

DLAAB UPDATE

The News sheet of the Disability Living Allowance Advisory Board

Issue No 4

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The Disability Living Allowance Advisory Board

There have been some changes to the membership of the Disability Living Allowance Advisory Board since Issue 3. Currently we are:

Chairman	Professor Rodney Grahame CBE
Vice Chair	Mr Sam Gallop CBE
Deputy Chair	Mrs Anne Spaight
Members	Mrs Simone Baker Dr David Cohen Mrs Jean Cooper Mrs Judith Holt Ms Marilyn Howard Dr Lee Illis Dr John Keen Dr Richard Lucas Dr Ian McGill Dr Audrey Oppenheim Mrs Clair Poole Miss Cynthia Smith Mrs Marion Westacott Mrs Christine Whitehead Mr Adebayo Williams

From The Editor

It has been a year of changes in case you had not noticed. Instead of the twice yearly workshops for Decision Makers, some Board Members have visited Disability Benefit Centres and had some very useful dialogue with Decision Makers at the coal-face, so to speak. As this approach continues to be rolled out, I hope that some of the questions asked and answers given will, in future, be incorporated into the text of appropriate Updates.

My co-editor has now completed his term of office on the Board, hence the delay in producing this edition of Update, which I hope you will find interesting.

Please remember that your feedback is crucial, so keep it coming.

The editors welcome letters, requests for future topics and comments on articles in DLAAB Update.

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“Health Warning” Please note – the articles contained in this news sheet are written for the benefit of decision makers, to help them with their job. The articles are *not to be quoted* in any decision or communications with members of the public or their representatives.

MULTIPLE SCLEROSIS

Multiple Sclerosis: Could any diagnosis be more devastating? Rapid decline into neurological hell, total care needs, wheelchairs.....wrong!. Granted there may be some adjustments necessary, and some bad days as well as good, but many people with multiple sclerosis lead normal, active and fulfilling lives.

Multiple sclerosis (MS) affects about 80,000 people in the UK and is commoner in females by 3:2. Caucasians are at highest risk, which also seems to increase with distance from the equator: It affects about one person in a thousand in Southern England, but almost twice that in Northern Scotland. It is also common in Scandinavian countries and in people with Scandinavian ancestors.

MS is a chronic disease characterised by the formation of many small plaques throughout the body's nervous system, causing a variety of neurological symptoms. The course of the condition varies widely from patient to patient, There are broadly four types of MS:

- benign MS: minor symptoms only, no worsening with time
- relapsing-remitting MS: affects 60% of patients and most people start with this type; relapses are variable in severity and duration, and may justify hospital admission; between relapses a good functional recovery is made
- secondary progressive MS: with incomplete recovery from relapses, representing a progression from relapsing-remitting type
- primary progressive MS: 10% of patients have this steadily worsening condition with no relapse/remit pattern

If MS is mild, life expectancy is not affected. After a first attack, patients may go some years before further symptoms develop.

Symptoms

MS may present with any of a wide range of symptoms, indistinguishable from other more common conditions. However it commonly starts with visual loss, or progressive weakness of the legs.

Other symptoms might include;

- balance and co-ordination problems
- muscle weakness, stiffness or spasm
- blurred or double vision
- fatigue
- bladder, bowel and sexual dysfunction
- numbness or altered sensation
- pain
- speech, language and communication problems

- rarely, those of epilepsy, dementia or euphoria
- very rarely, uncontrollable laughing or crying

Treatment

Drug, physical and psychological treatments aim to control symptoms, treat acute attacks, or modify the disease process.

Currently Britain is exhibiting a conservative approach to the use of the new disease-modifying therapies such as Interferon and Glatiramer Acetate – an MS patient in America is twenty times more likely to receive treatment than in this country - due to high cost. A recent innovative and widely-supported risk-sharing plan has been introduced to correct this, whereby some of the cost for ineffective treatment is borne by the supplying drug company.

Care Needs

These vary depending on the severity of the MS and the symptoms present (see list above). In particular, incontinence and muscle stiffness lead to greater care needs.

Mobility

Mobility can be affected by muscle weakness and stiffness, but also by problems with balance and co-ordination. During relapses, mobility may be very poor but can recover significantly afterwards.

Further Evidence

Most patients with significant MS will be under the care of a hospital, either a neurologist or rehabilitation specialist, and in some cases a specialist hospital MS unit; staff in these (eg. occupational therapists or specialist nurses) may be better placed than GPs to provide helpful information, as their involvement may be greater and more up-to-date.

