

Notes from the President

Strange Times

For the first time in our history our affiliated clubs cannot currently hold meetings because of the COVID-19 situation. The NALC office is closed, our staff are working from home and there is uncertainty about when we will be able return to our normal way of working.

Despite all of this our work continues. Patients are still having life-saving laryngectomies and NALC is supporting them. Our website and Youtube channel continue to see record traffic and the provision of support via the internet and email will be so important for months ahead.

Like many charities, we face the challenge of continuing our work despite the fact we, and our clubs, cannot put on our usual fundraising events. Please do not forget us if you are considering donating to one of the many deserving causes that are seeking your support at the moment.

NHS Staff

I am sure that many of you will have stepped outside on recent Thursday evenings to clap and make some noise to show support for NHS staff and care workers. They deserve all of this appreciation as they work to save lives, with thoughts for their own safety being a poor second consideration.

In my work for NALC I meet many clinicians, including those who are pre-eminent in their speciality. The common factor is their determination to do their best for their patients and sadly this has in some cases cost them their lives. NALC applauds all of them!

NALC Is Here for You

NALC can still help in many ways. Our contact details, whether by telephone, email or website are listed elsewhere in this edition of *CLAN*. We only have limited access to our office so please do not post letters to us, unless there is no alternative for you.

If you need information or advice please get in touch. Also hearing from you about your experience of care and treatment is very valuable. It enables us to send the right messages to our clinician partners, so we provide an accurate expression of patient views.



Malcolm Babb

Tony Hudson

NALC Vice-President, Tony Hudson, passed away in February. Whilst many of us were aware he was ill, we had had expected and hoped he would be back working with us before long.



I first met Tony in Oxford when he spoke about his experience having a laryngectomy and adapting to life without a voicebox. Before long he started to attend NALC General Committee meetings, along with his wife Maureen, representing our Amersham Club.

In 2015 Vice-President Andy Gage passed away and Tony was co-opted onto the Executive Group, in his place. The following year Tony himself was appointed as a Vice President, and served in that role until his death.

Two Key Areas

He took on responsibility for two important areas of our work. He took the lead role in updating our information leaflets, developing a new corporate style. More recently he led our safety project which aimed to provide training resources for community first-responders advising on the needs of neckbreathers. Tony had been involved with St Johns Ambulance Service at a high level for many years, so had much relevant experience for this role. He worked, initially, with South Central Ambulance Service (SCAS) which covered his locality. A NALC video and information leaflet is now used widely by SCAS and Tony was about to extend this work to other ambulance service areas.

One of the greatest privileges of my involvement with NALC for the past 10 years has been to meet some inspiring people, and Tony is up there with the best of them. He gave me tremendous support as I carried out my work as NALC President. Tony and Maureen have contributed so much to NALC at the most difficult time in its history. They became friends to all of us and our thoughts are now with Maureen and her family, whose loss is the greatest.

Malcolm Babb

Future NALC Meetings

As we face up to the challenges posed by the COVID-19 pandemic, NALC has been seeking to find alternative ways we can meet our statutory obligations as a registered charity and the demands of our constitution, as a charitable trust.

The normal processes are continuing with our accounts currently receiving independent scrutiny by auditors. Our first concern is the safety of our members hence the planned AGM could not take place in May, as we follow the guidance of HM Government. We will also comply with advice from the Charity Commission regarding alternative arrangements that may be needed. We will send affiliated groups our accounts as soon as they are available, along with a briefer annual report than usual.

Around 18 months ago the General Committee discussed the possibility of members being able to join meetings remotely, via telephone or video conference. Since then more options for video conferencing have become available and currently we cannot hold face to face meetings. In recent weeks the Zoom platform has become very popular and many of our partners make use of it. It has the advantage of being easy to use and can be accessed via a laptop, tablet or smartphone. NALC is likely to use the platform for a meeting later in the year. Ahead of this we will share guides to using Zoom and a link so that users can test that their device is ready to go before trying to join a meeting.



Really wish we had a dog right now but then I remember that old slogan.. a dog is for life, not just for a global pandemic.

In Germany, they are preparing for the crisis by stocking up with sausage and cheese. That's the Worst Käse scenario.

Esophageal Speech (ES)

Most laryngectomees now use a voice prosthesis as their primary method of speech. Of course for some this is not an option and an electrolarynx may be employed instead. The third method, esophageal speech, is rarely heard these days perhaps because of the shortage of instructors in its use.

