergency budget page.

The period for which a tax credit claim and certain changes of circumstances can be backdated will be reduced from three months to one month.

The 50 plus element will be removed from the Working Tax Credit.

A disregard of £2,500 will be introduced in the tax credits system before in-year falls in income affect tax credit entitlement.

DWP starts calling ESA time-limit claimants

The DWP has begun telephoning claimants whose Employment and Support Allowance (ESA) is due to end because of the time-limiting of contribution-based ESA for claimants in the work-related activity group (WRAG). Payments will cease for some claimants from 30 April 2012.

Claimants are now only entitled to 365 days of contribution-based ESA if they are in the WRAG. Time spent in the assessment phase which is immediately followed by being placed in the WRAG counts towards the 365 days. The new rules are retrospective, meaning that people who have already spent a year in the WRAG on contribution-based ESA will lose their benefit from 30 April unless they are entitled to income-related ESA.

Claimants in the support group will not be affected and payments of income-related ESA will also not be stopped.

The first payments are due to end on 30 April and the DWP have begun telephoning claimants whose payments are expected to end between 30 April and 3 June. They are being informed of the ending of their payment and asked if they wish to apply for income-related ESA.

Claimants whose payments are due to end after 3 June will be given eight weeks' notice.

Income-related ESA is means-tested. Claimants who have too much income (depending on their circumstances) typically those with capital of £16,000 or more or whose partner works for 24 hours a week or more are unlikely to qualify for income-related ESA.

The DWP claim that around 60% of those affected by the changes will be entitled to some income-related ESA.

Claimants whose condition has worsened may be able to ask for their award to be looked at again if they consider they should now be in the support group, where the time limit does not apply.

The Welfare Reform Act 2012: 12 Month Limit for ESA(CB)

www.dwp.gov.uk/docs/dmgch41.pdf 41471 and 41472

Entitlement to Contribution Based ESA (CB) will be limited to an aggregate total of 365 days in the Work Related Activity Group. The total is calculated as the sum of all the claimant's periods in the WRAG, within a single claim. Periods in different claims do not count towards the total. Claimants who have lost their entitlement to ESA(CB) and do not qualify for ESA(IR) but at some time meet the criteria for the Support Group will have their entitlement to ESA(CB) reinstated, providing they have continued to have Limited Capability for Work during the interim. Time spent in the Support Group will not count towards the total. The changes come into effect from 30th April 2012 and will be retrospective. This will apply from 30th April 2011. The people who it affects will have been told. Claimants who lose their ESA(CB) will be eligible to Income Related ESA, subject to their meeting the associated Means Test of assets, income, and partner's hours of work. The following examples explain the rule in more detail. All of them assume a date of 30th April 2012.

Implementation:

29th February 2012 onward the DWP will begin contacting (firstly by phone) people in receipt of contribution based ESA who have not been assessed for income related ESA and whose benefit will end between 30 April and 3 June to give them early notification of the expected change to their benefit and to ask if they wish to be considered for income related ESA.

9 April 2012 All claimants whose benefit is expected to end by the 3 June 2012 inclusive will be sent a notification on 9 April 2012 informing them of the date their benefit will end and whether they have an entitlement to income related ESA registered. Depending on the date the claimant's entitlement is due to end, a reminder notification will be issued if no contact is made with the Department.

After 3 June Claimants will receive 8 weeks' notice before their contribution based benefit ends.

Examples (*WRAG = Work Related Activity Group*)

- 1) Someone is placed in the WRAG, they are then moved to the Support Group, before being returned to the WRAG. Both periods in the WRAG count towards the number of days in the WRAG.
- 2) Some claimant is in the WRAG, they end their claim for ESA, sometime later they make a new claim for ESA (not due to the ESA linking rules) and are again placed in the WRAG. Only the second period in the WRAG counts towards the number of days in the WRAG.
- 3) Someone has been in the WRAG for less than 366 days. They will remain entitled to ESA (CB) until they have been in the WRAG for more than 365 days.
- 4) Someone has been in the WRAG for more than 365 days will lose their entitlement to ESA (CB) immediately.
- 5) Someone was originally placed into the WRAG for a period of less than 366 days; they are then moved to the Support Group, where they currently are. The claimant's entitlement to ESA (CB) continues, however, if at any time, they moved to the WRAG, then the count will continue until the total time in the WRAG exceeds 365 days when entitlement will cease, n.b. the count continues and does not reset in the second period in the WRAG.
- 6) Someone was originally placed into the WRAG for a period of more than 365 days; they are then moved to the Support Group, where they currently are. The claimant continues to be entitled to ESA(CB).
- 7) Someone was subject to the time limitation for ESA(CB) and did not qualify for ESA(IR). They have opted to receive NI credits and have maintained their Limited Capability for Work status. At some future point in time due to deterioration of an existing condition or a new condition, they meet the criteria for the Support Group. The claimant is placed in the Support Group and their ESA(CB) is reinstated, however, if at any time they no longer meet the criteria for the Support Group, their entitlement to ESA(CB) ceases immediately.

Employment & Support Allowance Forms

Quite often during conversations about ESA I use jargon, and ask people what exactly they have. Here is a list of what the ESA forms are for and why they might be issued.

A64A This appears to be issued when a claimant has an interest in a property other than the one they are living in. This may be issued to someone receiving ESA(CB)/ ESA1

ESA1 is the ESA application form, whether you complete the online form or you make a claim for ESA over the phone, this form needs to be completed and a signed copy returned to the DWP before your claim can progress

ESA50 is the standard questionnaire issued as part of the ESA assessment process (WCA). The form contains questions related to 10 physical and 7 mental health tests. This is the key form most Leger ME members have to complete and with which they have problems.

ESA55 This is the file that holds all of the other documents and reports relating to a claim. It is this file that is sent to ATOS for a medical assessment to be held and it is this file that ATOS subsequently return to the DWP after the assessment is held.

ESA65 often referred to as the Decision Maker's Statement of Reasons, is issued if you fail to score sufficient points in the ESA medical (WCA) and are found Fit for Work.

ESA85 is the medical report produced by the ATOS Health Care Professional as the result of a ESA medical assessment (WCA) being held. This is the key form if ESA is refused.

ESA85A The medical report produced by the ATOS Health Care Professional when they are able to make a medical recommendation without an ESA medical assessment taking place.

ESA113 This requests a summary of your medical conditions and their impact on you.

