

CLAN



THE NATIONAL ASSOCIATION OF LARYNGECTOMEE CLUBS NEWSLETTER

Issue No. 124

March 2013

Inside this issue

WORDSEARCH 2
Benefit System Changing 3

Not Lost For Words 4
Swallowing After Total Laryngectomy 5
Research Studies 6

Charlie's Voice 6
News from the Clubs 7 – 8
Plus lots of other news, thoughts, poems, letters and views

The New NALC Website

The new NALC website is up and running! Go and take a look if you have access to the internet. It's at: www.laryngectomy.org.uk But, if you've not got internet access, here is a brief guided tour:

Here's the Home page welcoming visitors. As you can see, you can now download present & past issues of *CLAN*.



The other pages are shown on the right. Just click on them and there's a huge amount of information on all sorts of subjects. The News tab. For example, tells of a new London Laryngectomee Club at UCLH in Euston Road, NW1.



Then there's a Publications tab listing a wide range of pamphlets & DVDs:

There's also a list of Clubs, an A-Z about Laryngectomy and

details of Laryngectomy developments such as laryngeal transplants. So why not have a browse and see for yourself. And what better way to relax than to read all those back issues of *CLAN*?

PS There's also the NALC Facebook page at: www.facebook.com/pages/National-Association-of-Laryngectomy-Clubs-NALC/258664087522564



A WORD FROM THE EDITOR

PLENTY TO READ!



We hope you've all had a good start to the year and are enjoying not being cut off by the snow any more! Our hens definitely did not enjoy it. Perhaps as a token of their disapproval, one of them laid an egg outside the henhouse right in the middle of a pile of snow. It still tasted good though. And the new NALC website is now fully up and running too. It's packed with useful information and links. It has all the back copies of *CLAN* you could ever wish for! So you need never run out of things to read. Especially as there are lots of useful publications you can download too. (This all assumes you've internet access of course. If not, we're still available in the paper version!)

Benefit Changes

There's some useful information in this issue on changes to the benefits system on 8 April 2013 when Disability Living Allowance (DLA) is being replaced. If you are 65 or over and already have a DLA award you will continue to receive it for the foreseeable future. But if you are under 65 and applying for the first time you will be assessed for a Personal Independence Payment (PIP) instead of DLA. So do read the article. There's also an item on Cruises which invites those who have cruised to share ideas on what you need to take with you if you're a Lary about to go on a cruise. We're off on yet another cruise in July so, who knows, we may bump into more Larries as we go sailing around Iceland!

Ian Honeysett
Ian Honeysett (Editor)

For all items for *Clan*:

Ian Honeysett (Editor), 53 Combe Road, Farncombe, Godalming, Surrey GU7 3SL
email: Honeysett@btinternet.com

For all other matters (including requests to be added to or removed from the mailing list):

Vivien Reed (Association Secretary), NALC, Lower Ground Floor, 152 Buckingham Palace Road, London SW1W 9TR Tel: 020 7730 8585 Fax: 020 7730 8584 Website: www.laryngectomy.org.uk

The views expressed by the contributors are not necessarily those of the Editor or NALC. Great care has been taken to ensure accuracy but NALC cannot accept responsibility for errors or omissions.

Deadline for issue No. 125: 1 May 2013

NALC Annual Lunch in Blackpool



WORDSEARCH

Many thanks to Kerry in the NALC office for the following Wordsearch. Can you find these lary-linked words?

STOMA, NECKBREATH, NALC, CLAN, LARYNGECTOMEE, LARYNX, VALVE, PROSTHESIS, SPEECH, CLUBS, THERAPIST, VOICE, ASSOCIATION, LARYNGEAL TRANSPLANT, NECK, HEAD