The COVID-19 pandemic has changed all our lives. For valve-users in particular there have been some major problems. Replacing a leaking valve is a high risk procedure, as a cough with an open stoma generates aerosols that would transmit the virus if the patient was infected. We have been provided with valve plugs and liquid thickeners to get us through until the situation eases. As it happens I have a basic duckbill valve and replace it myself so have not been inconvenienced. I am sure some others may ask why patient changeable valves are so rarely employed now, though that is a question for another day.

My thoughts have recently turned to esophageal speech. I have had discussions with a local laryngectomee friend who has had to turn to this as the only possible way he may regain speech. It has the advantage of being hands-free and if admitted to hospital may be very useful in communicating with doctors and nurses.

Facing a lock-down, I decided learning to speak using ES could be a very worthwhile use of time. With the assistance of my friend I have compiled a list of resources that are available to help others wishing to do the same. Most of them will require a laptop or smartphone and I hope any one without either of these may be able to get assistance from family and friends if they want to accept the same challenge.

Laryngectomees and COVID-19

The coronavirus pandemic has affected all of our lives in ways we may not have imagined, as we read occasional newspaper articles in recent years about the possible risks of such a scenario. For a laryngectomee, life has become much more complicated. Are we at greater risk than others? How can we stay safe? If my voice prosthesis leaks, how can I manage this situation and what service can I expect from my hospital?

A neck stoma provides an easy route to the lungs and this creates a greater risk. Using a baseplate and HME cassette, especially one with high filtration properties, will offer valuable protection. Hand hygiene is very important as the HME cassette may need to be taken out at short notice to clear mucous, not to mention occluding the stoma to allow for speech. Thorough hand washing or the use of sanitisers when away from home is essential.

Laryngectomees have had to cope with a limited service regarding valve changes when a leakage occurs. Any procedure involving the stoma may result in coughs which produce an aerosol and the possible transmission of the virus. Conversations with clinicians reveal they are aware that the restrictions are not sustainable over a period of many months; patients will need their valve to be changed.

Your Experiences?

NALC will be interested to hear of your experiences, whether positive or negative. This will help us provide an accurate patient perspective as we seek to influence patient care.

Public Health England (PHE) identified a group of around 1.5 million whom it felt were "extremely vulnerable". This group needed to stay at home and not go out for shopping for example. It promised arrangements would be put in place to support them. Laryngectomees were not specifically named on the list, but it was always anticipated the list would not be complete and other patients would be added to the group.

In my own area some laryngectomees have been added to the list but others have been turned down. It seems some GPs will not add anyone who does not have one of the vulnerabilities stated on the list.

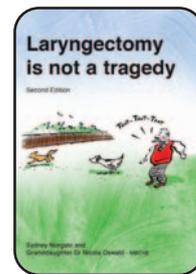
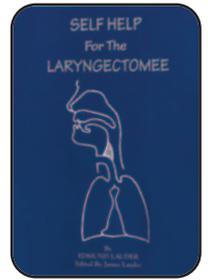
Cancer Policy England believes laryngectomees should be in the group. NALC joined the professional bodies of the clinicians who treat us in sending a letter to PHE recommending we should be added to the list. As I write this we await a response.

There is a link on the NALC website www.laryngectomy.org.uk to pages containing more information about COVID and guidance that may be helpful. The pages are updated regularly.

Malcolm Babb

Books and Videos

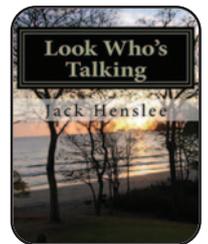
In the USA some years ago, Edmund Lauder wrote **Self-help for Laryngectomees** and a spoken version of this is available on Youtube. To locate it search on Google for 'Edmund Lauder Youtube'. It is also available in book form from www.electrolarynx.com for £5.



In the UK, Sydney Norgate wrote **Laryngectomy is not a Tragedy** and it is available to download for free from the Cancer Laryngectomy Trust www.cancerlit.org/thebook.html or

once again a book can be ordered, this time at no charge.

More recently there is **Look Who's Talking** written by Jack Henslee, a stalwart of Webwhispers in the USA. It is available from Amazon as a kindle download, for around £5.