ESA114 A simple "box format" form completed by the Decision Maker when a reconsideration only is requested, or one is triggered automatically by an appeal. It contains the claimant's name, NINO and DOB, whether the reconsideration changes the original decision being reviewed, and the effective date of the reconsideration. It is signed and dated by the Decision Maker.

ESA310 is a standard letter being sent to all claimants receiving Contribution Based ESA. The letter explains the planned removal of ESA(CB) entitlement after a claimant has spent more than 12 months in the Work Related Activity Group.

LT54 This is completed by the Decision Maker with respect to : Claims, revisions, supersessions, etc., determination of questions and reconsiderations. Part 3 of this form is used for an IB/IS/SDA transfer. It contains the claimant's Conversion to ESA decision, (LCW placed in WRAG) or (LCWRA placed in Support Group). It gives a written explanation of the "Conversion Decision", and details which relevant legislation and regulations have been applied under "The Law". It states the effective date of the decision. It may also include the length of the award, before it should be reviewed.

ESA medical - What forms do you ask for if you get a refusal?

The situation regarding the forms completed by the DWP when a claimant is successfully placed into the WRAG or the Support Group is very confusing, as there seems to be no standard within the DWP as to what needs to be filled in. The following represents our current and best understanding of what should be requested (n.b. these reports cannot be requested until after a Decision has been made as to your claim by the DWP).

ESA85 medical report (if you had a medical)

ESA85A medical report (if you did not have a medical)

ESA113 report from your GP (if one was requested) any medical reports from your GP or Consultants any queries, requests for clarification, correspondence, memos, emails or other communications between ATOS health professionals and the decision maker in relation to your claim, or any notes or records of conversations between ATOS and the DWP any other evidence considered by the decision maker in reaching their decision, a copy of any worksheet, score sheet or any similar document which sets out which descriptors, exemptions or exceptional circumstances the decision maker considered.

The Welfare Reform Act 2012: Miscellaneous Information on ESA

24 hour work rule for ESA(IR)

In order to qualify for Income Related ESA (ESA(IR)), your partner must not be in remunerative work for more than 24 hours/week. However there are some exceptions to this rule.

- Child-minding done in your partner's home,
- Voluntary work or work done for a charity or voluntary organisation in return for payment to cover your expenses.
- Attendance on a training scheme for which a training allowance is paid
- Receiving assistance under the New Deal self-employment route
- Work as a councillor
- Caring for a foster child or providing respite care in your partner's home being in receipt of a Sports Council National Lottery award (and no other payment for that sporting activity)
- Duties undertaken by part-time firemen, auxiliary coastguards, part-time lifeboat crews, members of a territorial or reserve force.

Your partner will not be classed as being in remunerative work if he or she is mentally or physically disabled and has reduced earnings or works reduced hours as a result of that disability involved in a trade dispute regularly and substantially caring for someone who is in receipt of Attendance Allowance or the highest or middle rate of the care component of Disability Living Allowance, or in receipt of Carers Allowance living in a care home, an Abbeyfield home or an independent hospital and requires personal care.

Asset rule for ESA(IR)

In order to qualify for Income Related ESA, your savings and assets must not exceed £16,000. In addition, for every £250 in excess of £6000, there will be a £1 deduction from any benefit payable. For example, You have £10,000 in savings and/or assets. The excess is £4000 (£10,000 - £6000). The deduction is £16 (£4000 / £250).

Adding pages to your submission

Whether you are adding pages to your ESA50, DLA application form, or Tribunal evidence, remember to add the following to the top of each page.

Your name, Your National Insurance Number , A page reference e.g. page 1 of 2

Make sure all your additional pages are firmly secured to the base form, where applicable.

Do I need to provide a Fit Note?

NB: You should always provide a fit note when asked to do so. Failure to provide a fit note may result in your claim not being allowed or being terminated. Below are the general rules about providing a fit note. In April 2010 the Government replaced the Sick Note with the Fit Note.

Although the new form talks about when you will be better, rather than specifying how long you will be ill, as the old form did, they still perform the same function of certifying whether a person is able to work or not.

New claim for ESA A Fit Note is required when you make a new claim for ESA, and throughout the ESA Assessment phase, which is targeted to take 13 weeks from application to Decision, but may take longer.

Main phase of ESA Once a claimant is placed into either the WRAG or Support Group, they do not need to supply further Fit Notes.

Appealing a Fit for Work Decision If you are found Fit for Work, either on a new claim, or following a re-assessment, and you decide to appeal the Decision, then you will need to supply Fit Notes to the DWP until your case is heard.

Appealing from the WRAG to the Support Group You do not have to provide Fit Notes.

Being Transferred from IB/IS/SDA to ESA As the transfer is considered part of your existing claim, there is no need to provide Fit Notes during the transfer.

ESA Medical – What to expect

The ESA medical is discussed in the 'Preparing for Your Medical' section in either the Employment and Support Allowance claims on physical health grounds (Page 63 onwards), or Employment and Support Allowance claims for Mental Health and Learning Difficulties (Page 67 onwards) guides in the ESA Claims section. The medical is also discussed in the WCA Handbook section 3. The Medical Assessment, see ESA – DWP Resources The WCA Handbook also details the procedures for a Home medical in section 3.12 Domiciliary visits. You are entitled to have a companion with you at the medical.

ESA50 too big for the envelope

You have added so many extra pages to your ESA50, either a additional content or evidence, that it no longer fits in the supplied envelope. Simply tape the supplied to envelope to the front of a new A4 envelope, ensuring that the address and the pre-paid stamp are still visible. The Royal Mail should still accept the new envelope and more importantly the pre-paid postage meaning that you can still send it Recorded Delivery by just paying the difference.

ESA Premiums

There are four Premiums payable with ESA(IR) note not ESA(CB).

Carer Premium You or you partner must be entitled to carer's allowance, even if you are not actually paid it because you receive another benefit. This premium is payable for each person who qualifies.

Enhanced Disability Premium You or your partner must satisfy one of the following:

be in the support group, be under the qualifying age for pension credit and receiving the high rate care component of Disability Living Allowance. If you have a partner you will be paid the couple rate of this premium.

Pensioner Premiums These are paid if you or your partner have reached the qualifying age for pension credit. If you have a partner you will be paid a higher couple rate of this premium.

Severe Disability Premium You or your partner must satisfy all of the following:

be receiving the care component of Disability Living Allowance (middle or higher rate) or Attendance Allowance, live alone (there are exceptions to this rule), no one else must be getting Carer's Allowance for looking after you. There is a couple rate if both of you qualify.

