

DLAAB

Disability Living Allowance Advisory Board

NEWS & UPDATE

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Topics for Future Issues

- ◆ Epilepsy
- ◆ Falls in older people

DM's suggestions for topics welcome. Please contact us.

Hello Everyone

Welcome to this edition of Up-date and News, which I hope will be useful. We have focussed on the young and the often not so young in the 2 articles.

In the first article we note that all infants and children under 2 years are expected to be dependant on their parents for feeding, dressing, toileting and personal hygiene, and in need of close supervision at all times, and, therefore, basic personal care needs of many children under 2 with Down's Syndrome without major congenital malformation are likely to be similar to children without developmental delay.

However, the author explains where difficulties are likely to cause care needs over and above what would be expected at such a young age.

The second article describes some of the difficulties people with amputation experience. The author explains that within this group of individuals ability cannot be judged purely on the site of their limb loss or limb deficiency. The picture is much more complicated and their abilities are affected by a range of other factors. Each individual's outcomes, circumstances and functional abilities will be different dependent on their pre-surgical health, co-existing conditions and age.

I hope you will find these two articles interesting and helpful.

Anne Spaight
Chair DLAAB

A tale of two babies

Dr Ben Ko

Introduction

This article aims to provide guidance to assessing applications for DLA from children less than 2 years of age with Down's Syndrome. Some children with Down's Syndrome are born with major congenital malformations such as heart defects, leading to severe medical complications and care needs. Others without such malformations may have very similar care needs to their peers at this age.

However, amongst these children, some will have additional care needs despite the lack of major medical complications. In particular, the demand on their parents in implementing therapy programmes, increased risk of poor health from upper airway narrowing, and in some babies extreme delay in development making physical handling and feeding more demanding. Two babies are described to illustrate some of the care need implications.

2 babies with Down's Syndrome

The following two children were born within a week of each other. They both have Down's Syndrome. They are now 2 years 6 months in age.

Child A: Kylie

- Down's syndrome, delivered at term by emergency caesarean section.
- Congenital heart disease diagnosed at aged one week, which caused poor oxygen level and heart failure.
- She was too tired to finish her feeds and gained weight poorly. She had heart surgery aged one month. She was discharged home on continuous oxygen and fed by tube.
- Tube feeding till 9 months, oxygen till 12 months. She continued to feed slowly so meal times were prolonged and exhausting for both child and parent.
- Bilateral fluids in middle ear detected from 8 months onwards (glue ear). Mild to moderate hearing loss. No specific treatment given, but needed to attend Audiology (hearing) clinic regularly.

Developmental progress:

- Sat up 1 year (normal: by 9 months)
- Crawling 15 months (normal: by 12 months)
- Pulling up to stand and cruising around furniture 2 years+ (normal: by 15 months)

- 2 years 6 months: Still not walking and no speech, vocalising. (Normal: Walking by 18 months and 1st word by 15 months). Does not respond when being called and has limited awareness and interest in family members.
- Developmental prognosis likely to be poor

Child B: Billy

- Elective Caesarean Section at 36 weeks, Down's diagnosed at birth. No congenital malformations noted at birth.
- Frequent colds, taken to hospital casualty on some occasions, no serious complications and no admissions.
- Middle ear fluid in both ears detected aged 11 months, mild to moderate hearing loss, hearing aid prescribed 2 year 6 months.

Developmental progress:

- Sat up 9 months (normal: by 9 months)
- Crawling 11 months (normal: by 12 months)
- Walked 23 months (normal: by 18 months)
- 1st word 23 months (normal: by 12 months)
- Indicates soiled nappy 24 months (normal: by 24 months)
- 2 years 6 months: developing early feeding and dressing skills (normal: self feeding and dressing by 5 years). Enjoys adult attention. Very active, short concentration and little awareness of dangers.
- Relatively good developmental prognosis

These two children are at two different ends of the spectrum, and it should not be difficult to guess who got DLA when an application was submitted at the age of 6 months!

Care needs for children less than 2 years with Down's Syndrome:

- All infants and children in this age range are expected to be dependant on their parents for feeding, dressing, toileting and personal hygiene, and in need of close supervision at all times.
- Therefore, basic personal care needs of many children under 2 with Down's Syndrome without major congenital malformation are likely to be similar to children without developmental delay.
- Communication skills in this age group are also at an early stage of development. The difference in speech and language skills between children with Down's Syndrome and others are unlikely to have significant functional impact. In other words, all children in this age are normally expected to need their parents' support for communication.
- Remember: there are many children in this age group without an obvious syndrome but with similar degree of speech and language, or developmental delay, and they would not normally be considered for DLA, for the same reason.
- But there are also some with additional care needs e.g. where the degree of delay is particularly profound necessitating additional parental efforts. For example, some may have such severe delay that even by 18 months they have insufficient control to sit up at all, and this makes caring for them much more demanding. Feeding, dressing and bathing will take much longer. Others may develop oromotor skills very slowly, leading to feeding difficulties. Some may require tube feeding till their feeding skills develop.
- The rate of developmental progress in children with Down's Syndrome is expected to be slower than other children and therefore the gap in delay widens, as the child with Down's Syndrome grows older.
- Physiotherapy and speech therapy programmes are often recommended from an early age, in order to encourage developmental progress. These are usually implemented by parents.
- Please refer to developmental charts previously published in **DLAAB Update**

- Some may have very serious congenital malformations, affecting their hearts and intestinal system in particular. As in *Child A*, there are significant additional care needs from the beginning as a result of the use of continuous oxygen and tube feeding.
- They all have congenitally narrowed upper airways. Therefore, the infants with Down's Syndrome are more likely to have breathing and feeding difficulties when they have a common cold, which other babies and children can cope with easily.
- It is not uncommon for them to require hospitalisation from a common cold. A history of frequent hospital admission is significant, even if there are no major congenital malformations. This problem improves with age as their upper airways widens with physical growth.
- For the same reason, they develop glue ear much earlier and this causes hearing difficulties. Hearing aids are sometimes prescribed (see *Child B*) as a temporary measure i.e. for a few months only, in the hope that ENT surgery may be prevented.
- In general, the degree of hearing loss due to glue ear varies from time to time in the same child (depending on how much fluid they have in the middle ear at any one time), and most will improve with age, though in children with Down's Syndrome this tends to persist to an older age.
- In addition, the incidence of sensori-neural deafness is also increased in Down's Syndrome, and this is a permanent condition.