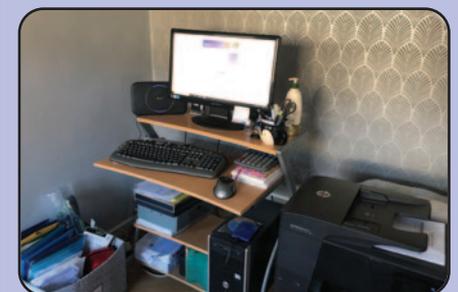


Learning ES is a serious challenge and the key to success is practice, practice, practice! Your speech therapist may be able to assist by providing exercises for you to try. Best of luck if you decide to try it!

Malcolm Babb

Our office at home

We are still working, so if you would like to talk to someone you can phone the office and Vivien will answer your call. If you prefer an email chat, Kerry will be at the end of the email. We also have an active facebook page and any updates relating to the COVID-19 are on our website. You can also check our twitter page #laryngectomy75



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Lockdown in Turkey

Christine Newton is a laryngectomee who is a member of the Oldham Quiet Ones.

I was on holiday in Turkey when the COVID-19 Virus struck and during the second week of our holiday we were informed that it was unlikely that we would be allowed to return home as planned, especially as we were in the over 65 age group. Turkey were very quick to act and put contingencies in place – streets were immediately cleaned and sprayed; we have only been allowed to go out on two occasions and a lovely lady Deborah Ugar has been doing our shopping for us. To my knowledge there have not been any confirmed cases of COVID-19 in the local area so these contingencies seem to have worked and we do feel safe out here.

When I go on holiday I always take extra supplies with me to care for my stoma but nothing prepared me for what would happen and how long I would be in Turkey. I have now been here since 28 February which is considerably longer than the two weeks we initially planned and have only been allowed out for four hours on two occasions on 10 and 17 May. I quickly realised that I needed extra supplies, but contacting my usual delivery company I use for my laryngectomy products was proving difficult. I was in touch with my friends at The Oldham Quiet Ones and news of my plight got out and I was relieved when the team at Kapitex – especially Denise and Joanna – contacted me directly to see if they could help.

It wasn't easy to get medical products from the UK to Turkey with many hurdles but thankfully between us we persevered and the products eventually arrived at no cost to myself. I cannot tell you how much this regular contact and support from the entire team at Kapitex reassured me and knowing that there was someone in the UK looking after this reduced my anxiety.



Every laryngectomy knows how important it is to protect their stoma but trying to explain this to the authorities in Turkey was another story but again this was taken out of my hands and numerous phonecalls and emails were made and thankfully the Kapitex products arrived by special courier at 2am one morning. We sometimes take these things for granted in the UK but I won't be taking this for granted in the future. I did eventually receive a box of supplies from my usual delivery company but this was at a charge of £50 – it really makes you appreciate our fabulous NHS and the free services we receive in the UK.

I can't wait to get back home to my friends and family who I miss terribly but I will never take the NHS for granted and the fantastic service that companies like Kapitex, who are associated with the NHS, provide.

For the first time in history,
we can save the human race
by sitting in front of the TV and
doing nothing.



Let's not
mess this
up!

The CLAN Cryptic Crossword Answers!

In the March issue of *CLAN* we featured a cryptic crossword by David Wright and his colleague, Mike. It would be interesting to hear from you how you did – as here are the answers! Just email the editor with how you did: Honeysett@btinternet.com

If you have ideas for similar items, let us know!

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CLAN via Email

In these difficult times of fundraising a way you could save NALC money is by signing up to an email version of the *CLAN* newsletter. It's easy to do. Visit our website www.laryngectomy.org.uk. On the right hand list you will see a link to *Newsletter*. Follow this link. At the top of the page you will see in blue 'sign up'. Click on the link and you will be directed to put in your details, name and email. You will then receive a confirmation email; your *Newsletter* will be delivered to your inbox every quarter.

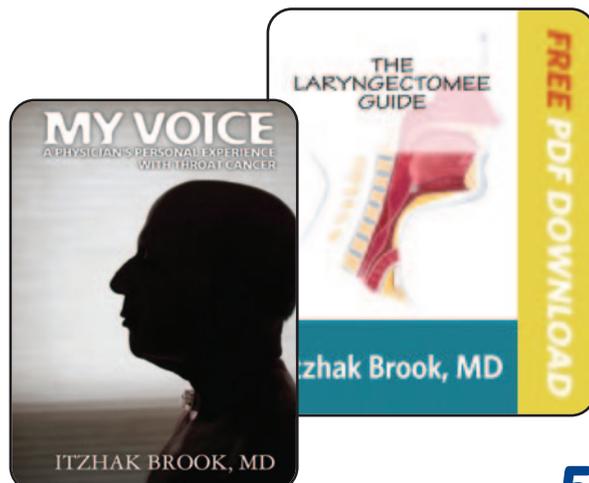
If you sign up and already receive your *CLAN* by post, don't forget to let us know to cancel your paper copy, either by phone 020 7730 8585 or email info@laryngectomy.org.uk. Don't forget to include your name and address.