How long do I have to complete the ESA50?

You need to complete your ESA50 within four weeks of the issuing date. There will be a return date on the covering letter that explains the exact date by which the questionnaire needs to be with ATOS. If you have not returned the ESA50 within three weeks, a reminder letter will be sent to you. It is important to note, that despite this letters wording, the original return date is still effective.

Asking for an extension The ESA legislation does not provide for the extension of the period allocated to complete the ESA50. Even if you are told by the DWP that you can return the form late, you should not do so unless you have the extension confirmed in writing. Whilst we would not recommend any claimant to do so, it is possible to return the ESA50 late, however, you may be asked to show Good Cause for the late return and you claim may be delayed as a result. Examples of Good Cause are; whether the claimant was outside Great Britain at the relevant time; the claimant's state of health at the relevant time; and the nature of any disability the claimant has.

How long until they make a decision?

Unfortunately there is no way to accurately predict when a Decision will be made on your claim, most Benefit Delivery Centres appear to be overloaded and this is definitely extending the time claimants are waiting to hear a result. The minimum period we have heard of is one week (this is very rare) the longest we have heard of is five months and at the time of writing the claimant was still waiting to hear, the average is probably now about seven weeks and getting longer.

Factors that can affect the time are; are you part of the IB/IS/SDA transfer, whether a medical was held, has the Decision Maker requested a report from your GP?, has the Decision Maker had to request additional medical support from ATOS due to the nature of your conditions?

You can contact your local DWP office, the phone number should be on any of the letters that you have received from them, and request an update.

How often will I be reviewed

There is no formal re-assessment timescale for ESA. Re-assessments are normally based on the prognosis determined by the ATOS Health Care Professional (HCP) at your last review. Claimants in the WRAG should expect to be re-assessed every 6-12 months with most towards the lower limit, but in some extreme cases the period can be as short as 4 months and as long as 24 months.

Claimants in the Support Group will also be re-assessed every 6-12 months, with the majority being towards the upper limit. It is very rare for someone to be assessed in less than 6 months and many will not be assessed for 36 months or more.

Permitted Work

Whilst you are not normally allowed to work while receiving ESA, there are circumstances where you may be able to carry out Permitted Work. It is important for anybody considering Permitted Work to notify the DWP of your intentions in writing, this is because; only the DWP can confirm that the work you are intending to do meets the requirements for Permitted Work, and starting Permitted Work counts as a Change of Circumstances. You should consider whether the work you are intending to do is consistent with your disabilities or conditions, and whether doing this work will affect your ability to meet the ESA WCA descriptors. You should expect the ATOS HCP to be aware that you are doing Permitted Work when interviewed as part of a WCA assessment.

Qualifying for the Support Group

In order to qualify for the Support Group you need to; meet one or more of the relevant descriptors, or meet one of the associated Exceptional Circumstances rules. The Support Group descriptors are listed on page 24, and the Exceptional Circumstances on page 27 of the Understanding ESA guide.

Using the PDF Version Of The ESA50 Questionnaire

Many members choose to use the interactive pdf version of the ESA50 Questionnaire, and it is perfectly acceptable to do this. As Leger ME we have noticed that the use of the variant is inked with a high chance of refusal.

Work Focussed Interviews

A wide range of claimants, and their partners, can be required to participate in a Work Focussed Interview (WFI), as a requirement of their continuing to receive benefits.

Specifically with regard to Employment and Support Allowance (ESA), members of the Work Related Activity Group are required to attend WFIs, with the following exceptions;

members of the Support Group

lone parents with a child under 5

ESA claimants who also receive Carers Allowance or the Carers Premium

There are normally six WFIs held with an personal advisor at your local JobCentre Plus. Attendance at the meeting is mandatory, although it can be deferred at the discretion of the advisor, it also possible to request that the meeting be held over the phone and in extreme circumstances in your home, but the claimant has no underlying right to these considerations.

Failure to attend a WFI or participate in Work Related Activity without Good Cause can lead to sanctions and loss of benefit. Sanctions can only be imposed by a Decision Maker (not the personal advisor), and they must take into account the claimants physical or mental health or condition.

Things you cannot be asked to do

You cannot be required to; apply for a job, undertake work, undergo medical treatment,

Things you may be asked to do

There is no specific definition of what constitutes Work Related Activity and therefore there is no specific agenda for a WFI, however, the following is a list of items a claimant should expect to be asked to do: assessing the claimants prospects for existing or future employment, (whether paid or voluntary); assisting or encouraging the claimants to improve their prospects of such employment; Identifying activities which the claimant may undertake to strengthen their existing or future prospects for employment; identifying current or future employment or training opportunities suitable to that person's needs; identifying educational opportunities connected with the existing or future employment prospects or needs of the claimant.

The Welfare Reform Act 2012: Personal Independence Payment (PIP)

Personal Independence Payment will replace DLA PIP from 2013. Bootle Benefit Centre (Bootle BC) will administer the first new claims from spring 2013, from areas including Merseyside, north-west England, Cumbria, Cheshire and north-east England. People in these locations will be the first to claim the new benefit. During this period, new claimants in all other parts of the country will continue to claim DLA as now. The remaining network of benefit centres currently administering new claims for DLA will start to take on new claims for PIP from summer 2013, once evidence is in place that processes are working as intended. In addition this network will handle continuing DLA claims for children. The Blackpool Benefit Centre will undertake PIP reassessment activity for existing DLA claimants aged 16 to 64.

Age limits

To qualify for PIP you will need to be aged between 16 and 65 or state pension age, whichever is higher. For the present children and older people will not be affected by PIP. However, guidance notes produced by the DWP make it clear that this may change in the future, once the government have had an opportunity to see how PIP performs in relation to working age claimants. People who receive PIP before they are 65 will go on being able to get it once they are over 65, according to the DWP.

Qualifying periods

For PIP, you will need to have had your current level of needs for at least six months and be likely to continue having them for a further six months. At the moment, for DLA, the qualifying period is three months in the past and six months in the future.

Length of awards

All PIP awards will be for a fixed period, except in exceptional circumstances. Short-term awards of up to two years will be given where the claimant is expected to improve significantly. Awards of 5-10 years will be made where changes in the claimant's condition are possible but less likely. On-going awards will only be given in a very small minority of cases where the claimant is unlikely to get either better or worse.