Summary

- Children with Down's Syndrome have a wide range of medical conditions and needs
- Despite the lack of serious congenital malformations, some children with Down's Syndrome may have increased care needs as a result of their vulnerability to common childhood illnesses
- Many young children with Down's Syndrome have similar basic personal care needs to their peers
- They have additional developmental needs as parents are often asked to implement physiotherapy and speech therapy programmes

- Some may have such profound developmental delay that caring for them requires additional efforts from an early age
- When considering care needs, attention should be given to normally expected developmental skills and parental input at different ages, by referring to developmental charts if necessary

Long-term physical issues affecting people following amputation

Sarah Vines

Approximately six thousand amputations are performed each year; a majority of these are lower limb amputations. The causes leading to amputation are varied, many arising from diabetes, heart and vascular disease and cancer. In the younger population it is mainly as a result of injury.

The level of disability resulting from the amputation will vary according to the site of the amputation, the health and fitness of the person prior to the amputation, co-existing conditions and other injuries.

The long-term effects of amputation are often over-looked but can have a considerable effect on the individual's functional ability.

I will endeavor to set out these effects and describe how they might impact on an individual's performance. During my clinical work I frequently meet clients coping with these issues.

Phantom pain

Phantom pain can be suffered by up to 80% of individuals following amputation. The pain can be described as crushing, burning, itching and shooting pains. These can be severe and debilitating. It is thought this is caused by the brain trying to "re-wire" when re-adjusting to the loss of a body part.

For many people this pain will reduce over time however, in some cases, this can be an ongoing distressing symptom and will require further treatment. These treatments can include drugs therapy, nerve blocks, spinal stimulation and hypnotherapy.

The affect of the pain can lead to reduced mobility and function, effect on mood and in some cases depression.

Stump pain

This is pain in the residual part of the limb. In the short term following surgery you expect all individuals to have pain, however it can continue in the long term. This may be caused by neuroma, bruising, poor prosthetic fit, and chaffing or skin damage. It may also be caused by poor circulation or nerve damage especially in the cases of diabetics. A result of this could be that the individual would not be able to wear a prosthetic limb when experiencing these symptoms and their mobility would obviously be compromised.

Joint pain

This may be a pre-existing condition or caused by increased load on other joints caused by compensatory techniques involved in all activities of daily living. Changed gait patterns and requirements to use walking aids can cause increased stress to joints in the arms and back. In some cases the use of self-propelled wheelchairs, and for drivers the lifting of wheelchairs in and out of vehicles may lead to shoulder pain through these repetitive actions. This pain can be treated but still may lead to a reduction in independence.

Cardiovascular conditions and Diabetes

It is known that many people requiring amputation will have severe cardiovascular problems and diabetes, which have lead to their amputation. These conditions continue to be present and require treatment. The symptoms caused are compromised circulation, poor healing, nerve damage, and severe pain in residual and other limbs and poor fitness. These symptoms can make it more difficult to participate in rehabilitation in some cases, and to use a prosthetic limb, which demands a greater amount of energy. Skin may be more prone to break down which will increase difficulty in wearing prosthesis.

A significant number of amputees will go on to have further surgery, revision of their stumps or have to have amputation of their other limbs.

Due to their health needs this group of people may have additional care and mobility needs.

Impact of ageing

In general most people having amputations are in the older population and therefore the universal effects on the whole population must be

taken into consideration. Muscle bulk and strength will tend to reduce with age and therefore there is an additional strain in using an artificial limb. Age should not prevent an individual receiving prosthetic limbs however in may be an indicator of success. The increased difficulties in self-care caused by any amputation may lead to greater care requirements and reduces the likelihood of becoming independent with a prosthetic limb.

Conclusion

Within this group of individuals ability cannot be judged purely on the site of their limb loss or limb deficiency. The picture is much more complicated and their abilities are effected by a range of other factors. Each individual's outcomes, circumstances and functional abilities will be different dependent on their pre-surgical health, co-existing conditions and age. It is important to realize that a person's self-care and mobility can change and in some cases they will improve. However over time these long-term physical issues can prevent an individual wearing a prosthetic limb and therefore reduce their mobility.

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.

NEWS

The Board has been undergoing a review and the results of this are available on our website.

Since the last issue our structure is changing and developing in response to the recommendations of the review.

Our website is regularly updated to contain new publications by the Board including this year's Annual Report. The conclusions of our study of Special Rules cases are also available on our site. We now have an internal search engine giving easy access to articles from all past issues of the News and Update as well as all Annual reports.

THE BOARD

Chair:

Mrs Anne Spaight MBE

Members:

Dr Amit Arora

Mrs Simone Baker

Mrs Jean Cooper

Mrs Judith Holt

Mr Zubair Khan

Dr Ben Ko

Dr Mohammad Obaidullah

Dr Ronald Pearce

Ms Sarah Playforth

Mrs Clair Poole

Mr Douglas Ross

Prof David Scott

Prof Tom Sensky

Ms 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 or suggestions please contact us via the Secretariat.

FOR YOUR INFORMATION

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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