

DLAAB UPDATE

The News sheet of the Disability Living Allowance Advisory Board

Issue No 3

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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 2. Currently we are:

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| Chairman | Professor Rodney Grahame CBE |
| Vice Chair | Mr Sam Gallop OBE |
| Deputy Chairs | Dr Ian McKinlay OBE Mrs Anne Spaight |
| Members | Mrs Simone Baker Dr David Cohen Mrs Jean Cooper Mrs Judith Holt Ms Marilyn Howard Dr John Hunter OBE 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 |

A NOTE FROM THE EDITORS

Much has happened since the last publication of the DLAAB Update, including some very interesting and informative meetings with a variety of organisations. As a result, we hope that you find the contributions in this Update helpful. We would like to thank the authors of the articles in this issue for their helpful contributions.

We are always willing to make the Update useful to its readers. If you are a Decision Maker and have dealt with a case where a decision has been made that has raised new or interesting medical questions, and you would like the Board to comment, please let us know. We are not able to use the DLAAB Update to offer advice in particular cases, but are happy to draw on the Board’s expertise and bring new or interesting medical issues to a wider audience. You can do this by contacting us via the DLAAB Secretariat, by phone, fax, letter or e-mail.

Likewise, if there are specific topics you would like us to write about, then just let us know.

Finally, we hope you enjoy this edition of Update and wish you all a very happy Christmas and New Year.

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.

INFLAMMATORY BOWEL DISEASE

What is it

Inflammatory bowel disease (IBD) is a condition in which the gastro-intestinal system (the gut) becomes chronically inflamed.

There are two types: **ulcerative colitis (UC)** and **Crohn's disease**.

The cause of both types is unknown, although there is a genetic element. Recently a link between Crohn's and the MMR vaccine has been suggested, but this is not supported by scientific evidence. Interestingly UC is up to six times more common in smokers, but Crohn's is exactly the opposite – it is up to six times more likely in non-smokers (a rare example of a health benefit from smoking).

IBD tends to affect people in their teens and twenties.

Symptoms

These vary enormously, from none at all or very mild, to severe. Commonly they include diarrhoea, abdominal pain and rectal bleeding.

In severe cases, the diarrhoea can be 10 or more times per day and at night, with great urgency to start. There can be significant weight loss, malnutrition and poor general health.

How does it develop

Most people suffer a single first attack which settles on treatment; they may then go on for many months or years with very minor symptoms or none at all.

Some people settle into a pattern of remission with some occasional acute attacks.

A small number of people do not respond well to treatment; they may ultimately require an operation to remove the diseased part of the gut, probably leading to a stoma (artificial exit point for the gut), which collects waste into a plastic bag.

Care needs

These usually arise in the most severe cases only, when the IBD has had a significant effect on health, leading to frailty and general debility.

Those people who have a stoma can generally manage these well, unless other complications (such as poor eyesight or co-ordination) are present.

However, there is often considerable scope for clinical improvement (stomas can be reversed, and malnutrition and debility corrected); the care needs would reduce accordingly and therefore restricted awards with a review may be appropriate.

Mobility needs

IBD causes no direct effect on mobility and all but the most severe cases will be able to manage independently.

Further evidence

The medical care of people with IBD is usually shared by GPs and hospital consultant physicians (usually gastro-enterologists). Either should be able to provide helpful reports.

HEPATITIS C

This is inflammation of the liver caused by a viral infection and can be transmitted by blood to blood contact. It may also be found in other body fluids such as semen and saliva. Those infected with Hep C generally have the virus through:

- Transfusion of blood or blood products where blood has not been tested for Hep C virus
- Sharing of contaminated needles
- Tattooing and skin piercing with non sterilised equipment
- Mother to baby transmission (rarely)
- Sexual transmission (on rare occasions)
- Unknown causes and occupational transmission (healthcare workers).

Current evidence suggests that only 20% of individuals who have been infected with Hep C appear to clear the virus from the blood, whilst 80% will remain infected and can pass the virus to others. If a person continues to be infected they could develop the following complications:

- Chronic hepatitis
- Liver cirrhosis
- Liver cancer.

All the implications of Hep C are not known; there is a lack of scientific and medical knowledge on the subject. Current thinking is that the majority of people with the virus will remain well, but a proportion will go on to develop severe liver disease. Some individuals have become co-infected with Hepatitis C and HIV, the majority being people with a history of intravenous drug use, by sharing needles with an infected user.

Symptoms and prognosis

There is a range of symptoms associated with chronic Hepatitis C and a range of severity. Some people will have no symptoms at all. Some will feel tired, out of sorts, generally ill, lacking in energy and depressed.