L	A	A	A	S	S	O	C	I	A	T	I	O	N	Z	V	E	M	N	S
I	A	T	A	S	M	N	L	O	P	A	U	F	S	C	Z	E	T	S	T
B	N	R	O	B	A	E	U	D	C	L	S	E	F	Y	P	P	O	B	O
A	C	A	Y	M	B	X	B	C	Q	K	Y	E	X	K	R	W	D	G	M
A	S	L	Z	N	O	W	S	K	S	T	C	N	X	F	O	H	I	J	A
X	L	Y	A	P	G	D	C	Q	R	F	Y	Q	E	R	S	G	M	O	R
F	C	L	O	T	T	E	S	G	E	R	L	E	C	K	T	T	R	O	S
M	C	Z	T	U	N	U	A	E	A	F	M	J	X	G	H	W	E	U	X
G	S	P	E	E	C	H	H	L	G	O	F	E	N	O	E	U	H	K	C
K	L	V	V	K	W	O	N	S	T	Q	V	H	Y	P	S	O	T	L	V
W	B	A	L	L	R	D	V	C	F	R	G	N	G	P	I	U	A	C	I
N	Y	M	A	H	B	Y	E	I	I	O	A	G	C	H	S	N	E	H	K
I	N	O	V	X	V	G	I	K	F	J	N	N	E	J	I	J	R	J	R
Z	I	Z	V	Q	N	L	C	E	P	O	E	O	S	S	H	B	B	O	T
B	V	X	K	Y	Z	A	D	L	J	R	S	P	R	P	W	B	K	K	L
Q	Y	Z	R	P	Q	R	A	T	K	C	Q	S	G	D	L	F	C	G	K
R	W	A	A	J	T	H	E	R	A	P	I	S	T	M	A	A	E	V	L
B	L	V	T	E	M	T	H	S	I	R	A	J	Q	Z	O	C	N	K	B
C	C	E	R	A	B	M	R	Z	O	N	E	C	K	N	E	R	B	T	L
V	O	I	C	E	Z	A	E	E	J	O	O	F	S	C	N	Z	M	A	B

Experiences of Laryngectomees

Ron Mattoon - Jan 2010

"When I got cancer, I started thinking about my physical healing and it taught me to think about things a day at a time. I now concentrate on what I need to do each day to beat this new challenge. Learning to deal with each new thing was just another goal. Get through the radiation and chemo. Deal with swallowing and the lack of smell. Learn to make my tongue work again and another way to talk. Although this was new to me, many others have gone through it and I can deal with it too. A day at a time and I can beat this. Through WebWhispers, I have met so many great people who have gone through it all. You give me hope and role models that show me how to do this, and my family has been there to give me the

strength and support I needed."

Bob Keiningham - 2008

"My Daily goal: To organise each day for the things I 'Must' do, then add one or two of the things I 'Should' do, and fill the time remaining with the things I most 'Want' to do. That's my first thought every morning, and the last each night.

My Weekly goal: To review the week ahead and organise it to ensure I'm prepared to get the 'Must' do's out of the way as quick as possible and select a few specific 'Should' do's for the coming week, so I can have maximum time available for the 'Want' to do's."

Lillian Parra - 2001

"I'm a pretty simple person; I'd like to sit on

My Cancer Treatment

Is a new patient website that provides access to detailed reports for thousands of clinical teams across England. The clinical team refers to the multi-disciplinary team (MDT), composed of a group of doctors and other health professionals with expertise in specific cancer types, who together discuss and manage an individual patient's care and plan the options for best treatment.

The reports are based on assessments of the clinical teams that have taken part in the NCPD quality assurance programme. My Cancer Treatment is the only resource that provides the public with access to detailed information about the quality of a cancer service at the clinical team level, specific to tumour site. The tumour sites currently covered include Brain and CNS, Breast, Colorectal, Gynaecology, Head and Neck, Lung, Sarcoma, Skin, Upper GI and Urology. Chemotherapy and Radiotherapy services are also included.

In the next stage of the website development Acute Oncology, Children's, Teenage and Young Adults, Complementary Therapy, Psychology, Rehabilitation and Specialist Palliative Care services will also be included. This initiative was driven by the NCPD National User Steering Group (NUSG), a group of cancer patients and carers who work closely with NCPD and have emphasised the need for this information to be readily available to the general public.

How does it work?

In up to three easy steps, you can search by: location, cancer team and hospital, to locate and compare NHS cancer services by reading the reports which detail the quality of the services.

The reports available on My Cancer Treatment are based on the most recent assessments for that clinical team. If you would like to know more about the IOG, please visit the NICE website www.nice.org.uk/guidance

the terrace of Nepenthe Restaurant in Big Sur, CA and just take in the wonderful view of the ocean, sip on something yummy and enjoy the redwoods. I hope I can move back to Hermosa Beach, CA, from whence I came, for the remainder of my days (the sooner the better for the move), but most importantly, I want to be right with God when my time comes, so I try to talk to Him everyday and make sure my heart is right and that I'm doing my best to treat people decently."

(From WebWhispers)

The Benefit System Is Changing!

