



Disability Living Allowance Advisory Board

NEWS & UPDATE

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Topics for Future Issues

- ◆ Epilepsy
- ◆ Post Traumatic Stress Disorder
- ◆ Severe Mental Impairment

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



INTRODUCTION BY THE CHAIR

Hello Everyone

In this edition you will find the next instalment on Child Development, which has proved to be very popular. We have had many comments on how helpful the article in the last edition was, so I hope you will find this as helpful.

As requested we have also updated the article on Laryngectomy. This is quite a rare condition but results in some very disabling effects.

I do hope you enjoy these features and again I do encourage you to send us your comments, thoughts and requests for further information.

Anne Spaight
Chair DLAAB

LARYNGECTOMY

Laryngectomy is the surgical method of treatment for laryngeal cancer. In early laryngeal cancer, radiotherapy may be used on its own. Some patients will have both surgery and radiotherapy and may also have chemotherapy treatment, particularly where the disease has spread.

Cancers of the larynx are closely associated with smoking.

Laryngectomy is the excision of the larynx (voice box) and usually a section of the trachea (windpipe). A permanent stoma (opening) is created at the front of the neck. The operation results in complete removal of the means of speech and a completely changed method of breathing.

The bodily functions impaired as a result of the surgery are:

- Communication
- Breathing
- Eating

Communication

As the larynx (voice box) has been removed, the normal means of speech is lost. Some patients learn to "speak" artificially. They may use:

- Oesophageal voice where expelled air is vibrated against the oesophagus;
- Electronic larynx, a mechanical vibrating device, held against the neck;
- Valve or prosthesis, a small plastic valve which diverts air into the oesophagus;
- Pen and paper.

All artificial forms of voice production may diminish or fail under stress or during intercurrent illness e.g. chest infection. Users of the electronic larynx need to use one hand to operate the machine. Some valve users need assistance to remove and reinsert the valve for cleaning, or during an emergency, or if their sight or manual dexterity are reduced.

Whichever method of artificial "speech" is used, problems are encountered and complete strength and clarity of "speech" is rare. Families usually learn to understand, but other people find it difficult, particularly during telephone conversations.

People may depend on their partners or relatives to assist them with communication after their laryngectomy. Despite speech therapy, some may have difficulties making themselves understood, particularly by strangers, causing problems outdoors, in unfamiliar surroundings, or if they are alone.

Breathing

After a laryngectomy, breathing takes place through the stoma at the base of the neck and not through the nose and mouth. The airway is directly open to the environment with no natural means of protection or filtering system against airborne germs and adverse weather conditions.

Strong winds and cold air can make the mucous (a thick, sticky fluid produced by the air passages) set quickly and create a 'plug' at the stoma, which needs cleaning and removal. People who have had a laryngectomy are far more vulnerable to chest infections, including bronchitis and/or pneumonia.

The stoma needs careful cleaning and to be kept free from obstruction or water inhalation. Care must be taken when bathing or showering to prevent water entering the stoma.

Eating

The oesophagus (gullet) is narrowed after a laryngectomy and therefore food does not pass down it as easily as before the operation. There may be difficulties with swallowing. Some people will only be

able to eat soft foods; some people may need help to cut food into small pieces. Some people are only able to eat liquidised foods.

The psychological effects of the operation should never be underestimated, it is a devastating procedure leaving the person without a voice and with other problems requiring care. Socialising can also be a problem, partly because of the difficulties with communication.

Cancer is debilitating, without the postoperative effects of major surgery. This type of cancer usually occurs in the older age group, when postoperative recovery can be slower. It can take time to achieve artificial "speech". The operation is performed for cancer of the larynx, and the cancer may not have been entirely removed and secondary spread has to be considered. This will require more treatment, probably chemotherapy that is a debilitating procedure.

Normal Development in Children

(Ben Ko, Paediatrician member, DLAAB)

