

DLAAB UPDATE

The News sheet of the Disability Living Allowance Advisory Board

Issue No 2

This is the second of the newly styled DLAAB Updates, under new editors – the Deputy Chairs.

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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 recently, currently we are:

| | |
|----------------------|--|
| Chairman | Professor Rodney Grahame CBE |
| Vice Chair | Mr Sam Gallop OBE |
| Deputy Chairs | Dr Ian McKinlay Mrs Anne Spaight |
| Members | Mrs Simone Baker Dr David Cohen Mrs Jean Cooper Dr Margaret du Feu Ms Marilyn Howard Dr John Hunter OBE Dr Lee Illis Dr John Keen Dr Richard Lucas Dr Ian McGill Mrs Clair Poole Mrs Marion Westacott Mrs Christine Whitehead Mr Adebayo Williams |

FROM THE EDITORS

At last, a belated DLAAB Update.

The editors apologise for the delay in publishing this paper. However, the delay has not been without merit. During the summer we received feedback - something we have been trying to encourage, from decision makers, which was extremely helpful. Consequently the articles were edited in such a way to reflect the content the decision makers wanted. The editors are very open to any suggestions regarding DLAAB Update, so please feel free to make any constructive comments and we will try to respond.

Please enjoy the Update.

Merry Christmas and a Happy New Year.

PARAPLEGIA AND TETRAPLEGIA

Introduction

Damage to the spinal cord will result in paralysis and loss of sensation. PARAPLEGIA involves both lower limbs and results from damage to the thoracic and lumbar region of the spinal cord (middle and lower part of the back). A person with paraplegia will suffer from paralysis or weakness, sensory loss or impairment, and bladder / bowel function loss or impairment.

TETRAPLEGIA (QUADRIPLEGIA) involves all 4 limbs and results from damage to the cervical region (neck). A person with tetra/quadriplegia will suffer similar problems as in paraplegia but to a larger and wider extent. There may also be paralysis/weakness of their arms and hands.

Care and Mobility

The resultant disability from either of the above is major. As far as mobility is concerned, the subjects are unable to walk unless they have a very low spinal lesion.

The care need will be influenced by whether or not the subject has learned to transfer. Where loss of sensation has occurred (in nearly all cases) then there is the problem of the development of pressure sores. Bowel and bladder dysfunction may be dealt with by self-catheterisation, a penile sheath, absorbent pads, medication and enemas.

Subjects with paraplegia are usually expected to attain a fair degree of independence but even so, significant help may be needed at the beginning and at the end of the day and there are likely to be night needs. The repeated breakdown of pressure sores or repeated urinary infections indicates that care is not adequate and more help is needed. Older people lack stamina and strength and are more likely to need care. All

these problems may be significantly aggravated by a failure to adjust psychologically, and may be compounded by any associated brain damage particularly in a traumatic spinal lesion.

Subjects with tetraplegia have all the problems of paraplegia but much worse.

Care Needs

These are dependent on the level at which the damage has occurred. Being able to transfer, eg., from chair to bed, will influence independence, as will the ability to balance and lean in sitting.

The brief guide here gives a picture of the dependence / independence of the person, according to the level of the lesion.

Lesion Level

| | Independent | Assistance | Dependent |
|----------------------|---|---|--|
| 1. Neck | Various from talking / swallowing only to being able to transfer and use wheelchair. Some can use an adapted car. | Various from breathing, coughing, feeding to assistance with dressing, standing (standing frame). | Various from feeding, turning, washing. All will need help with toileting. |
| 2. Trunk | All personal needs. | Standing (with callipers / frame). | |
| 3. Lower back | May be able to walk with crutches. Some can walk with short callipers and sticks. | | |

Duration of Needs

The exact duration can rarely be given with any accuracy. The rehabilitation of a subject to the best potential usually takes about two years. Most subjects with paraplegia become well adjusted and well rehabilitated but even so they still usually need care at the beginning and the end of the day. A subject with tetraplegia is going to need ongoing care.