The prognosis is very hard to judge, particularly for people infected as children. Research suggests that liver disease may progress more slowly in those who get Hep C virus as children than those who get Hep C in later life. However more research is necessary.

Treatments

Those infected should limit alcohol intake, and may be advised to avoid fatty foods and follow a low salt diet. Interferon and Ribavirin combination therapy is most commonly used. Ribavirin is a capsule taken twice daily and Interferon is injected into the fat under the skin, usually 3 times a week.

The side effects can be considerable. Commonly people experience flu-like symptoms with muscle aches and nausea. In more severe cases depression, thyroid problems, hair loss and anaemia can occur. The side effects may force some people to stop treatment.

Care and Mobility needs

Needs will vary greatly according to the stage of the disease. Many will cope well with independent living; others who are symptomatic will experience adverse effects on function and mobility.

HAEMOPHILIA

The general term haemophilia describes a group of inherited blood disorders in which there is a lifelong defect in the clotting mechanism of the blood. It affects about 6000 people in the UK, occurring almost exclusively in males. It is an inherited condition, whilst males have the condition, it is passed through the female line of the family.

In most cases, minor cuts and scratches do not pose any problems for a person with haemophilia. For those severely affected the major problem is internal bleeding into the joints, muscles and soft tissues. Without treatment there follows pain and stiffness, limitations of use, and the site of the bleed will become swollen and tender.

The majority of bleeds occur into the large joints of the elbows, knees and ankles. These internal bleeds can vary in frequency from three or more times a week to three or four times a year in the same person. Children tend to bleed more frequently than adults.

Treatment

Haemophilia is treated by replacing the missing clotting factor. This has to be given into a vein by intravenous injection. Initially these injections have to be given in hospital. As a child

grows, his parents learn to give the injections at home. Eventually the person with haemophilia learns to give his own injections, usually when he is a teenager.

Prophylaxis treatment is now commonplace, in which injections are given regularly, usually two or three times a week to prevent bleeding.

Effective treatment for bleeding has only been readily available since the early 1970's, so it is noticeable that older people with haemophilia are more severely affected by arthritis and joint deformities than youngsters who have benefited from modern therapy.

Hepatitis and Haemophilia

Approximately 4000 people with haemophilia have been infected with the hepatitis C virus as a result of contaminated blood products. In the mid 1980's heat treatment to destroy viruses in blood donations was introduced and since 1986 no clotting factor concentrates should have transmitted hepatitis C.

HIV and AIDS

Approximately 1220 males in the UK with haemophilia were infected with HIV as a result of injection with contaminated blood products; many of these have died subsequently.

Care and mobility

The majority of people are able to lead normal lives. People with severe haemophilia learn to treat themselves at home or at work and can travel and play an active part in work and social life, carrying their treatment with them. For others arthritic deterioration in damaged joints can lead to constant pain and limited mobility.

NARCOLEPSY

Narcolepsy is a rare neurological disorder which comprises two main symptoms: sleep attacks and sudden unpredictable loss of muscle tone. Both symptoms are usually very frequent occurring many times each day and cause involuntary episodes of unconsciousness and paralysis. Some sufferers exist in a persistent state of jet lag; paradoxically some are very alert between episodes.

The fundamental problem is the inability to stay awake which causes paralysis and loss of awareness. This results in both transient motor and intellectual defect. These continue throughout life and in that sense are irreversible.

The condition is lifelong and does not remit. There are varying levels of disability in different subjects but in severe cases, despite treatment, a number of sufferers will become chairbound.

There is no treatment specifically for the condition. Any drugs used cannot address all the symptoms and side effects can and do lead to further serious illness and debilitation.

At best, treatment may partially alleviate symptoms on a temporary basis but cannot ever normalise the situation and cannot be relied upon in any situation. The best that can ever be hoped for is some form of therapeutic management which includes drastic lifestyle changes and use of class A drugs and knowledge of the fact that these episodes will occur frequently.

Narcolepsy is a very poorly understood condition, even within the medical world. It is frequently misdiagnosed and confused with respiratory sleep related conditions or epilepsy, or “laziness”. There is no disease relationship to any of these. It is none of those things. The pathology is now known to be neurological, centred on the hypothalamus, and research confirms there are at least two further major symptom areas – those of autoimmune failure and metabolism defect.

It should be pointed out that although triggers for motor failure can include emotional stimuli, it is important to understand the concept that this is effect, not cause.

With no cure on the horizon, it must be accepted that narcoleptics will continue to suffer frequent episodes of unconsciousness and paralysis. Some may never be fully alert and some will be very alert between episodes.

NOT TO BE QUOTED IN DECISIONS