On 8 April 2013 the system is changing. Disability Living Allowance (DLA) is being replaced.

If you are 65 or over and already have a DLA award you will continue to receive it for the foreseeable future.

If you are under 65 and applying for the first time you will be assessed for a Personal Independence Payment (PIP) instead of DLA.

If you are under 65 and already receive DLA, from October this year the Department of Works and Pensions (DWP) will be contacting you to inform you that they are withdrawing your benefit. You will then be given the opportunity to apply for the new benefit (PIP).

Attendance Allowance will remain the same for the foreseeable future.

We strongly advise those under 65 currently receiving DLA to be prepared for the change by making enquiries in your local area about how to proceed. Although the contacts with people already receiving DLA will begin in October 2013 the DWP has now realised that the number of people affected will take a much longer time to process than originally thought so we cannot tell you when your particular call will come or how long the waiting time will be. We assume that those DLA awards due for re-appraisal around that time will be contacted first with information about their position.

Our Priority

NALC's priority is of course to look at how this situation will affect our laryngectomee community and we have spent a lot of time and effort in attempting to protect their particular needs by taking part in all the consultations and reviews that the government has instigated. The managing of the situation is not helped by the fact that the claim forms for PIP are not yet available, even to the professionals working in the field and our volunteers have even less chance of getting access. We will obtain a copy of the relevant documentation as it becomes available and circulate the details to the best of our ability.

One aspect of the changes that gives us great concern is that system being introduced for claiming PIP expects the



use of the telephone as a means of both giving and taking of information. The first step in making a claim is to telephone the DWP who will take the basic details and carry out a preliminary interview over the phone.

For the laryngectomee it may be difficult and stressful to attempt to contact DWP themselves over the telephone. In any event if they are able to sustain an adequate voice through the conversation this may undermine their claim, much of which may involve communication problems. Call centre staff will have little knowledge of the variability of laryngectomee voice and the episodes which make speech impossible.

Making a Claim

We are told paper forms will be available for those claimants that are unable to make the claim by phone. Therefore we need to stress, that someone other than the laryngectomee needs to make the telephone contact and arrange to have the paper forms delivered.

NALC asks that every professional working with laryngectomees attempts to get across to all laryngectomee patients the importance of obtaining the paper PIP claim forms with the help of another person. Similar difficulties will apply in the appeals process.

Disclaimer: Information about precise details of the changes is taking a long time to appear and in some cases is contradictory. The information above is the best available to us for the date this item is written. The prediction of an individual's entitlement needs a full consideration of all their circumstances. This news item is offered only to warn laryngectomees of some significant changes ahead.

**How is it one careless match
can start a forest fire,
but it takes a whole box
to start a campfire?**

Exquisite

Tina Rykens-Weir recently attended a pre-Christmas craft fair and was impressed by the exquisite hand beaded necklaces



made by Lorraine Hodgkinson. Tina has attached some photographs and feels that our female readers may be interested in them. They are all available for under £15 each. Lorraine can be contacted as follows:

Lorraine Hodgkinson
17 Culverton Hill, Princes Risborough
Buckinghamshire HP27 0DZ
Tel: 01844 347230
Email: ddrhodgkinson@btinternet.com



Just Cruising

Would you mind putting a call out for all information from experienced laryngectomee cruisers as to what I need to take with me, what to be prepared for etc as my wife and I are going on a 12 night cruise in Sept/Oct this year and have no idea what medical stuff (apart from nebuliser of course) to take with us. We are going from Southampton to Portugal to the Canaries and return, so all English speaking and we have already sorted out travel insurance. Please e-mail advice to admin@2020cancerappeal.org or post to Phil Johnson, 37 Windley Road, Leicester LE2 6QX. Thank you all, in advance, for your help.

Phil Johnson, Leicester Club

The Editor writes: I asked John and Shirley Jones for their ideas and they gave the ones below. But you might have other ideas too?

The list of 'must take' items are:

Antibiotics from my doctor in case of a chest infection;
Sufficient laryngectomee protectors;
Ointment such as Germolene in case of external soreness around the stoma;
If using a Servox machine, remember to take spare batteries and the charger. *NB:* check that the ship has a facility for recharging batteries.

