

SUNDERLAND LARYNGECTOMEE CLUB

in conjunction with

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and

THE NATIONAL ASSOCIATION OF LARYNGECTOMEE CLUBS

The aim of this leaflet

This leaflet was put together to try and offer support and encouragement to people experiencing healing problems. It can sometimes feel as if you are the only person who has had such problems but all the quotes are from people who eventually got through this difficult time and began to eat and drink again.

This leaflet does not aim to give advice about your particular problem. If you are ever concerned or have any worries or questions about tube feeding, the ward staff will be more than happy to advise.

Remember healing time varies

Not everybody's throat heals in the 'average' 10-14 days – everybody's swallowing progress is different. For example, for some people it takes a few days extra before they can start to eat and drink again, while for others it can take quite a lot longer. Just as you think everything is going well you find the wound breaks down and this means eating and drinking by mouth is not possible until the wound heals.

Sometimes it can feel as if you go 3 steps forward and 2 steps back.

"I was delighted when I had my first drink after 10 days and everything was going well – but then, just before I left hospital, it started to leak and they had to keep me in for another 2 weeks. It meant the valve had to be taken out so I felt really depressed – I'd lost my voice and couldn't eat – I felt very isolated."

(DJ)

This was in fact only a short term setback and indeed most problems like this will be sorted out in a few weeks, though it may mean you have to stay in hospital longer than you anticipated.

Some people's experiences of long term tube feeding

For people whose recovery does take longer, i.e. up to several months, some will go home with a naso-gastric tube in place. Doctors will want to see these people regularly to watch and check progress. An extreme and fortunately rare case was S.J.

He remembers:

"I felt depressed when I came home — I couldn't eat and I couldn't speak. How was I going to cope ...? I was told I would never swallow again."

In fact over many months, S.J. has managed to regain his swallowing and although he continues to liquidise his food, he manages a reasonable diet that he does enjoy.

However, for people confined to tube feeding, this period can be frustrating, embarrassing, time consuming and awkward.

"The worst part of having a laryngectomy was having to live with the tube; it was so boring – I couldn't have a meal."

(BJ)

It can feel as if the time will never come when you will be able to eat and drink again.

This woman who had a naso-gastric tube (which is the feeding tube that goes up the nose) for several months, tried to lead a normal life as possible:

"I tried to go out as much as possible – people always had a good look at the tube, but I got used to that ... I thought I can't stay in or I'll get even more depressed."

Looking back she found the best way to cope was:

"Looking to the next day and thinking, it won't be long".

Long term healing problems can sometimes be frightening as well as frustrating, particularly if you have been discharged home with the tube in place and are supervising your own feeds. C.B. remembers his long recovery and advises:

"It's important that if you do have a problem you go back to the ward to let them deal with it. What may seem a major problem to you may easily be dealt with by the experts."

Please remember you can always contact the ward if you have any concerns or queries or would like advice about tube feeding.

Produced and distributed with the compliments of

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