MS – A PERSONAL VIEW

Imagine. You are standing alone in your bedroom. The house is quiet. You close your eyes, you feel nervous, expectant. Taking a deep breath you put a foot forward and begin to walk across the room. Every fibre of your being is screaming at you, willing you to walk. Your legs turn to jelly and crumple underneath you, twisting as you fall, you hit your arm against something on the way down. There you are on the floor – again. You pick yourself up, carefully going down the stairs. You make a coffee and carry it slowly to your table. You sit. You pick up a pen and stare at form DLA 1A. Now you must convince a decision maker at the Benefits Agency that you have MS and are ‘virtually unable to walk’. You can’t believe it yourself. You don’t want to believe it. The application for DLA is essential but it is also the first ‘label’, the first step into the world of the ‘disabled’. It will lead to orange/blue badges.

A new world where you look at a car in terms of fitting a wheelchair in it instead of a surfboard.

As a person with MS, I was first tentatively diagnosed in Plymouth in 1993. Mild symptoms were followed by assurances that many people with MS have only the odd relapse and lead a full and normal life. With 3 children under 10, I hoped so. Two weeks later, my husband of 15 years walked out. Three years on and I was in London. I had a GP who knew nothing about MS and an 8 month wait to see a neurologist. During this time I was constantly told I was fine. Whatever symptoms I had were as a result of ‘a non-organic cause’. I wished that my problems were of a psychiatric nature – that could be treated, cured. For those 8 months I put myself through hell, telling myself over and over that I was fine, I could walk, I must be imagining the pain.

Then the neurologist – “Of course you have MS. No doubt about it. No, nothing we can do. Fill in a form for DLA, the money will help. Good grief woman, it’s no good making a fuss, you could have something serious like Motor Neurone”.

This was the frame of mind I was in as I sat down to fill in my DLA application form. I just wrote what I felt. The unfortunate Decision Maker must have had a hard job picking out specific facts from the emotional ramble. I remember writing about my gait – “ I look like I have drunk a half bottle of vodka when I take my son to school, on a good day”.

I backed up my claim with evidence from my OT and my neurologist filled in Statement 2. A doctor came and visited me at home. She was businesslike, but I felt as if I was on trial – would she understand what I was saying when I had problems believing it myself?

That was in 1996. I was given a 2 year HRM award. By the time my next assessment was due I had transferred to the National in Queen Square, London, was on Beta Interferon and had a few MRI’s to add weight to my diagnosis. I now had a lifetime award of HRM.

I agree with DLA being a self assessment benefit with additional evidence being given if needed. As my experiences were very common I would say look out for understatement in MS cases. The lack of additional medical evidence could well be because the client hasn’t had access to a specialist, or could still be waiting. A real problem for those of us with MS is getting a diagnosis. For many of us that can take a year or more even if we are living with severe symptoms.

Sometimes the delivery of a diagnosis can cause a sense of relief as there are many other possible causes of the same symptoms. The “Thank God it’s only MS” feeling is something most of us with the disease have experienced. This may lead us to understate our symptoms when filling in forms. MS causes a huge variety of symptoms and most of us who live with it try to cope with whatever it throws at us. The hardest part is the uncertainty. The award of DLA is a huge help. With access to other benefits it can often be the first positive thing to happen to us for a long time.

C. Poole

OBSERVATIONS ON THE MEETING BETWEEN REPRESENTATIVES OF THE THALIDOMIDE SOCIETY AND THE DISABILITY LIVING ALLOWANCE ADVISORY BOARD – 30 APRIL, 2002, LONDON

The first presentation was made by REACH Association for Children with upper limb impairments. Sue Stokes reported on the problems facing parents of children with upper limb disabilities in receiving DLA.

It was suggested by Board members that the DLAAB website (part of the Government website) had the handbook which Decision Makers use and this could be accessed for guidance and guidelines for individuals and their advisers.

A points system was discussed particularly with reference to people with limb 'deficiencies' as this might help to standardise assessments.

The Thalidomide Society was then invited to present evidence to the Board through their representatives, Vivien Kerr, Co-ordinator, and Edward and Geraldine Freeman. Vivien gave brief background details about the inception of the Society, its activities, its funding, and its membership. Vivien also spoke about the deteriorating health being experienced by Thalidomide impaired people and mentioned the recent research project. The Board requested a copy of the full report and it was agreed that a copy would be forwarded to them.