From Shock and Fear to Acceptance and Joy

The IAL News features an article about Kathy Turbucz Poirier and her laryngectomy. Here are a few extracts:



30 March 2012: My first visit to the cancer centre in London, Ontario, I already know I have a tumour but I'm feeling good. They will just take the tumour out, give me some radiation and life goes on. WRONG! This is the day I found out that I would be having a full laryngectomy with a possible removal of my oesophagus and a stomach pull up. I sat in the office and I was numb. I felt nothing. I had been diagnosed with Adenoid Cystic carcinoma, a rare form of cancer with no known cause. I also have 10-15 undetermined spots on my lungs that will have to be monitored. Surgery date is set for 20 April 2012 and we (husband, Claude) go home.

It wasn't until later that night that reality hit me, I was going to lose my voice forever, I cried like I have never cried in my life. What was I going to do? Was my husband still going to love me, find me attractive? So many doubts played in my mind.

Next Morning

The next morning I was determined to be positive that everything was going to be OK. I went to the store and bought recordable story books, nine in total, and recorded three for each of my kids.

20 April: Surgery starts at 8 am, we get to the hospital at 6, our daughters meet us there. We hug and start the longest but shortest walk of my life in silence. No one speaks, we are lost in our own thoughts I suppose. I don't know to this day what they were thinking, but I was thinking it was the last time I was going to see them. I was terrified, I wasn't sure if I was going to make it and, if I did, did I want to? We said our goodbyes and I was whisked away to the operating room. I remember lying down on the table, having my IV started and not much else.

Guess what? I woke up! I wasn't sure if I was happy about that or not at first, I was so sick. Great news!

Not Lost for Words

Rev. Gunter Helft has sent CLAN a copy of his book entitled *Not Lost for Words*. He was born in 1923, spending his early childhood in Berlin where he witnessed the beginnings of Nazi brutality. Brought up as a Marxist atheist in a Jewish family, he was only as an adult to learn that he had been adopted as an infant and he writes with feeling about adoption and parenting. With his parents he fled to England, with no knowledge of the language, and describes his assimilation at a London Grammar School, his exploration of Judaism and discovery of Christianity and his ordination and work at an Approved School, as a Mission to Seafarers chaplain in Japan and the Sudan, his involvement in various aspects of education, ultimately as Head of a very large Comprehensive school.



The book contains an interesting review of educational developments in the 1960s. He suffered throat cancer and discusses the peculiarities of cancer. He had to learn again to be 'Not Lost for Words'. With a mastery of oesophageal speech, he was able to exercise an active retirement ministry in church and education in Worcester. More recently his mobility has been much impeded by a stroke and he continues to be supported by his wife of 59 years.

His autobiography is available on Kindle as well as in traditional form from Amazon etc priced £7.19. The photo is of Gunter and his wife, Diane.

Now Read On...

Here's an extract: "Before my laryngectomy operation, I had a visit from the speech therapist to explain how the operation would take away my voice and how she would afterwards be able to teach me to develop 'oesophageal speech'. At the time it was all pretty academic and deep down I believed neither her prognosis nor the hope she held out. As I have said, one cannot imagine oneself without a voice while one still has it. I am not alone in having sometimes tried to imagine what blindness must be like by shutting my eyes for a while; but, of course, blindness is so much more than that, and those of us with sight cannot imagine it. So it was with my perception of voicelessness. When Sylvia Paine, the therapist, re-visited after the operation, I began to understand what I had lost, but not yet how I could acquire something in its place."

"At this time I also received visits from two former laryngectomee patients. I was so grateful that they took the trouble to encourage me in this way. It was, on the other hand, good to see how these men had learned to communicate again, to progress from silence to the ability to make themselves heard. On the other hand, their visits provided my first encounter with this very different kind of speech and I found it ugly and frightening. I have tried to be sensitive to both aspects when I have myself since then visited laryngectomee patients before and after their operations. It is encouraging to learn there is life after the operation, but a shock to find that one is going to sound like that."

Never Lose Hope

CLAN's friendly correspondent in Uganda, Emmanuel Bychance, has sent us the following message for 2013: I am so grateful to welcome my fellow laryngectomees and members of the CLAN in wonderful new year 2013, for those whom we have lost may their soul rest in peace. As for us with life, I strongly believe that together we can reach our goals. Once you take God at heart, "No matter how poor you are and what challenges you have faced in life", God still remains our light forever in our life. One question that I asked my doctor before my operation was: "If you remove my vocal

cord and I have to breathe through neck, will I survive for some good years?"

