



Disability Living Allowance Advisory Board

NEWS & UPDATE

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Topics for Future Issues

- ◆ Epilepsy
- ◆ Learning Disabilities Amongst Adults
- ◆ Severe Mental Impairment
- ◆ Laryngectomies

If DM's have any questions on these issues, please contact us.

INTRODUCTION BY THE CHAIR

Hello Everyone,

Welcome to Issue 4 of the DLAAB News Update. Throughout this year we have tried to include in these News and Updates topics which we know cause some difficulty to decision makers. Issues on conditions affecting children are common so I hope that you will enjoy the article on Autistic Spectrum Disorder.

Another topic highlighted to us as an issue causing some problems is Disability associated with Chemotherapy and Radiotherapy so we hope that this article will also be of use to you.

Yet another year has almost passed and we hope that the information in the 4 issues this year has been helpful.

Anne Spaight
Chair DLAAB

AUTISTIC SPECTRUM DISORDERS

DR. BEN KO

What are Autistic Spectrum Disorders (ASD)?

These are developmental disorders. People with ASD have significant difficulties in three areas (known as the 'triad of impairments'):

1. **Communication:** some may not develop useful speech at all and others use speech in a peculiar way, such as saying the same thing over and over again, whether it is relevant or not. Their communication problem goes beyond speech. They are poor in using gestures and facial expressions to communicate. They may interpret what others say to them in a strictly literal way.
2. **Social interaction:** they have difficulties in developing the instincts of behaving in a socially acceptable way. They may get into trouble by upsetting other people without realising. Conversely, they may be taken advantage of because they are socially naïve. Many do not show interest in socialising or interacting with others. They may appear to be in a world of their own, or very passive. Others may seem to be intrusive.
3. **Social imagination:** They tend to have obsessive and repetitive behaviour. They have difficulties in coping with changes in environment and routines. Some may have unusual obsessions, phobias and rituals. Strange mannerisms and stereotypical gestures

e.g. hand flapping, spinning of body, unusual way of walking etc. are common.

What are the different kinds of ASD?

For most practical purposes, individuals with ASD can be divided into two main groups:

1. **Classical autism:** 70% of people with ASD have an IQ of less than 70, that is, significant learning difficulties. Many of them do not develop speech properly. Challenging behaviour is common. Their families need to develop strategies to cope with their obsessive and ritualistic behaviour. They tend to have more severe needs.
2. **High functioning autism:** their difficulties may be more subtle, depending on their underlying cognitive ability ('intelligence'), and their family and social environment. They may have challenging behaviour, fail to achieve their potential, become victims of bullying etc. They might not function independently in society, and need a lot of support. Others could be coping so well that they may not even be identified or diagnosed.

Other forms of autism:

People with **Asperger's syndrome** are those with high functioning autism, who also appear to have normal speech and language development by 3 years of age. Nevertheless they do have communication impairments, as they may use speech in a non-communicative way, for example interpreting others literally. There is very little real difference between older children and adults with Asperger's Syndrome and those with high functioning autism.

Semantic Pragmatic disorder is a condition where individuals have major communication difficulties due to inappropriate use of speech and language. They speak in a similar way to those with autism. It is not such a popular diagnosis, and many professionals consider this merely a descriptive term for the nature of communication difficulty found in verbal people with autism.

No two individuals with ASD are the same. Some may have difficulties in all three areas, and others mainly in one or two areas. They have different cognitive abilities that influence their level of functioning greatly. Hence the concept of a 'spectrum' of disorders was developed.

What causes ASD?

The exact cause of ASD is not known. It is thought that it may be caused by a combination of factors, and there is a very strong genetic component. There is no scientific evidence that the MMR vaccine causes ASD. Some medical conditions are associated with ASD. The most notable conditions are Fragile X syndrome (a chromosome disorder), Tuberous Sclerosis (an inherited condition affecting the nervous system) and Rett's Syndrome (a neurodegenerative condition affecting females).

Who is affected?

The number of people diagnosed with ASD is on the rise. This is partly due to a change in the criteria for diagnosis and increased awareness. More boys are affected than girls. It affects individuals of all races. Its prevalence is estimated at 91 per 10,000, or a total of over 500,000 individuals in the UK

How are individuals recognised and diagnosed?

Children with classical autism usually present early, before the age of 5 years, often with speech and language delay, and/or unusual behaviour. Individuals with high functioning autism and Asperger's syndrome may not appear to have difficulties until they are at school, where they fail to socialise, not making friends or causing disruption. But looking back, their problems could be traced to a much earlier age. Diagnosis requires detailed assessment by a child development team, led by a paediatrician, sometimes with child psychiatry or psychology input. This is often a lengthy process, with long delays between presentation and the diagnosis being made. It is likely that many affected persons have not been diagnosed.

What other developmental problems may be present?

In addition to learning difficulties, children with ASD have a higher chance of having other developmental problems, such as developmental coordination disorder (or 'dyspraxia' – see recent article in DLAAB). ADHD has also been described. All of these add to a more demanding profile of needs.

What are the personal care needs?

This depends very much on the underlying intelligence of the person. The presence of coordination problems can make this worse. Many individuals need more help than an average child till they are much older. Some may need extra supervision because of their challenging behaviour, e.g.; unawareness of danger may lead to individuals

putting themselves and others at risk. Sleeping problems are more common than in the general population, which may have nighttime care implications.

What are the mobility needs?

Most people with ASD have no physical difficulty in walking. They may need supervision for going out as a result of their learning difficulties or challenging behaviour. Sometimes their obsessions or phobias make it difficult for them to get about without supervision.

What is the long-term outlook for affected individuals?