Further Evidence

In non-traumatic cases of paraplegia the cause *must* be identified. A hospital report is necessary. In spinal cord injury a report from the patients' spinal injury unit is almost always necessary.

MOTOR NEURONE DISEASE

What is Motor Neurone Disease

Motor Neurone Disease or MND is the name given to a group of related diseases affecting the motor neurones in the brain and spinal cord. Motor neurones are the nerve cells that control muscles and their degeneration and or death leads to muscle atrophy or wasting.

MND is a progressive disease for which the cause is unknown. Its onset occurs most frequently between the ages of 40 and 60 years, but sometimes younger people can also be affected. It is important to remember that MND affects individuals very differently.

Life expectancy following diagnosis varies. Modern medicine and technology has helped to increase it, but nevertheless 14 months average is common. There are approximately 5,000 people living with MND in UK, with an average of 3 people dying each day.

Symptoms of MND

The first symptoms of MND will depend upon which motor neurones are mostly affected and how severely they are damaged. When it is a bulbar presentation the first symptoms are problems with Speech and Swallowing. This can lead to respiratory difficulties and a poor prognosis. When the presentation starts with weakness of the upper and / or lower limbs, finer movements are affected and mobility becomes impaired. The muscle weakness progresses with time, eventually leading to complete loss of function.

Care needs and mobility considerations

The care and mobility needs of someone with MND will depend on the extent of the muscle weakness and whether or not there is bulbar involvement. The speed at which these symptoms occur is clearly a crucial factor in the care needs of people living with MND. However, the need for help with, for example, dressing, undressing, toileting and personal care are often present from the beginning.

Upper limb involvement may cause care needs such as getting in and out of bed or a chair, or to turn in bed at night.

Weakness in the legs, causing mobility difficulties, may be presenting symptoms before diagnosis is confirmed.

The average life expectancy from first symptoms of MND is two to five years. However, the average time from diagnosis to death is 14 months. This delay in diagnosis is due to difficulties in confirming MND.

Practically, there may be significant care and mobility needs by the time diagnosis is confirmed.

Further evidence

This may be obtained from hospital consultant or from nurse specialists, physiotherapists, occupational therapists, or speech and language therapists.

PATHOPHYSIOLOGY AND MANAGEMENT OF THE POST-POLIO SYNDROME - A CRITICAL REVIEW

A recent conference reviewed past and present research into polio and Post Polio Syndrome.

The management of PPS was explained by various speakers, who described some of the difficulties which have to be overcome when considering surgery or respiration or orthotics.

In each case, any intervention had to be considered in the light of effect on independence. The majority of people with PPS are living independent lives, whether ambulant or in wheelchairs. In surgery, therefore, it had to have maximum benefit in order to be considered, for example, correction of spinal curvature to aid respiratory function, or shoulder intervention to allow for continuing crutch-walking.

The main speakers gave an 'across the pond' perspective, citing a US study in Minnesota, and a UK study in London.

Both studies reviewed medical records, used questionnaires, and laboratory and disability tests to ascertain the effects of polio on people several years following the acute illness.

Interestingly, both studies were inconclusive about what exactly is going on with PPS but both admitted that in some PPS sufferers symptoms of fatigue, pain and neuro-muscular weakness were obviously present but had no scientific explanation.

The most enlightening talk came from Tony Gould, himself a polio victim of many years, who has and is leading an independent life against some severe mobility problems. He described a 'polio' mentality of determination but also admitted that even a minute loss of muscle power could 'tip the balance' in the fight for independence versus dependence.

Post Polio Syndrome is little understood. That symptoms of fatigue, pain and muscle weakness has an effect on a person's ability to walk, to manage activities of daily living, which may then result in both mobility and care needs.

As a result of PPS symptoms, a previously mobile, self-caring person, may become virtually unable to walk or wheelchair bound, resulting in perhaps a higher rate mobility claim.

With regard to care needs, consideration may be given to the description of the effect of severe fatigue and/or muscle weakness on daily activities, including ability to prepare and eat meals.

Night needs may result if sleep is impaired which was highlighted by one of the speakers as being prevalent in PPS sufferers.

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