Hospital

After 28 days, PIP will also not be payable to in-patients in hospital or residents of care homes where all or part of the costs are met from public funds. This applies to both the daily living and mobility components. An underlying entitlement will continue during periods in a hospital or care home, so that payment can be resumed when the claimant leaves, providing all the other qualifying conditions are still met.

Method of assessment

Claimants will go through a very similar process to the assessment procedure for employment and support allowance (ESA). There will be an initial questionnaire to complete, followed, for most people, by a face-to-face assessment by an ATOS doctor or nurse.

A decision maker will then consider all the evidence, including any additional medical evidence obtained by the claimant, before making a decision about how many points should be awarded.

Components and rates

PIP will have two components: daily living component & mobility component

Each component will have two rates: standard rate & enhanced rate

Claimants who are assessed as having:

“limited ability to carry out daily living activities” will be paid the standard rate of the daily living component;

“severely limited ability to carry out daily living activities” will be paid the enhanced rate of the daily living component;

“limited ability to carry out mobility activities” will be paid the standard rate of the mobility component;

“severely limited ability to carry out mobility activities” will be paid the enhanced rate of the mobility component.

PIP daily living component points

To get an award of the daily living component, you need to score:

8 points for the standard rate
12 points for the enhanced rate

For daily living, the points need to be scored from activities 1-9 below.

You can only score one set of points from each activity, if two or more apply from the same activity only the highest will count. So, for example, if:

4 d. Needs assistance to groom. 2 points
4 g. Needs assistance to bathe. 4 points

both apply you will receive only the 4 points for the 'Bathing and grooming' activity. These can then be added to points for other activities, such as 'Dressing and undressing'

PIP mobility component points

To get an award of the mobility component you need to score:

8 points for the standard rate
12 points for the enhanced rate

For mobility, the points need to be scored from activities 10-11 below.

As with daily living above, you only score the highest points that apply to you from each activity, but you can add points from activities 10 and 11 together to reach your final total.

Addition Information

Variable and fluctuating conditions

Taking a view of ability over a longer period of time helps to iron out fluctuations and presents a more coherent picture of disabling effects. Therefore the descriptor choice should be based on consideration of a 12 month period. Scoring descriptors will apply to individuals where their impairment(s) affects their ability to complete an activity on more than 50 per cent of days in the 12 month period. The following rules apply:

If one descriptor in an activity applies on more than 50 per cent of the days in the period – i.e. the activity cannot be completed in the way described on more than 50 per cent of days – then that descriptor should be chosen.

If more than one descriptor in an activity applies on more than 50 per cent of the days in the period, then the descriptor chosen should be the one which applies for the greatest proportion of the time. Where one single descriptor in an activity is not satisfied on more than 50 per cent of days, but a number of different descriptors in that activity together are satisfied on more than 50 per cent of days – for example, descriptor 'B' is satisfied on 40 per cent of days and descriptor 'C' on 30 per cent of days – the descriptor satisfied for the highest proportion of the time should be selected.

Awaiting treatment

If someone is awaiting treatment or further intervention it can be difficult to accurately predict its level of success or whether it will even occur. Descriptor choices should therefore be based on the likely continuing impact of the health condition or impairment as if any treatment or further intervention has not occurred.

Reliably, in a timely fashion, repeatedly and safely

An individual must be able to complete an activity descriptor reliably, in a timely fashion, repeatedly and safely; and where indicated, using aids and appliances or with support from another person (or, for activity 10, a support dog). Otherwise they should be considered unable to complete the activity described at that level.

Reliably means to a reasonable standard.

In a timely fashion means in less than twice the time it would take for an individual without any impairment.

Repeatedly means completed as often during the day as the individual activity requires. Consideration needs to be given to the cumulative effects of symptoms such as pain and fatigue – i.e. whether completing the activity adversely affects the individual's ability to subsequently complete other activities.

Safely means in a fashion that is unlikely to cause harm to the individual, either directly or through vulnerability to the actions of others; or to another person.

Risk and Safety

When considering whether an activity can be undertaken safely it is important to consider the risk of a serious adverse event occurring. However, the risk that a serious adverse event may occur due to impairments is insufficient – there has to be evidence that if the activity was undertaken, the adverse event is likely to occur.

Aids and appliances

The assessment will take some account of aids and appliances which are used in everyday life. In this context:

Aids are devices that help a performance of a function, for example, walking sticks or spectacles.

Appliances are devices that provide or replace a missing function, for example artificial limbs, collecting devices (stomas) and wheelchairs.

The assessment will take into account aids and appliances that individuals normally use and low cost, commonly available ones which someone with their impairment might reasonably be expected to use, even if they are not normally used. Individuals who use or could reasonably be expected to use aids to carry out an activity will generally receive a higher scoring descriptor than those who can carry out the activity unaided. The assessment will take into account where individuals need the support of another person or persons to carry out an activity – including where that person has to carry out the activity for them in its entirety. The criteria refer to three types of support:

Assistance is support that requires the presence and physical intervention of another person i.e. actually doing some or all of the task in question. This specifically excludes non-physical intervention such as prompting or supervision which are defined below. To apply, this only needs to be required for part of the activity.

Prompting is support provided by reminding or encouraging an individual to undertake or complete a task but not physically helping them. To apply, this only needs to be required for part of the activity.

Supervision is a need for the continuous presence of another person to avoid a serious adverse event from occurring to the individual. There must be evidence that any risk would be likely to occur in the absence of such supervision. To apply, this must be required for the full duration of the activity.

Unaided Within the assessment criteria, the ability to perform an activity 'unaided' means without either the use of aids or appliances or assistance/prompting/supervision from another person.

Epilepsy is a marked example of a fluctuating condition where an individual can have no functional limitation one minute and considerable limitation the next. Assessment should be based on the impact this causes. Key to assessing individuals with epilepsy is the consideration of risk. Within each activity, the relevant descriptor should apply to a person with epilepsy if there is evidence that a serious adverse event is likely to occur if the person carried out the activity in that descriptor. It is essential to consider the likely effects of any seizure – type and frequency of fit, associated behaviour, the postictal phase and whether there is likely to be sufficient warning or prodromal phase.

