



*Adjusting to a
new way of communicating
after laryngectomy*

SUNDERLAND LARYNGECTOMEES CLUB

in conjunction with

Mhairi Dyer, Medical Social Worker

Anne Powell, Chief Speech and Language Therapist

and

THE NATIONAL ASSOCIATION OF LARYNGECTOMEES CLUBS

Methods of communicating after laryngectomy

There are several options for communicating after laryngectomy:

- An Electronic Larynx
- A Voice Prosthesis (Valve)
- Pen and Paper
- Oesophageal Voice
- Silent Articulation (Mouthing Words)

Your Speech and Language Therapist will explain the options available to you and answer your questions. This leaflet does not aim to describe the different methods of communication but aims to offer support and encouragement as you adjust to a new way of communicating.

All the quotes are from laryngectomees or their families and describe common experiences you may recognise.

First experience

Laryngectomy will obviously have a big effect on your communication. Everybody goes through the stage of having to mouth their words and your family will find they have to become expert lip readers – overnight! One laryngectomee remembers his first few days after surgery.

“I hated having to write everything down – it was slow – but my family found it difficult to lip read – I realised pen and paper was best for the time being. It didn’t stop me getting cross or angry – but at least I could get my message across.”

Some problems in the early stages

A new method of communicating can bring varying and sometimes strange reactions from people. you may recognise some of the following things people have said about their experience of communicating after Laryngectomy.

“I was in the Post Office and wrote a note to the lady at the counter. I was astonished when she wrote a note back to me. I wrote another note back saying I’m not bloody deaf.”

(SJ who communicated by writing for several weeks)

“You get strange reactions when you talk, people mouth words or shout, thinking you are deaf or stupid.”

(DB who acquired a quite rather whispery voice with a valve)

“I feel annoyed at people – especially neighbours of my mam who before the operation always spoke but now don’t bother. People she knew before the operation cross the road to avoid her and when they do speak they tend to shout instead of talking in a normal voice.”

(BS the daughter of a laryngectomee who communicates with an electronic larynx)

“At the beginning I leaned very heavily on my husband and wouldn’t go out without him – I was embarrassed about using the electronic larynx.”

(BJ who now shops, socialises and meets new people without any hesitation two years after surgery!)

“The thing that irritates me most is when people pretend they understand.”

(RD who communicated with a valve)

These thoughts are from people in the early stages of getting used to their new method of communicating. In time most people find they get accustomed to it and communicate very effectively.

“The people in my area – at the club or the shops – all know me and understand me now without any difficulty.”

(SJ Electronic Larynx user)

At first it can be distressing and annoying if strangers react in ways you do not expect. Many laryngectomees speak about this aspect and recommend trying to keep a sense of humour and determination rather than letting a few people’s reactions affect your process of adjusting.

“When I first used to go out and speak with my valve some people used to stare at my neck as I blocked my stoma to speak. I felt very self-conscious and decided the best way to tackle it was to tell people I had had a throat operation. This brought it out into the open so we could talk about it instead of them just looking

surprised or being too polite to say if they could not always understand me.”

(BN who communicates with a valve)

“My valve had to be removed as it wasn’t working properly. I really felt I had failed and disliked using the electronic larynx. People do stare but I found if I spoke to shop assistants when their back was turned I could really make them jump! They usually see the funny side and I’m always greeted with smiles at the local supermarket.”

(JR)

Family reactions

At first family will often find that they try to speak for the relative who has had the laryngectomy.

“At first I used to answer for my mam and it was only when I was thinking about it I thought I should stop doing this.”

It is important to try and encourage the person who has had a laryngectomy to speak for themselves as much as possible.

Also remember your family share in your frustration too when they cannot understand.

“I tried desperately hard not to get irritated when I couldn’t understand him.”

(RF)

People are often afraid that young children will be scared of the electronic larynx or valve voice but it seems that in fact they are the ones who often don’t even notice!

This is the daughter of a laryngectomee talking about her children:

“My daughters have taken to it really well – probably because I’ve always told them everything about the operations and about why their nanna talks the way she does. I think for all they are only 7 years and 2 years old they have a right to know, as it is affecting

them too. They don't treat her any differently from the way they did before the operation ... My youngest daughter even wears her nanna's glasses and uses the servox because as she says she 'wants to be like her nanna'."

(MB)

Another grandmother recounts how:

"Amy at 2 years, had to be restrained from poking a finger down the opening in my husband's neck."

The way that you communicate is one of the many changes but nevertheless perhaps one of the most important that you will face. Following your operation there will be many times you feel frustrated and angry, but keep trying – it does get easier with practice, patience and perseverance and it is vital you are heard!

Produced and distributed with the compliments of

THE NATIONAL ASSOCIATION OF LARYNGECTOMEE CLUBS

Lower Ground Floor, 152 Buckingham Palace Road, London SW1W 9TR

Telephone: 020 7730 8585

Fax: 020 7730 8584

info@laryngectomy.org.uk www.laryngectomy.org.uk

An associated charity of Macmillan Cancer Support



*September 2012 * Version 2 * Review 2014*