

DLAAB UPDATE

The News sheet of the Disability Living Allowance Advisory Board

Issue No 1

This is the first 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 many changes to the membership of the Disability Living Allowance Advisory Board recently, currently we are:

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| Chairman | Professor Rodney Grahame CBE |
| Vice Chair | Mr Sam Gallop OBE |
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| Members | Mrs Simone Baker Dr David Cohen Mrs Jean Cooper Mrs Nicole Davoud OBE Dr Margaret du Feu Ms Marilyn Howard Dr John Hunter OBE Dr Lee Illis Dr Richard Lucas Dr Ian McGill Dr Karin Moses Mrs Clair Poole Mrs Lisa Shend'ge Mrs Marion Westacott Mrs Christine Whitehead Mr Adebayo Williams |

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, a very slow method of communication.

All artificial forms of voice production diminish or fail under stress or during intercurrent illness eg. chest infection. Users of the electronic larynx need to use one hand to operate the machine. Many 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.

Most people, after a laryngectomy depend on their partners or relatives to assist them with communication. Despite speech therapy, many 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.

Mobility can be a problem due to air pollution from traffic fumes, smoke etc and also due to lack of head, neck and shoulder movement.

The stoma needs careful cleaning and to be kept free from obstruction or water inhalation . Care must be taken when bathing or showering and most people who have had a laryngectomy will not feel safe to bath or shower unless someone is with them in case they need help.

Bending the head can sometimes be a problem as the chin could obstruct the stoma, and hence the breathing.

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 which could lead to excessive air intake. Many people will only be able to eat soft foods, although some people may be able to eat ordinary food if it is cut into very small pieces. Some people are only able to eat liquidised foods. After a laryngectomy all people eat slowly and regurgitation and vomiting can be a problem.

The psychological effects of the operation should never be under-estimated, 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 and also because they have become "neck breathers". Many may prefer to stay at home.

Cancer is debilitating, without the post operative effects of major surgery. This type of cancer usually occurs in the older age group, when post operative 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 which is a debilitating procedure.

DEAFNESS

Deafness may be partial, severe or profound. Onset can be from birth or in early life, or at any later time, particularly in old age. Deafness may be sudden or progressive. Each deaf person needs to have access to alerting, information and communication. The methods used depend on all the above variables, and also on the presence of any additional visual, physical or learning disability.

The majority of deaf people (over eight million in total, one in seven of the general population) have partial, late onset deafness. They have spoken and written English as their first language, and benefit from hearing aids and written material. A significant minority of deaf people (about 50,000, about one in 1,200 people in the general population) have been profoundly deaf from early life and use British Sign Language (BSL) as their first or preferred language. For many, education has not given them fluent English literacy or speech and lip reading skills. They form a linguistic and cultural minority, with strong social networks.

For everyday life a deaf person needs to function differently from a hearing person in a variety of ways, either using technology, or using the services of other people, such as speech-to-text operators, lip speakers, note takers and BSL interpreters.

For alerting, there are vibrating pagers, under-pillow pads, or flashing lights for fire and smoke alarms, doorbells and phones. For access to information, there are television loops or subtitles and BSL videos. For travel, there are visual announcements. For telephony, there are faxes-textphones (including mobile ones) videophones, e-mail, message pagers and Type Talk. For communication, simple deaf awareness training facilitates lip reading (appropriate light, clear speech, avoidance of background noise).

BSL Interpreters should be available for situations such as doctors' appointments and in the legal system. However, interpreters are scarce, relatively expensive and may not be readily provided. Lip readers and speech-to-text operators are even scarcer.

The Disability Discrimination Act makes clear the responsibility for providers of goods and services to give equal access, but as yet this is limited for deaf people, who often need to rely on others to help them in everyday life. In addition, the early life and education of many deaf people has not equipped them to function as independently as they could, particularly if they have been denied access to appropriate communication in childhood.

It is important that the needs of each deaf person are considered on an individual basis. For example, it cannot be assumed that a hearing aid is beneficial for speech reception, or that a deaf person can use a textphone, or have the confidence and experience to travel independently.

While the level of hearing loss clearly needs to be assessed, the impact this has on an individual's life depends on many factors. They may not be aware of potential technological aids, or necessarily be able to benefit from them.

SIGHT LOSS (PARTICULARLY IN THE ELDERLY)

Sight loss is devastating at any age; when the onset of this disability occurs over the age of 65, it can be exacerbated by additional factors. In order to cope with sight loss, basic life skills have to be re-learned – everything from personal hygiene, food preparation and moving around (in and out of the home), to finding a new way to access information. Learning new skills – such as Braille, gaining mobility with a guide dog, arranging one's home in such a way that life becomes manageable again – requires confidence, determination, great dexterity and excellent memory. In addition, with the loss of one vital sense, the other senses (hearing and touch) will need to be fully functioning in order to help compensate for the loss of sight.

Following is a summary of the particular problems of sight loss post-65

- Over one million people in the UK are blind or partially sighted – over 75% of them lose their sight after the age of 60.
- Despite eligibility, only one in four blind or partially sighted people is **registered**.
- The most severe forms of visual impairment commonly occur in the elderly (macular degeneration, cataracts and glaucoma).
- The skills and strategies that might help visually impaired people are less likely to be acquired by people over 65 – younger people are more able to cope with the changes and learning process these demand.
- The 'system' doesn't help – statutory authorities and medical specialists tend to work in isolation - there is no automatic referral from one to the other, in order to access rehabilitation and mobility training. What little training is available is more likely to be accessed by those still in education or employment.
- Elderly visually impaired people are more likely to have multiple disabilities: and, in these circumstances, one disability will exacerbate the other (for example a slight deterioration in hearing will make it much more difficult to communicate or remain mobile, as a blind person will rely on hearing to compensate for sight loss).
- RNIB surveys show that the majority of older blind people do not know of their entitlements, have never been visited by a representative from Social Services, and feel isolated.
- Spouses tend to be the main carers for blind people: as this group gets older, blind people are more likely to be alone through bereavement.

(The above summary is based on a survey by the RNIB entitled 'Lost Vision: older visually impaired people in the UK')

And as a footnote and reminder to Decision Makers, the Board are still carrying out studies of the following:

Cerebral palsy in adults

Osteoarthritis – under age 50

HIV/AIDS (including Special Rules)

If you have any of these cases, please send the files to the DLAAB Secretariat once your action has been completed.

The editors welcome letters, requests for future topics and comments on articles in DLAAB Update or presentations at workshops.

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