Age	Vision and Manipulation	Hearing and Speech	Gross motor/mobility	Social behaviour and Feeding, dressing & toilet
By 2 years	<p>Vision: Picks up threads and small pellets accurately and quickly</p> <p>Manipulation: Dexterity develops. Able to hold a crayon for drawing, and turn pages, several at a time</p>	<p>Hearing: Understands more complex and less familiar commands e.g. 'take shoes to daddy'. Will come from another room if called, without seeing the caller.</p> <p>Speech: Putting words together to form simple phrases e.g. 'Mummy, drink'</p>	<p>Serious concerns should be raised if still not walking by 2 years.</p> <p>Most children will be running well, avoiding large obstacles. Should be able to walk upstairs, perhaps holding onto rail or an adult.</p>	<p>Social behaviour: Continues to be curious, and still not aware of dangers. Constantly demanding parental attention. Rebellious behaviour emerges. Peak time for temper tantrums.</p> <p>Feeding, dressing & toilet: Getting better in spoon - feeding. Can remove some clothing. Plays with water but not properly washing hands. Aware of soiled nappy.</p>
By 3 years	<p>Vision: Visually competent for most daily activities. Recognises minute details in picture books. Matches colours.</p> <p>Manipulation: Scribbles well with crayon. Develops preference for one hand. Able to place fine objects accurately and use both hands cooperatively by 3 years e.g. threading beads.</p>	<p>Hearing: Able to understand simple daily speech and questions by 3 years, to enable simple conversation to take place</p> <p>Speech: Speech develops rapidly. By 3 years, able to speak in short phrases, indicating basic needs (e.g. toilet) and asking some questions</p>	<p>Definite serious problem if still not walking by 3 years.</p> <p>By 3 years, should be able to walk up and down stairs, running, jumping and climbing well with good balance.</p>	<p>Social behaviour: Beginning to have some awareness of dangers, but still requires frequent supervision. Social awareness develops, learning to share and take turn. Plays well alone or with others with decreasing adult support. Knows nursery rhymes. Engages in symbolic and imaginative play.</p> <p>Feeding, dressing & toilet: Skilled in using spoon by 3 years. Can undress partially and helps with dressing. Cooperates with washing hands. Toilet training progresses, and many will not be using nappy during day - time by 3 years.</p>

Normal Development in Children

(Ben Ko, Paediatrician member, DLAAB)

Age	Vision and Manipulation	Hearing and Speech	Gross motor/mobility	Social behaviour and Feeding, dressing & toilet
By 4 years	<p>Vision: Able to recognise colours. Visual acuity can be tested reliably at a distance of 3 metres</p> <p>Manipulation: Holds crayon and pencil with a proper grip, and copies recognisable shapes and figures. Can be taught to use a pair of scissors.</p>	<p>Hearing: Understands speech well enough for daily purposes. Beginning to understand more abstract concepts and listens to stories.</p> <p>Speech: Speaks well in short sentences, with improving grammar. Eternally asking questions ‘why?’ ‘when?’. Knows several nursery rhymes.</p>	<p>Very agile, runs, climbs and jumps well. Can pedal a tricycle, and getting good at ball games. Should be able to walk up and downstairs safely by 4 years.</p>	<p>Social behaviour: Social awareness continues to develop. Plays cooperatively with others and able to conform to routines and rules in nursery with adult direction.</p> <p>Feeding, dressing & toilet: Can manage feeding self, with some help. Can undress completely and put on some clothing. Washes and dries hands, and attempts to brush teeth. Toilet training should be well underway to completion if not already achieved.</p>
By 5 years	<p>Vision: Any significant visual problems should have presented by this age</p> <p>Manipulation: Drawing well with crayons and pencils, and should have developed hand preference by now. Sufficient hand functions for most feeding, dressing & toilet activities, including tasks that require both hands.</p>	<p>Hearing: Good understanding of speech, including some abstract concepts. Enjoys jokes and riddles by 5 years.</p> <p>Speech: Speaks fluently in sentences, with correct grammar, and speech should be intelligible to strangers by 5 years. Able to express self and ask questions well.</p>	<p>Fully mobile, and agile. Can manage some movements that require good balance e.g. standing on one foot. Enjoys ball games.</p>	<p>Social behaviour: General behaviour more independent. Conforming well to routines in nursery or school with little adult direction by 5 years. Plays cooperatively and interactively with others, observing rules in games.</p> <p>Feeding, dressing & toilet: Can manage a whole meal with minimal help. Can put on main items of clothing, but not fastenings. Can wash and dry hands, and probably face. Will still need help for baths. Can take self to toilet, though may need help with cleaning after. 80% are dry at night by 5 years.</p>

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 been preparing to study topics under our remit.

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.

Our website is in the final stages of its redesign and will be relaunched before the end of the year. There will be new links together with an internal search engine for easier access to subjects. Accessibility has been the highest priority and this has been a great opportunity to simplify access to articles and information.

THE BOARD

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Prof. Tom Sensky

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.

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

DLAAB at The Adelphi
1-11 John Adam Street,
London, WC2N 6HT

0207 962 8056
0207 962 8982
0207 962 8053

Or on the web at:
www.dlaab.org.uk