Many thanks.

Itzhak Brook MD

The *Laryngectomee Newsletter* presents suggestions how laryngectomees can cope with the COVID-19 pandemic. It is presented by Itzhak Brook MD. Dr Brook who is a physician and a laryngectomee. He is the author of *The Laryngectomee Guide*, *The Laryngectomee Guide Expanded Edition*, and *My Voice, a Physician's Personal Experience with Throat Cancer*. You can access it via this link: laryngectomeenewsletter.blogspot.com.

Dr Brook is also the creator of the blog *My Voice*: dribrook.blogspot.com. The blog contains information about head and neck cancer, and manuscripts and videos about Dr Brook's experience as a patient with throat cancer.



Lockdown: an Editor's Experience

The Editor with his new grandson, Dylan. (Dylan is the one with the bright socks on!)

In February and March the Editor, Ian, and his wife, Jan, were fortunate to be able to spend six weeks in New Zealand, staying with their daughter, Amy, husband, Colin, and the new baby, Dylan. The Corona virus was, of course, already having an impact when the time came to fly back to Gatwick. The airline crews were equipped with face-masks by then as were some of the passengers. But we'd not yet heard of social distancing so we all sat next to each other and chatted as usual. The flights back went very smoothly. No health checks at any of the airports. Back home on the train as usual.

One of our daughters had just moved to a house a few minutes away so we happily went round there to help here decorate. Then came the Lockdown! No more such visits. We're very involved in our local parish but no more Masses. Jan is the Secretary of the local U3A (University of the Third Age) but no more meetings. Everything stopped. Except for the need for daily exercise. So we started alternating walks with bike rides. We soon realised that we weren't the only ones doing this so we began searching for routes that not many others had discovered. Given we live in leafy Godalming, surrounded by the Surrey Hills, this wasn't too difficult. Though, as time goes on, it becomes more and more of a challenge.

Many of the meetings have been replaced by Skype and Zoom virtual meetings. On Sundays about 60 of us join an on-line service which works very well. For 35 years, I've run a "Dads' Group" (now a "Grandads' Group") and we meet regularly in various Godalming pubs. So now we



have our Zoom calls, naturally with a glass of beer. One of our group now lives in Brussels so he is able to join us. Another is sailing round the world in a yacht and has joined us from the Galapagos Islands. Not quite the same but the beer's a lot cheaper now. Sadly we fear that many of our local pubs may not reopen.

So we're adapting. We realise we're lucky to be retired, to live surrounded by beautiful countryside and that we also have excellent broadband so that we can keep in touch with family and friends. In fact, I've used the time to ring several old friends we've not seen for years. But how are you, our readers, coping? Do let us know. And, if you have a photo, please email it to me!

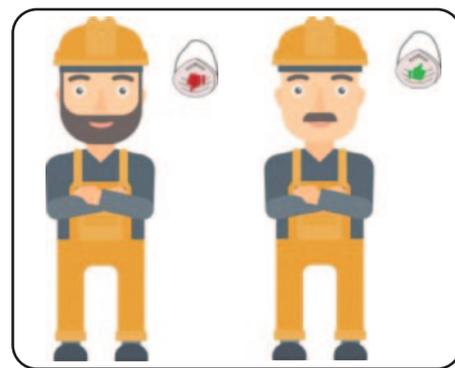
Ian Honeysett

COVID-19 and Facial Hair

The US Centre for Disease Control recommends wearing face covering (e.g., face mask, respirator) in public settings where other social distancing measures are difficult to maintain (e.g., grocery stores and pharmacies), especially in areas of significant community-based transmission. Although neck breathers (laryngectomee and those with tracheostomy) breathe through their stoma, it is recommended that they wear a facemask in addition to covering their stoma with a modified mask or Home Medical Equipment.

Ensuring the face mask seal is a vital part of respiratory protection practices. Facial hair that lies along the sealing area of a respirator, such as beards, sideburns, or some moustaches, will interfere with respirators that rely on a tight face piece seal to achieve maximum protection. Gases, vapours, and virus particles in the air will take the path of least resistance and bypass the part of the respirator that captures or filters hazards out. This can allow the COVID-19 virus access to the respiratory tract.