The doctor replied: "I will do my part and the rest will be to God." Well I had hope and trust that God still is with me. So far it is now five years since my operation and I am still doing well. My message to laryngectomees is to be firm in everything and a promised life is still there. Wish you all the best and also thank you for your encouraging news you send in your magazine.



Hey Presto!



Roy Cook from Pontefract wonders if readers might be interested in his idea which is to take the centre out of a Provox HME filter cassette and just leave the outer ring that fits into the baseplate. Place a cheap plastic whistle into the cassette housing and secure with a fixative such as 'instant nails'. One deep breath and, hey presto, a warning device for next to nothing.

Avocado Ice Cream

Ingredients

2 ripe avocados – stoned & peeled
¼ pint single cream
10 fl oz double cream
3 oz caster sugar
Juice ½ lemon
2 oz almonds – finely chopped & toasted



Method

Place avocado and single cream in electric blender and work until smooth. In a large bowl whip the double cream until it forms soft peaks. Fold in the sugar, avocado mixture, lemon juice and almonds. Place the mixture into a freezer-proof container, cover, seal and freeze. Transfer to the fridge 30 minutes before serving to soften. Scoop into chilled glasses to serve.

Ian and Rose Browse

Taken from *Soups & Puddings* produced by THANCS Group. Minimum donation (from non-laryngectomees) of £2.00 per copy. THANCS group: Hawthorn Suite, Worcestershire Royal Hospital, Charles Hastings Way, Worcester WR5 1DD.



Swallowing After Total Laryngectomy

Swallowing problems (dysphagia) can occur after total laryngectomy. The dysphagia may be temporary or long term. Risks of dysphagia include poor nutritional status, limitations in social situations and reduced quality of life.

The laryngectomy procedure involves complete surgical separation of the respiratory and gastrointestinal tracts. For this reason, the laryngectomised individual does not risk aspirating swallowed material. Instead, dysphagia following total laryngectomy is mostly characterised by problems with propulsion of material through the 'new' post-surgical swallow passage (sometimes referred to as the neopharynx).

The nature and degree of surgical closure used with total laryngectomy is unique for each patient. As a result of the surgical closure, some patients may end up with a fold of tissue (pseudoepiglottitis) at the base of the tongue. The pseudoepiglottitis may form a pocket or pouch that can collect food or liquid, resulting in effortful swallowing when the patient attempts to clear pocketed material. If the pouch is large enough, another surgical procedure might be needed to fix the problem. Effortful swallowing might also occur as a result of the overall tightness of the surgical closure. Patients require removal of different amounts of surrounding tissue during surgery. For patients requiring significant tissue removal, the surgical closure will need to be tighter and swallowing may subsequently require more effort. In severe cases, the narrowed passage might result in backflow of swallowed material all the way up to the oral cavity or nasal passages. Liquids might be the only consistency the patient can swallow. Another outcome from surgery may be the development of scar tissue which can create a stricture or significant narrowing in the swallow passage. Sometimes this problem can be temporarily relieved with stretching procedures (dilatation). This is only done under the care of a physician. In some cases, a surgical procedure might be necessary to release the stricture.

Critical

Videofluoroscopic evaluation of swallowing conducted by a qualified speech pathologist is a critical component of post-laryngectomy rehabilitation. Not only does this dynamic radiographic procedure provide objective evidence regarding swallow function in this unique patient population, it affords the speech pathologist opportunities to introduce compensatory interventions. For example, alternating food and liquid consistencies or swallowing multiple times for each bite of food might be effective strategies for some patients. Patients experiencing backflow of material might benefit from using a head rotation to assist with opening up a narrowed area in the swallowing mechanism. It is only during the swallow x-ray that these types of interventions can be evaluated for usefulness. Diet consistency recommendations and potential for other treatments can also be addressed during the evaluation.

For patients undergoing radiation treatment after total laryngectomy, another potential problem is lack of saliva (xerostomia) which can greatly impact oral manipulation and propulsion of food. Diminished sense of smell is also very common after total laryngectomy since transnasal airflow has been removed as a result of the surgery. These factors can impact appetite and result in reduced food intake and poor nutritional status during a time when optimal nutrition is necessary.

For speech pathologists, it is critical to discuss potential for dysphagia during the pre-operative counselling session ahead of total laryngectomy. Speech pathologists must also advocate for the videofluoroscopic evaluation of swallowing post-operatively when indicated. For patients, close attention to the act of swallowing is crucial for relaying any new or persistent problems related to ingestion of food and liquid (including weight loss) to the appropriate health care professional so that appropriate evaluation and interventions can be initiated as soon as possible.