The Society had conducted a survey of its members. The results showed an apparent discrepancy between people with similar upper limb impairments and the awards made. A number of issues were raised and debated as follows;

- the necessity for people to avoid injuring themselves because it would incapacitate someone who otherwise could manage their disability
- it appeared to be unnecessary for someone with the higher rate of care to be assessed at regular intervals – it was possible to make a note that it should be an indefinite award
- claimants need to look at themselves holistically when trying to assess what they could and could not do
- keeping a diary might be an effective way of a claimant assessing what they could and could not do – this issue was particularly emphasised by Eddie and Gerry who pointed out that as children they had been encouraged to be as physically independent as possible. This had not only had the effect of over-use of some limbs and/or parts of the body, but made it psychologically difficult for people as adults to ask for help
- equipment which solved a need should not be an automatic shut off to claiming DLA or applying for a re-assessment
- with reference to artificial limbs, the assessors do take into consideration the enabling factor in the use of artificial limbs
- the possibility of sending a photograph of the claimant (sitting in a chair etc) attached to the claim form was discussed.

THE THALIDOMIDE SOCIETY

MEETING WITH REPRESENTATIVES OF THE DISABILITY LIVING ALLOWANCE BOARD – 30 APRIL 2002

The following statements have been compiled to illustrate some of the issues facing people with thalidomide impairments.

Personal care

Many Thalidomide impaired people (TIPs) who rely on using their feet and toes in place of arms and fingers are finding that over-use of their lower limbs means knee and hip problems which take away this ability, and therefore their ability to manage some tasks.

People who have a Closomat toilet, and can manage toileting with a Closomat may say that they can manage toileting (even though outside of the home they cannot).

The length of time personal care takes, ie, it may take up to four times as long to wash hair, to dry after washing, to dress.

Many TIPs have noticed recent degeneration, as they are no longer able to contort their once supple bodies into positions to continue personal care (ie, dressing, washing, climbing in and out of the bath/bed).

The majority of TIPs experience 'overheating', whereby any amount of physical exertion means they break out in a sweat. When dressing, this can cause problems, as often the ability to dress and undress relies on the ability to slide clothing around on the body. When sweating, this becomes impossible.

Injury (even slight, such as a stiff shoulder) can often mean that somebody is unable to carry out personal care until the injury has healed.

Preparing and Eating meals

Preparation of food is sometimes difficult and presents danger. Cutting vegetables is often done in close proximity to the body because of reduced arm length. Lack of thumb and fingers means reduced grip and strength.

Carrying hot dishes has to be done in proximity to the body because of reduced arm length. This presents a hazard.

Lifting and moving pans full of food is difficult for the same reasons.

Cutting food once on the plate is difficult for the same reasons.

Taking Medication

Many TIPs, because of lack of a thumb or fingers, may find it impossible or very difficult to open medicine bottles, or to remove tablets from blister packs.

Lack of the fine ‘pincer’ grip movement means it is very difficult to pick up small items, such as coins, pills.

Difficulty in taking inhalers (lifting to mouth, triggering action without use of a thumb).

Mobility

Many TIPs are now facing reduced mobility because of joint degeneration.

Obesity is a problem amongst many TIPs because of the inability to exercise.

Often in the case of somebody with severe upper limb shortening, balance is affected. Being able to regain balance after a trip is difficult, and often injury can be severe, as when falling a TIP is unable to break their fall by extending their arms and hands forwards. Following a fall, TIPs often find it difficult to get back onto their feet (not having use of arms and hands to push themselves up off the floor, this all has to be done with the legs). Often passers by are unable to assist, as they are not certain of how to lift somebody with total or almost total absence of arms.

TIPs with very short arms (ie, hands at the shoulder) are unable to carry items.

Many TIPs find it difficult or impossible to wear outdoor clothing such as coats and jumpers because the thickness of these garments causes restriction and means they are unable to then get their hands together in front of them.

Popular ‘myths’ amongst Thalidomide Group with regard to DLA

- The benefit is means-tested. I work, I have an income from the Thalidomide Trust, therefore I would be ineligible
- I live alone, and manage my personal care with some difficulty, but I would be ineligible because nobody lives with me to help me with personal care tasks
- I can walk, even though I can’t walk far and I get a lot of pain and/or severe discomfort, so I wouldn’t be eligible for the mobility component
- I have lots of gadgets (ie, electric tin opener, dressing stick, tumble drier, dishwasher) so I would be ineligible