Activity	<u>Speculative PIP ACTIVITIES AND POINTS</u> <i>Personal Care</i>	<u>points</u>
1. Preparing food and drink.	a. Can prepare and cook a simple meal unaided.	0 points
	b. Needs to use an aid or appliance to either prepare or cook a simple meal.	2 points
	c. Cannot cook a simple meal using a conventional cooker but can do so using a microwave.	2 points
	d. Needs prompting to either prepare or cook a simple meal.	2 points
	e. Needs supervision to either prepare or cook a simple meal.	4 points
	f. Needs assistance to either prepare or cook a simple meal.	4 points
	g. Cannot prepare and cook food and drink at all.	8 points
2. Taking nutrition.	a. Can take nutrition unaided.	0 points
	b. Needs either –	2 points
	(i) to use an aid or appliance to take nutrition; or	
	(ii) assistance to cut up food.	2 points
	c. Needs a therapeutic source to take nutrition.	4 points
	d. Needs prompting to take nutrition. e. Needs assistance to manage a therapeutic source to take nutrition.	6 points
f. Needs another person to convey food and drink to their mouth.	10 points	
3. Managing therapy or monitoring a health condition.	a. Either (i) Does not receive medication, therapy or need to monitor a health condition; or	0 points
	(ii) can manage medication, therapy or monitor a health condition unaided, or with the use of an aid or appliance.	
	b. Needs supervision, prompting or assistance to manage medication or monitor a health condition.	
	c. Needs supervision, prompting or assistance to manage therapy that takes up to 3.5 hours a week.	1 point
	d. Needs supervision, prompting or assistance to manage therapy that takes between 3.5 and 7 hours a week	4 points
	e. Needs supervision, prompting or assistance to manage therapy that takes between 7 and 14 hours a week.	6 points
f. Needs supervision, prompting or assistance to manage therapy that takes at least 14 hours a week.	8 points	
4. Bathing and grooming.	a. Can bathe and groom unaided.	0 points
	b. Needs to use an aid or appliance to groom.	1 point
	c. Needs prompting to groom	1 point
	d. Needs assistance to groom.	2 points
	e. Needs supervision or prompting to bathe	2 points
	f. Needs to use an aid or appliance to bathe	2 points
	g. Needs assistance to bathe.	4 points
	h. Cannot bathe and groom at all.	8 points
5. Managing toilet needs or incontinence.	a. Can manage toilet needs or incontinence unaided.	0 points
	b. Needs to use an aid or appliance to manage toilet needs or incontinence.	2 points
	c. Needs prompting to manage toilet needs.	2 points
	d. Needs assistance to manage toilet needs.	4 points
	e. Needs assistance to manage incontinence of either bladder or bowel.	6 points
	f. Needs assistance to manage incontinence of both bladder and bowel.	8 points
	g. Cannot manage incontinence at all	8 points
6. Dressing and undressing.	a. Can dress and undress unaided.	0 points
	b. Needs to use an aid or appliance to dress or undress. C	
	. Needs either—(i) prompting to dress, undress or determine appropriate circumstances for remaining clothed;	2 points
	or (ii) assistance or prompting to select appropriate clothing.	2 points
	d. Needs assistance to dress or undress lower body.	3 points
	e. Needs assistance to dress or undress upper body.	4 points
f. Cannot dress or undress at all.	8 points	
7. Communicating.	a. Can communicate unaided and access written information unaided, or using spectacles or contact lenses	0 points
	b. Needs to use an aid or appliance other than spectacles or contact lenses to access written information.	2 points
	c. Needs to use an aid or appliance to express or understand verbal communication	2 points
	d. Needs assistance to access written information.	4 points
	e. Needs communication support to express or understand complex verbal information.	4 points
	f. Needs communication support to express or understand basic verbal information.	8 points
	g. Cannot communicate at all.	12 points
8. Engaging socially.	a. Can engage socially unaided.	0 points
	b. Needs prompting to engage socially.	2 points
	c. Needs social support to engage socially.	4 points
	d. Cannot engage socially due to such engagement causing either –	
	(i) overwhelming psychological distress to the claimant; or	
(ii) the claimant to exhibit uncontrollable episodes of behaviour which would result in a substantial risk of harm to the claimant or another person.	8 points	
9. Making financial decisions	a. Can manage complex financial decisions unaided.	0 points
	b. Needs prompting to make complex financial decisions.	2 points
	c. Needs prompting to make simple financial decisions.	4 points
	d. Cannot make any financial decisions at all.	6 points

<u>Activity</u>	<u>Speculative PIP ACTIVITIES AND POINTS Mobilising</u>	<u>points</u>
10. Planning and following a journey.	a) Can plan and follow a journey unaided.	0 points
	b. Needs prompting for all journeys to avoid overwhelming psychological distress to the claimant.	
	c. Needs either – (i) supervision, prompting or a support dog to follow a journey to an unfamiliar destination; or (ii) a journey to an unfamiliar destination to have been entirely planned by another person.	4 points
	d. Cannot follow any journey because it would cause overwhelming psychological distress to the claimant.	8p points
	e. Needs either – (i) supervision, prompting or a support dog to follow a journey to a familiar destination; or (ii) a journey to a familiar destination to have been planned entirely by another person.	10 points
11. Moving around.	Can move at least 200 metres either – (i) unaided; or (ii) using an aid or appliance, other than a wheelchair or a motorised device.	15 points
	b. Can move at least 50 metres but not more than 200 metres either – (i) unaided; or (ii) using an aid or appliance, other than a wheelchair or a motorised device.	0 points
	c. Can move up to 50 metres unaided but no further.	4 points
	d. Cannot move up to 50 metres without using an aid or appliance, other than a wheelchair or a motorised device.	8 points
	e. Cannot move up to 50 metres without using a wheelchair propelled by the claimant.	10 points
	f. Cannot move up to 50 metres without using a wheelchair propelled by another person or a motorised device. g. Cannot either – (i) move around at all; or (ii) transfer unaided from one seated position to another adjacent seated position.	12 points
		15 points

Who will lose out under PIP?

The main purpose of replacing DLA with PIP is to reduce the cost of the benefit by 20% by making the criteria more difficult to meet. In this section, based on what we know so far about PIP, we look at who is most likely to lose out when they are moved from DLA to PIP. But do bear in mind that the current activities and descriptors are draft ones only, they may change before they are finalised.

Moving around indoors

If your award is based in a large part on difficulties you have with moving around indoors then it may be under threat. There is little, if any, reference to moving around indoors in the PIP daily living activities. It would appear that mobility issues will only score points in relation to the mobility component, which according to DWP guidance looks at your ability to move around outdoors. The current DLA claim pack has a section on 'Moving around indoors' which covers such issues as difficulties walking around, using stairs, getting in and out of a chair and transferring from a wheelchair. PIP daily living activities, on the other hand, seem to exclude such things as problems with using stairs or with moving around generally. For example, the definition of 'toilet needs' appears to be so tightly drawn that it excludes any consideration of whether a claimant needs help getting to and from the toilet, although problems getting on and off the toilet will be taken into account. In addition, transferring from one seated position to another is listed under mobility for PIP rather than being considered as a daily living activity.