Carol Blossom Stach, MA, CCC-SLP, BRS-S and Michael E. DeBaakey VA Medical Centre, Houston, Texas

From: www.webwhispers.org/news/Feb2013.asp

Odd Sign: "Bottomless Pit – 65 feet deep"

Hippopotomonstrosesquippedalio phobia: Fear of long words.

Research Studies Need You!

The number of Head and Neck Cancer research studies and clinical trials has increased greatly in the past five years. Every research project needs the involvement of patients or carers from the planning stage (writing the protocol and patient information leaflet) at the start and, in the running of the study, by a steering group over two or three years.

Involvement in a project will mean reading some scientific and medical information. There will be telephone conferences, exchanges of emails and occasional meetings where the concerns and opinions of patient representatives can be raised. Expenses such as the travel costs of patient/carer representatives will usually be met. Training courses are available from Macmillan and the NCRN on such topics as the Biology of Cancer or the Basics of Research to help prepare for what may be unfamiliar work.

In many regions there are groups called Consumer Research Panels where patients and carers involved in research can share ideas and assist their local hospitals and universities.

If you would like to know more or think you could make a contribution to this work please contact Vivien Reed at the NALC office or visit the webpage www.hnchelp.org.uk and follow the link for patients involved in research.

Malcolm Babb



The photo shows Malcolm in action at the North Trent Conference

Doug meets Bill at the bar after work and is once again looking down in the dumps. "What's wrong now, Doug," asked Bill. Doug replies, "They called in a management team and gave everyone in the office an aptitude test to see what they were best suited for." "Yeah, so what's the problem with that?" Doug sighs, "Well, it seems that I am best suited for unemployment."

(Still Talking NSW Newsletter)

Charlie's Voice

"Pay it forward" is a term still used frequently in the United Kingdom and Canada.

Basically, it simply means to respond to a person's kindness to oneself by being kind to someone else. That is what we laryngectomees do. It is what is expected of us if we are able.

I have tried to do what was asked of me. I had three excellent teachers: the U.S. Navy where I spent eight years as a hospital corpsman; the late founder of WebWhispers, Dutch Helms; and my speech language pathologist, Caryn Melvin, Ph.D..

I have probably done 20-25 counseling sessions since my surgery in March 2005. All of them, though, were on the phone or in person. It wasn't until a few weeks back I was asked to help on the internet. (The story is on pages 6,8 and 10.)

First, the newbie, Kathy Turbucz Poirier, was terrified, and she is very bright, meaning in the beginning I had to choose every word carefully. For this I called on mainly what I had picked up from Dr. Melvin. Listen/read carefully before responding. Jumping in with a bunch of mind-numbing advice can exacerbate a serious problem. Better the counselor just send the patient back to his/her SLP or physician than to be the least bit dogmatic.

Now the Navy training. Never advise or speculate if a problem is the least bit over your head. In fact, I once sent Kathy back to her SLP. And I had her make up a list of questions for her physician.

Surgeons are busy people. Write your questions and have them ready.



Finally, the time comes when the newbie/patient has to be told by his/her peer that some things are a given for a laryngectomee. You are going to cough, so learn to do it as unobtrusively as possible. In the beginning, for most of us, we must be careful what we take out to eat.

I remember when I really wanted to go see "Walk The Line." But I hesitated because of coughing. "You better get rid of that attitude," said Dutch, "unless you want to sit at home the rest of your life." I went, coughed like I had been taught and nobody paid any attention. And I very much enjoyed the movie.

Kathy was really easy because she listened and sincerely wanted her life back. And it seemed as if every day she would make a stride of some sort.

First she began to get over her imagined fears. I certainly don't take credit for this. Her doctor, SLP and counselor were mostly responsible. But after every visit we would talk about what she had been told and how she had put it into practice. All of us have many similarities.

I remember the first day she walked outside and had courage to leave her yard. If I am not mistaken, it was about one-half mile. This she forced herself to do. That was the first and it abated most of her fear.

Then it was the grocery, then driving. She just bubbled. She was getting on with her life. Things began rushing out in a flood. Having her hair done. Visiting her co-workers at the bank. And, with me, she began taking about going to work. Now she and her husband, Claude, have all kinds of trips and the like planned.