Once again this depends largely on the underlying intelligence. In common with other developmental problems, children tend to improve to a certain extent over time. Some individuals may live independently when they grow up, and are gainfully employed, and indeed achieve in careers. Others may need support all their lives.

What are the sources of information that may help with decision-making?

It would be helpful to have a paediatrician or child psychiatrist's report, to confirm the diagnosis claimed. These may give information on intellectual or cognitive abilities, and could be extremely helpful. A school report and/or a social worker's report that include details of the support provided at home and at school will give some indication as to the level of needs.

Further reading and information on ASD

L. Wing (1996) *The Autistic Spectrum: A Guide for Parents and Professionals* (Constable: London)

The National Autistic Society produces a catalogue of information leaflets, which are very worth looking at. These are placed on their website: <http://www.nas.org.uk>

Disability Associated with Chemotherapy and Radiotherapy

Dr Ian McGill

Many malignant cells are more susceptible to the lethal effects of poisons and ionising irradiation than normal cells, and this difference forms the basis of chemotherapy and radiotherapy.

These anti-cancer treatments can be given in a number of settings.

1. Topical. The treatment is applied to a superficial limited area. This type of treatment is often used for skin cancers, and usually results in minimum impairment of function.
2. Neo-adjuvant. The treatment is given before the definitive treatment (usually surgery) to enhance the effectiveness of that treatment, or to make a tumour more easily removable.
3. Adjuvant. The treatment is given shortly after the definitive treatment to destroy malignant cells which have spread beyond the tumour (metastases), but which are at that time undetectable. The objective is to prolong disease free survival if metastasis has occurred.
4. Palliative. The treatment is given with the prime objective of the relief of distressing symptoms. If effective, such treatment may prolong survival, but this would be regarded as a bonus. Radiotherapy can be used to treat localised lesions, such as a metastasis in a bone. Chemotherapy may be used to treat more widespread disease, such as multiple metastases in liver or lungs.
5. Radical. The treatment is given with the objective of complete eradication of the malignant disease. This may entail radiotherapy (as in the treatment of some types of prostate cancer), or chemotherapy (as in the treatment of acute leukaemia), or a combination of the two modalities. Very high cure rates follow such treatments for testicular cancer, and many lymphomas such as Hodgkin's disease.

Some malignancies may be treated with a single chemotherapeutic agent, or low doses of radiotherapy, and may be associated with surprisingly few side effects, and therefore little impairment and disability.

Most radical treatments are associated with side effects, which may be disabling. Common among these side effects are loss of appetite, nausea, vomiting, hair loss, loss of weight and adverse effects on blood

cells, which may lead to anaemia, bleeding or infections. However, the past decade has seen the development of many agents to alleviate or prevent such side effects, and the duration of these side effects rarely extends more than a few weeks beyond completion of treatment.

However, some side effects can produce prolonged disability. Some examples follow: -

Peripheral neuritis. Some agents used in chemotherapy may damage the ends of nerves. This may affect motor function, which may lead to diminished mobility, or even paralysis, from which recovery may be prolonged or incomplete. Alternatively, it may affect sensory function, leading to unpleasant abnormal sensation (paraesthesiae), which may make day-to-day minor activities, such as making a cup of tea, quite distressing. Sometimes, both motor and sensory functions are affected, leading to problems with mobility and care needs.

Fatigue. This is probably the most unreported side effect of aggressive chemotherapy and radiotherapy. It may be severe, unremitting, and disabling. Treatment is rarely effective, but recovery is the rule, albeit over a period of many months or years.

Breathlessness. This may be a consequence of anaemia, or lung problems, or heart failure, or any combination of these problems, all of which may be caused by chemotherapy or radiotherapy. Lung damage from certain drugs may be irreversible or progressive.

Anxiety and depression. The knowledge that one has cancer, and the knowledge that one will have to make repeated visits to hospital for unpleasant treatments, can overwhelm some patients with feelings of helplessness and hopelessness. In fact, many cancer specialists never cease to be amazed by the fortitude of most patients, but some patients may have severe and prolonged psychological trauma as a result of their disease and treatment. They may be unable to cope with the basics of day-to-day living, and may have substantial care needs.

Finally, it must not be forgotten that many treatments used in the palliation of malignant disease, such as opiates and antidepressants, may be associated with incapacitating side effects such as confusion, drowsiness, loss of motivation, and overwhelming generalised weakness.

DLAAB NEWS

MEETINGS WITH OUTSIDE ORGANISATIONS

The Board meets regularly with outside organisations. At these meetings Board Members with relevant skills, expertise or interest have discussions with representatives of various groups.

The Board invites specific groups and also welcomes approaches from any group who feels it would benefit from meeting the Board.

We use the News and Update as a means of directly informing DM's of changes that are new or brought to the Board's attention. This is in addition to the information already available in the Disability Handbook.

Updates to the Disability Handbook are being made via ICT where appropriate. Meeting with the Board gives access to representatives of outside organisations to inform us of issues needing clarification.

Since the last issue of DLAAB News and Update the Board has met with representatives of Macmillan Cancer Relief. Our Research Group has been monitoring new developments and treatments for various conditions with the focus being on subsequent changes in the level of Care and Mobility needs.

THE BOARD

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~Mrs Sarah Vines

~Mrs Christine Whitehead

THE REMIT

The Board has three main functions:

- To give advice to the Secretary of State on matters referred by him/her.
- To give advice to Department of Work and Pensions Medical Services doctors on cases referred for expert advice.
- To present an Annual Report on its activities over the year to the Secretary of State.

INVITATION TO DM'S

If you have any specific questions or general queries please contact us via the Secretariat.

We wish to use the News & Update as a forum for discussion.

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 communication with members of the public or their representatives.

GETTING IN TOUCH

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