It is therefore recommended that all individuals including neck breathers remove their facial hair prior to wearing a mask. Shaving may be challenging for those who had radical neck dissection because of their facial numbness. Using an electrical shavers allows safe removal of the hair without injuring the skin.



Upcoming Webinars

Severn Healthcare are excited to confirm that their trio of Clinical Specialist Speech and Language Therapists, Andy Plumpton, Fiona Robinson and Paula Barnes, together with Mr Malcolm Babb, the President of the National Association of Laryngectomee Clubs (NALC), will be providing their first series of webinars, designed to support the laryngectomee community. The panel are going to address the common concerns connected to Coronavirus (COVID-19) and the scheduled easing of lockdown, as suggested by members of the laryngectomee community. In addition to a question and answer section, the topics to be covered will include:

The latest guidance on the management of a leaking voice prosthesis (valve).

Managing a leaking valve at home – a laryngectomee's tips and

tricks on placing a Voice Prosthesis Plug Insert.

The valve change clinic during the Corona Virus pandemic – what to expect.

Use of a mask – should it be placed over the mouth and nose, the stoma or both?

Learning to self-change a voice prosthesis.

Anyone interested in viewing the webinars simply needs to contact Severn Healthcare's Office Administrator, Julie Lee, either by email: Julie.Lee@severnhealthcare.com or via telephone: 01635 887640. Julie will register you and send you a weblink to the event of your choice, together with the relevant passcode.

Dave Turns To Exercise After Cancer Battle

This article was published by Laura Nolan for the Bury Free Press on 28 October 2019 and appeared in the Plymouth HNC Club newsletter.

A Bury St Edmunds man has said "cancer saved my life" after he turned to exercise following successful treatment. Dave Hills, 58, had to learn to speak again after undergoing surgery following a diagnosis of stage three cancer of the larynx. Since treatment, Dave now regularly mentors cancer patients at Addenbrooke's Hospital.

He said: "For head and neck cancer (HNC) patients, we have what's called a buddy scheme where a patient who is about to undergo a laryngectomy is paired up with someone like me who has previously been through the surgery so they can see what's what and ask the million questions they generally have. I know I did, and we also show them what it's like, what's what and how it all works. I found it very reassuring when I was buddied up with someone and hopefully new patients find it the same. I like doing the buddy scheme as I feel I am giving something back and my positive, can do attitude seems to rub off on the patients, although each patient needs approaching a little differently depending on how they are feeling prior to the surgery.

A Transition

The buddy scheme is entirely voluntary, but it feels great to do as you feel it's a transition from actually being a patient into someone who helps patients which was such a major step in the journey."



*Spa staff with Dave Hills in the gym.
Picture by Mark Westley.*

Dave now spends a lot of time at Bannatyne Health Club in Bury St Edmunds to regain his physical fitness. "One thing I do know is that 'cancer saved my life'. Prior to cancer I was an unhealthy individual, who ate, drank and smoked to excess. Now my life is turned around and I am doing at least one class or something at the gym every day," he said. With the support of the club's staff, Dave now enjoys yoga, Pilates, step, body balance, Zumba classes and regular sessions in the gym.

He is also working towards using the pool with special training. "My aim initially at the gym wasn't to lose weight but to improve my overall health and improve my breathing and breathing techniques now that I'm solely a neck breather and can't breathe with my mouth or nose. The weight loss will come naturally as my health improves," he said.

Thank You!



AYMES manufacture an Oral Nutritional Supplement to help manage disease related malnutrition. As part of their commitment to make as large a positive impact in their local communities as possible, they pledge to give 5% of their profits to charity. This year they decided to offer the opportunity for the healthcare professionals that they work closely with, to choose the charities they would like to see benefit.

The National Association of Laryngectomy Clubs was nominated by two ladies, to receive a £500 donation from AYMES.

NALC received the email from Stephen O'Sullivan the Customer Support Manager he said:

"Normally we would like to arrange a presentation cheque to be presented to you so that we can use photos in some of our marketing and highlight your charity on our website, draw attention to your cause and encourage others to keep on nominating, but due to the current circumstances we will make the donation and send an email to all parties once it's been made."

Hopefully we can have a photo at a later date.