And two weeks ago, she began "paying it forward."

Charlie "Buck" Moore is editor of The IAL News.

from the November 2012 IAL News

It's on YouTube

There are quite a few clips on youtube made by and about laryngectomees. Here are three we recently found.

1. A ten minute video made in 2010 by grandfather, Graham Taylor and grandson, Alex Ratcliffe (who operated the camera), about life as a laryngectomee. Over the months, Alex kept a video diary of his relationship with Graham and his developing cancer. Graham clearly kept his sense of humour to the end!

www.youtube.com/watch?v=Q94zKmq2fbk

2. A 2011 video about communication, specifically after total laryngectomy (surgical removal of the larynx). This video also highlights good communication skills and can be used in training for anyone working with the public. Produced by the South East Coast Laryngectomy groups: YakityYak in Brighton and Necks Best in Eastbourne/Hastings.

www.youtube.com/watch?v=R4azcU6i2IE

3. A 2011 video about Steve, who started smoking at six years old and stopped six years before he got cancer. www.youtube.com/watch?v=PzwnO6o-V6w



News from the Clubs

Windpipers, Blackpool

Their Christmas Meal at the St Ives Hotel, St Annes, was enjoyed by everyone and the overnight stay was the icing on the cake. At their February meeting, Oliver Maudsley from the Dept of Works and Pensions gave a presentation on the changes in the various benefits taking place this year. Their annual charity Bowling Competition takes place on 7 April at Newton Hall, Staining. And the Cancer Trust Summer meal at the Savoy Hotel is on 8 June.

Plymouth

Club Members had a delightful Christmas Luncheon at the Legacy Hotel at Marsh Mills, Plymouth on Tuesday, 11 December 2012. Everyone said the food was excellent! Thanks go to Fiona and Ron for organising the event. It was made even more special by being joined on the day by members of the Torbay Laryngectomy Club. On 8 January at the Mustard Tree Cancer Support Centre, they had a talk by Eunice Halliday, the Project Manager of the Plymouth Foodbank. On 12 February they had a visit to Plymouth City Museum and Art Gallery. And on 12 March 2013 they had a talk by Annabel King of Crossline. In April they plan a visit to the Lord Mayor's Parlour, Plymouth.

Speak Easy Club, Cornwall

Christmas lunch at the Inn for All Seasons was a great success and well attended. They were delighted that the Recovery Club joined them again this year, as well as several from the hospital, which all helped to make a joyful atmosphere. The Inn kindly donated a 'carvery for two' raffle prize. This was followed by a short but very interesting talk on budgies by Maurice Roberts, who has made a fascinating career travelling the globe attending World Conventions on behalf of the Budgerigar Society. The January meeting was at the Victoria Inn, Threemilestone, when plans were made for the coming year.

Speakers' Corner, Shropshire & Mid Wales

Their Newsletter notes the continuing decline in club membership and led to a discussion on the future of the club. Any decisions were deferred to the AGM in February at the Hamar Centre with a view to implementation in 2014. In the meantime, members were asked to consider all ideas to ensure specific needs or wishes are taken into account. Such ideas included:

- Ceasing to operate as a 'Laryngectomee Club' but to meet regularly as friends
- Continuing as a club but with reduced number of meetings
- Meeting monthly for pub lunches only

Their November meeting included discussion of their Festive Dinner which was to be at the Lord Hill Hotel on 12 December. Lunch venues were The Grapes Inn, Bicton Heath, Shrewsbury in January; The White Horse, Wenlock Road, Shrewsbury in February and The Horseshoe Inn, Pontesbury in March.

The photo shows club members preparing the raffle at Elsie Tong's garden party in August 2012.



'20-20 Voice' Cancer Appeal

Their lady supporters in Wokingham (JJ and Sherry) raffled off a couple of Christmas Cakes (thanks to M&S and Tesco's) and raised a magnificent £81.85 for the '20-20 Voice' Cancer Appeal. Thanks to Kay Wakes, landlady of the Two Poplars Pub, for hosting the event. The photo shows Keith receiving his Christmas Cake. Meanwhile, in Leicester they held a raffle at the Leicester Royal Infirmary



where the first prize was a magnificent hamper consisting of Champagne, White wine, Red wine, Ham and chocs etc, which a delighted Mr Tony Bell won.