Night-time needs

Claimants who get the middle rate of the care component of DLA for night-time needs only may struggle to get an award of PIP. Under DLA, care needs that are too few or brief to attract an award in the day may get an award of the middle rate of the care component if they take place at night. Under PIP no distinction is made between day and night needs. In fact, night is not mentioned in any of the daily living activities. Nor is there any mention of help needed with getting into bed or getting out of bed or with help needed when you are in bed in the PIP daily living activities.

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Supervision

There is little reference to supervision needs under PIP. The guidance states that there is a requirement that activities can be carried out safely. So, if you need someone to keep you safe when cooking a meal, for example, this will be taken into account. But, under DLA a claimant who has severe epilepsy, for example, may get an award because they need supervision in case they have a seizure. People who are prone to falling indoors because of Parkinson's may get an award of the middle or higher rate of the care component of DLA. Similarly, someone who may be a danger to themselves or other people because of a mental health condition might, under DLA, get an award of the middle or higher rate of the care component. Under PIP there is no award whatsoever specifically for supervision needs. Instead, it looks as if claimants will need to show how they are a danger to themselves or other people in relation to specific activities, such as cooking, managing medication and communicating in order to try to get an award of the daily living component.

Communication

Problems with communication will still potentially attract an award under PIP. But it seems that the criteria will be very much more strict. The very lowest points scoring descriptor is 9(b) which is 'Can communicate only with communication support'. The definition given of 'communication support' is: 'either support from a person trained to communicate with people with limited communication abilities - for example, lip speakers - or from appropriate aids or appliances.' So, claimants who need help with communication from friends and family who are not 'trained' are unlikely to score points unless their problems with communication are so severe that they cause such things as uncontrollable distress or uncontrollable behaviour. Communication is listed as a high scoring activity, but there must still be a strong suspicion that simply being deaf and needing trained support to communicate will not, on its own, be sufficient to attract an award of PIP.

Cooking a main meal

The 'main meal' or 'cooking' test is an important route to the lower rate of the care component of DLA for many thousands of sick and disabled people. PIP has a similar 'Preparing and cooking' activity. It also has a separate 'Planning and buying food and drink' activity which looks at your ability to work out what food and drink you need, to plan your budget and to buy things, but not to actually physically get to and move around in a shop. Though it should be noted that you will only score points if you need 'continual' prompting or assistance with planning or with buying. However, the PIP cooking test has some important differences from DLA. For example, a 'simple meal' can be made using 'fresh or frozen ingredients' which may mean, regardless of the DWP guidance, that the decision maker need not take into account problems with peeling and chopping. The higher scoring descriptors also require the claimant to show that they need 'continual' prompting or assistance with either preparing or cooking a meal, not just help with some parts of the activity. This is very different from DLA, where showing that there is any one part of the activity that you cannot manage without help is sufficient to get an award. The very highest scoring cooking descriptors require you to be unable to cook using a microwave without continual help or to be unable to prepare even a simple uncooked snack without continual help. Until we know much more about the points scoring system we won't know whether even the highest scoring descriptor in this activity would lead to an award of PIP. But what is clear is that many people who currently pass the main meal test will score few, if any points, under the PIP test.

Mobility

It will not be possible to predict who may lose out in relation to mobility until the points system has been published. However, it is worth noting that in relation to the 'Planning and following a journey' activity, your ability to plan and follow a journey by car, bus or train will be taken into account – not just your ability to walk outdoors. In relation to moving around, to score the higher points you will need either to be unable to propel your manual wheelchair 50 metres or more, be reliant on a powered wheelchair, be unable to move at all or be unable to transfer. Simply being unable to walk 50 metres or more with the aid of a walking stick or frame, for example, is only (d) out of descriptors (a)-(g), with (g) being the highest scoring descriptor. There is a real possibility then, that the level of mobility problems that currently attracts an award of higher rate mobility for DLA will be insufficient for an award of the enhanced rate of the mobility component of PIP. Please check back for updates on this issue as more details of the scoring system are published by the DWP.

Social and leisure

In relation to DLA it was accepted, after hard fought legal battles, that disabled people have a right to enjoy an ordinary life, which includes social and leisure activities, in the same way as people who are not disabled. In the PIP scoring system, there is no mention whatsoever of help needed with social and leisure activities. It seems that help with anything other than the most basic of human activities will not be relevant when scoring points for PIP.

Medication

If your award of DLA is based in a large part on the help that you need with managing medication or monitoring your health condition then it is likely to be more difficult for you to get an award of PIP. This is because, astonishingly, taking medication and help with therapy are the only two activities that are classed as 'low scoring'. This means that, for example, someone who needs help with dressing can score more points for that activity than someone who needs help with taking vital medication or with life-preserving therapy.

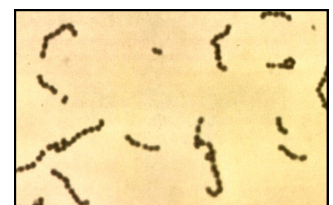
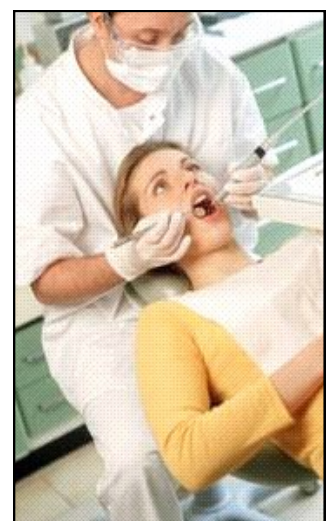
Poor oral hygiene links to heart attack risks

Don't be tempted to skip your hygienist appointment, says the American Heart Association. After studying the oral health habits of more than 100,000 people over seven years, they found that frequent professional cleaning reduced heart attack risk by 24% and that of stroke by 13%. This is because having your teeth scraped and cleaned at least once a year helps to reduce the inflammation that can lead to these conditions.

A recent study carried out at Bristol University has determined the reasons why not brushing teeth regularly can increase the risk of a heart attack. Although the link between the two has been speculated upon for a number of years, the exact reasons have not been found. However, a dental scientist from Bristol recently discovered that the kind of bacteria that commonly causes gum disease and tooth decay can make its way into the bloodstream and increase the risk of blood clots forming. This increased risk can, in turn, be responsible for more strokes and heart attacks.