And over at Glenfield Hospital the '20-20 Voice' Cancer Appeal raffled off a giant 'Gingerbread House' kindly donated by John Lewis Stores (Leicester). The lucky winner was 'Mo Birrell'.

The two raffles raised nearly £100 for the '20-20 Voice' Cancer Appeal. Could you start a '20-20 Voice' Cancer Appeal group in your area? We need to be nationwide – can you help? We are alive and kicking on



Facebook for all you social networkers, drop in and see us and you can always contact me on:
admin@2020cancerappeal.org.

Phil Johnson, Leicester Club

Happy Larrys, Liverpool

Their January meeting was at the Queen of Martyrs Centre, Liverpool. On 18 December they held their Christmas Lunch at the Prince of Wales Hotel, Southport

The photo from their website (www.happylarrys.org) shows members swimming at the Bounty House.



News from the Clubs

Chesterfield Club, HNCHELP

They concluded the year with their biggest ever Christmas Lunch. Members generously supported a raffle and were grateful for support from the Cancer Laryngectomee Trust for the event. Their membership has grown over the year, partly because they welcome all head and neck cancer patients, not just laryngectomees. Another factor has been the closure of nearby clubs, so they are now trying to support laryngectomees from Nottinghamshire as well as North Derbyshire. They have a busy social programme planned and are also involved with other cancer support groups in Chesterfield. They will be holding a fundraising event towards the cost of

providing a bus service from Chesterfield directly to Weston Park Hospital in Sheffield, where they get radiotherapy and chemotherapy services. The photo shows the raffle draw.



London Club (new)

The first meeting of the Central London Laryngectomee Club was held on 12 June 2012 at the impressive new UCLH/Macmillan Cancer Centre at Huntley Street WC1E 6DH. The event – opened with welcome speeches from UCLH Speech and Language Therapists Sarah Eli and Lindsay Lovell, also Francis Vaz, Consultant Surgeon in ENT and Head and Neck Cancer, and Lynda Farmer and Khalda Meer, Clinical Nurse Specialists in Head and Neck Cancer – was well attended with around 25 guests, including laryngectomees, their friends and families. Springtime events include walks and fundraising on Hampstead Heath.

Being Heard

I am now 51 years old and I was 40 when I had my operation. Since this time, I have raised a son and he will be graduating from Uni in Brisbane next month. He has taken all that I have had to cope with in his stride and we have a unique ability to communicate without the Servox.

I used to be a health professional at a local hospital but had to retire following the surgery. I thought my work days were over but I started my own medical transcription company and worked for hospitals and doctors all over the world. I communicated with clients, staff and colleagues all over the world using email, MSN and Skype and even then we used instant messaging dialogue. My professional life got bigger and my cup runneth over as to the joy I experienced in my professional life.

I have spent the last few years travelling all over the world as I wanted to fulfil my dreams of seeing the world and I found people in every country to be most accommodating when it came to my disability. In a world where we have to gain support services via the internet or via a telephone, communicating for a laryngectomee owner is not so easy and our role is to educate others patiently so they can have patience to cope when speaking to us.

Empowering

However I think the internet has made achieving our goals less frustrating and it empowers us to do for ourselves and relieve our family and friends of some of the burden. I still hate it when I have to use the telephone with someone I don't know. I find that it's so tough to deal with their freaking out about NOT BEING ABLE TO HEAR ME. It usually takes two or three calls before they stop

Good Vibrations, East Lancashire

Held their Christmas party 13 December 2012 at the Peel Park Hotel, Accrington.



Here are some photos from their website: www.goodvibrationsclub.org.uk/index.asp



freaking out and realise that they in fact have a human being on the end of their line.

I am now swimming again. I used to love competitive swimming and loved going to the beach. I have overcome my fears and can now swim and paddle around to cool off. I have heard of laryngectomy owners who have sailed the Sydney to Hobart and we even have one here who goes surfing on a daily basis. I am not that confident but it does make you wonder.

I keep healthy and do not go out into crowded places very often. I find that the internet provides me with a great outlet for my shopping needs including supermarket items. I am involved in arts and crafts projects and sell them at the Eumundi Markets.

I also love gardening and am growing veggies, tropical fruits, spices and herbs. I have chickens and, until recently, I had a wonderful little dog (Timmy) but he was taken by a tick in September. Tim and I communicated through hand commands and he was able to do so many things that made our lives fun and a joy. He is sadly missed.

*Deb Melrose
(from Still Talking – the NSW Newsletter)*