The type of bacteria responsible, *Streptococcus mutans*, is usually restricted to the mouth but if an individual starts to suffer from bleeding gums the bacteria can make its way into the bloodstream. Once present in the bloodstream the bacteria used a protein named PadA, which forces the blood platelets to join together to into a protective shield. 'What we have done is whittled down to a single protein molecule on the surface of bacteria that can activate platelet formation,' stated Professor of Oral Microbiology, Howard Jenkinson. 'It is the first time that a mechanism from a single bacterium has been shown to activate platelets and make them spread.' Jenkinson continued, 'When the platelets clump together they completely encase the bacteria. This provides a protective cover not only from the immune system, but also from antibiotics that might be used to treat infection. Unfortunately, as well as helping out bacteria, platelet clumping can cause small blood clots, growths on the heart valves or inflammation of blood vessels that can block the blood supply to the heart and brain.' Professor Jenkinson called the unearthing of this new protein information as a new "tool" with which to experiment drugs for clotting blood. Along with Dr. Steve Kerrigan, Professor Jenkinson is working on how the protein's functions can be blocked; 'This could eventually lead to new treatments for cardiovascular disease, which is the biggest killer in the developed world.'

He also highlighted the importance of brushing daily, especially flossing; 'People need to be aware that as well as keeping a check of their diet, blood pressure, cholesterol and fitness levels, they also need to maintain good dental hygiene to minimise their risk of heart problems.'



Recipe Corner:**NEW ZEALAND MOIST CARROT CAKE**

by Anne

(This the secret of the cake Anne brings to meetings)

Pre heat oven to gas mark 2, 300f, 150c

You will need one 8" (20cm) round cake tin or 2lb loaf tin lined with greaseproof paper and 2 mixing bowls.

Method

In the first mixing bowl you place the eggs, oil, vanilla essence and soured cream, then sieve the sugars into it as well (to avoid any lumps).

Into the other bowl you sift the flour, nutmeg, cinnamon, soda and salt.

Now beat the wet ingredients and the sugars together, then fold in the dry ingredients, followed by the carrots and coconut.

Mix well to distribute everything evenly, then spoon into the cake tin and bake on the centre shelf for 1 1/2 to 2 hours.

When the cake is cool mix the topping ingredients together and spread thickly all over the top.

Recipe donated by Yolanda Couchman to "The Food Aid Cookery Book"

GINGERED PRAWN, MANGE TOUT AND**PASTA** by Carolyn

(serves 4 or, 2 greedy ones)

(Your Chairman loves this one served with a bottle of chilled Chardonnay!)

Method

If you are using uncooked prawns, shell and divide them, but leave the tails intact. If using frozen prawns (best to use big/King prawns), defrost thoroughly and blot with paper towels to remove as much moisture as possible.

Combine the prawns, lemon grass, coriander and ginger in a bowl. Cover and refrigerate for an hour or two.

Cook the pasta according to the package instructions and steam the peas until just tender.

(You may want to cut them in half as I did, to make eating easier.)

To make the butter sauce, combine the cornflour (which you have already blended with the water), lemon juice and grated ginger in a small saucepan. Stir continuously until the sauce boils and thickens. Remove from the heat and stir in the butter/marg until it is melted. Keep warm. Heat the oil in a wok or (a large frying pan will do fine). Add the prawn mixture and stir-fry until the prawns are cooked (or heated, in the case of frozen prawns) through. Add the peas, pasta and butter sauce and heat through, mixing thoroughly. Serve immediately.

Ingredients:

9oz (250g) wholemeal flour
 6oz (175g) raw sugar
 (muscovado or Barbados)
 6oz (175g) soft brown sugar
 3 large eggs
 6fl.oz (175ml) sunflower oil
 2fl.oz (55ml) soured cream or milk and
 a squeeze of lemon
 2 tsp vanilla essence
 1 tsp grated nutmeg
 2 tsp cinnamon
 1 tsp bicarbonate of soda
 1/2 tsp salt
 11oz (300g) grated carrot
 3oz (75g) coconut or other nut

Topping

4oz (110g) full fat soft cream cheese
 2oz (50g) unsalted butter
 2oz (50g) sifted icing sugar
 Juice of 1/2 lemon

**Ingredients**

750g uncooked medium prawns
 (or 500g frozen cooked prawns)
 2 stems fresh lemon grass,
 finely chopped
 1 tsp ground coriander
 2 tsp ground ginger
 200g sugar snaps or mange tout
 500g pasta
 2 tsp olive oil

For the sauce:

1 tsp cornflour
 2.5 Tbsp water
 2 Tbsp fresh lemon juice
 1 tsp grated fresh ginger
 70g butter (or margarine)

How to deal with Multiple Chemical Sensitivity by Dr. S Myhill

Do A Good Chemical Clean-Up: chemicals make you fat and fatigued! From Dr Sarah Myhill
We live in an increasingly polluted world containing an increasing number of toxic chemical which are toxic to our genes, to our brains, to our internal metabolism and to our immune system. These nasty chemicals almost certainly account for our ever-increasing incidence of cancer and birth defects and our declining fertility due to lifetime exposure. I believe they also make us more susceptible to chronic fatigue syndrome because they are toxic to the immune system, to the brain, to our hormonal control and our internal metabolism.

It is impossible to completely avoid every chemical - if I did blood tests I would find a wide range of organo-chloride pesticides in everybody. However anything which can be done to reduce the chemical load will be helpful in allowing our bodies to recover.

I was very interested by a book recently published "The Detox Diet" by Dr Paula Baillie Hamilton which explains how chemicals in foods and the air interfere with internal metabolism to make us fat and lethargic - indeed she points out that farm animals are deliberately fed hormones, antibiotics and pesticides to make them fat and lethargic, and therefore they do not have to eat so much in order to put on weight (cheap meat!). Many chemicals are persistent and concentrate up through the food chain - it is very likely that if we were the farm animal we would be declared too toxic to eat.

The following issues need to be addressed to reduce your chemical exposure:

Foods

- * Eat small amounts of the best quality food.
- * Choose foods grown as naturally as possible.
- * If organic food is available, go for it.
- * Eat foods as unprocessed as possible - most foods in tins or packages have preservatives or have been irradiated.
- * Eat foods which have not been plastic wrapped - the plasticizer gets into food.
- * Avoid foods wrapped in aluminium foil, or in aluminium cans.
- * Eat fresh foods - if they have to be stored, deep freezing is probably the least harmful method.
- * Contact the Soil Association or Henry Doubleday Research Association.

Water

A clean water supply is essential - the water companies are only interested in bacterial counts - they will not measure pesticide levels, heavy metals, hormone residues, volatile organic compounds or fluoride in your tap water. I consider bottled or filtered water an essential for potable use.

Clean air

- * If you can smell it, it can make you ill - the obvious offenders are air fresheners, sprays, perfumes, cleaning agents but there are a host of other chemicals in everyday use.
- * New paints and carpets (especially rubber backed, stuck down) out-gas toxic fumes for months after - use water based paints where ever possible.
- * Pesticides - dog and cat flea treatments, fly repellents, house fumigations, timber treatments all contain toxic pesticides which persist for months and years.
- * Gas central heating and gas cookers can make some people ill.
- * Carbon monoxide poise rung can present with CFS.

Cosmetics

Nearly all deodorants contain aluminium which applied to warm sweaty areas are readily absorbed. Aluminium is extremely toxic and has a known association with Alzheimer's disease. Perfumes and smellies can be a real problem especially with Multiple Chemical Sensitivity.

Garden chemicals

Many are extremely hazardous. Children should not be allowed to play on treated lawns for at least 6 weeks after spraying.

Drugs

Most CFS's know that alcohol makes them feel awful.

This is also true of many prescription drugs such as beta blockers, antidepressants, cholesterol drugs, diuretics, hypnotics etc. prescribed; each one should be tried with great caution.

* Head lice treatments contain pesticides and should not be used at all. Lice can be easily controlled with wet combing or electric "zappers".

Outdoor air pollution

Many industries discharge pollutants directly into the local air, water and soil. The worst offenders are power stations which burn toxic waste, manufacturing industry, nuclear power stations leaking radiation and the drug and chemical industry. Busy roads create traffic fumes. Nasty chemicals are dumped at toxic waste sites where they pollute ground water and soil. You need local knowledge to identify these issues, get further information from Friends of the Earth. Ask specifically about:

- * Heavy metals - arsenic, cadmium, nickel, copper, lead, aluminium etc.
- * Radioactive waste
- * Pesticide residues - organochlorines and dioxins, organophosphates, pyrethroids etc.
- * Small particulate matter (down to PMs 2.5 - don't settle for PMs 10)
- * Volatile organic compounds (VOCs) - solvents, benzene compounds
- * Polluting gasses (SOx, NOx, COx - sulphur, nitrogen and carbon compounds)

Good nutrition

This is highly protective against toxic stress - this is further reason to take nutritional supplements - we all have nasty toxins on board which cause on-going damage to the body. Good levels of antioxidants (vitamins ACE and selenium) help protect, good levels of B vitamins help detoxify, good levels of protein, essential fatty acids and other minerals help to repair the damage.

A good example of this in action came out of the research into thalidomide. This drug prescribed to women in pregnancy as a "pregnancy-safe hypnotic" caused serious birth defects if the women took it between the 38th and 42nd day of pregnancy. But not all babies were affected. This drug was tested in rats - no offspring were abnormal. This was a mystery to researchers, until someone had the bright idea of putting the rats onto nutritionally depleted diets. Then they started to get the foetal abnormality of phocomelia ("flipper limbs"). It was a combination of toxic stress (the drug) and nutritional deficiency which caused the problem to become apparent.

North of Doncaster. *Personal comment by Trevor Wainwright*

ADVOCACY versus SUPPORT GROUPS - What is the difference? Part 1

Many people think they are one and the same, but an anonymous article I came across during my days as an active campaigner shows that there is a difference. So let's have a look at them beginning with ADVOCACY:

An Advocate is a person who pleads for a cause or propounds an idea, but does not have to be a member of a support group; all though it may be considered a good idea. They recommend or push for something else or something new. They are the people who deal with the Rules, Laws & Facts. They do not accept the status quo and instead preach, speak or argue in favour of changes. They are the CHANGE AGENTS, or perhaps more simply they get off the fence and do what needs to be done.

To be a successful Advocate:

You don't need to know everything about the law, but you DO need to know the rules that can impact your cause.

It's important to connect with the people who support your cause on a regular basis in both casual and formal settings, continuous updating is paramount particularly if fundraising is involved so supporters know where their money is going

- Talk with patients, Doctors, government agencies and researchers. Help connect everyone involved
- Speak up when you have concerns, don't accept that those in authority are the experts, often they are not; be active in discussions. Solicit feedback. Offer supporting information.
- Keep good notes, records, files, examples, list of contacts and resources
- Be a good detective and gather information constantly:
- Read books; do research; Attend conferences/workshops
- Join a support group; participate in discussion lists; volunteer to help.
- Ask LOTS of questions; ask for details and clarification.
- Use the current 'jargon' or terminology. Stay up-to-date.
- Don't be shy; learn to be assertive, not aggressive.
- Take some calculated risks. Be creative. Think outside the 'box' when exploring solutions.
- Specify outcomes; request information and results in writing.
- Point out the positives and strengths of any plan; minimize any weaknesses
- Expect small, continuous improvements, but always look at the big picture.
- Focus on what's working and build on that; discard the rest
- Makes sure everyone follows through consistently so progress isn't impeded. Look for ways to keep relationships positive and productive.
- Don't sweat the small stuff. Keep your eye on the overall experience.
- Knowing the specifics of a law or regulation is helpful, but constant arguing over small details wastes time & makes it hard to work together.
- Remember every issue has at least 2 sides. Be sure to listen to all of them before you assume something is personal.
- 'Winning', or punishing someone you feel has treated you or others unfairly, is a waste of time and energy.

If you feel a change in roles or leadership is necessary, do it in a respectful and caring way.

Make every effort to be part of the solution and never part of the problem. Focus on the goal - negotiate the best possible outcome for all concerned. In all likelihood the patients are facing a chronic, life-long condition. Mastering self-advocacy will be one of the keys for successfully managing their lives. Each may not be ready right this minute to self-advocate, but in time it's important for them to know how and to do all that they can, when they can...for themselves and for the cause (illness).

The list goes on but Perhaps an Advocate is best summed up in an adaptation of a marking from Dag Hammarskjold, written in 1955 but still relevant today:

They break fresh ground because they have the courage to go ahead without asking if others are following or even understand. They have no need for divided responsibility in which others seek to be safe from ridicule.