**Happy 90th Birthday
David Lyall
NALC Committee
Member**

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Cancer Sufferers at Risk

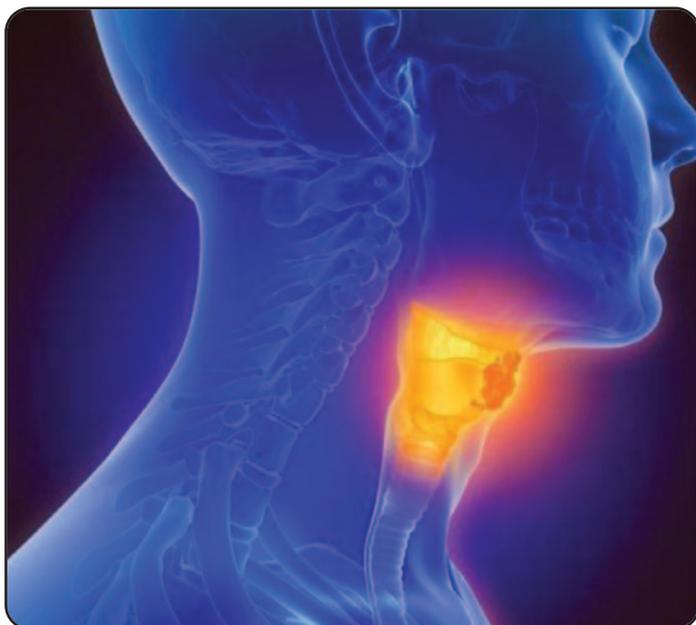
This article was published by Laura Mowat for The Express on Tuesday, 14 April 2020.

The Founder of head and neck cancer charity, The Swallows, has expressed his concern at the number of operations which are being cancelled because of COVID-19 and what this could mean for cancer patients. Chris Curtis, who founded The Swallows, said to Express.co.uk: "People are frightened. Without these operations going ahead, there is every chance they won't survive. I am very worried that a lot of our patients will die who would not have died normally." The charity head, who has survived cancer himself, said patients being told they have cancer on the phone, rather than as normal in a hospital, can also be extremely detrimental to their mental health.



There are fears for cancer patients as hospitals prioritise COVID-19 sufferers. (Image: GETTY).

He added: "It is frightening enough when you are told you have cancer, if they are told by the doctor and not on the phone they can find out that most people survive. They often call us frightened and we calm them down." Mr Curtis highlighted the importance of early diagnosis, which is imperative for higher survival rates. He said: "With stage four cancer, this is the worst situation a patients' tumour could develop very quickly and then you are talking palliative care only."



Around 12,000 cases of head and neck cancer are diagnosed each year in the UK. (Image: GETTY)

From Stage 3 to 4

"Also, don't forget you can go from a stage three to stage four in a matter of days." The effects of Coronavirus panic-buying to the majority of people is simply an inconvenience. However, when cancer patients have had radiotherapy or chemotherapy and can't get hold of easy to eat foods, such as custard or rice pudding, it can be more serious. In a Zoom support call organised by The Swallows group, one patient said: "I was diagnosed with advanced cancer in my tongue and left jaw five weeks ago. I was scheduled for an operation in Coventry nine days ago but was cancelled a few days before."

"Oncology was prescribed instead, though this is unlikely to help me much. I have surgery booked in April, they realise the pain I'm going through and how quick the cancer is advancing but, of course, it could be cancelled at any time." Another patient from New Zealand pointed out surgery is being delayed which might not be lifesaving but is important for people's quality of life. Other people have taken to Twitter to voice their concerns about delayed operations. Jamie Burn wrote: "My mother in law was due to have a bowel cancer operation this week but unfortunately it was cancelled due to Coronavirus." There are also concerns of the secondary effects of missed operations, Maggie BLOWER said on Twitter: "I am almost 72, not afraid of Coronavirus, more afraid of eventually being confined to a wheelchair if my back operation is delayed or is unsuccessful."



The Government opened the Nightingale Hospital in London to cope with the extra COVID-19 patients.

Need to Prioritise

The Christie hospital in Manchester which deals with patients with head and neck cancer have said: "We are sure however that people understand that COVID19 is causing severe pressure on the NHS and that all hospitals across Greater Manchester including The Christie are having to prioritise treatment of the most urgent cases and change or defer treatment of other patients until the pandemic is over." Barking, Havering and Redbridge University Hospitals Trust said in March it had cancelled chemotherapy and routine cancer operations for a fortnight. It said in a statement: "These measures will help us to protect our patients, including those with COVID-19, and those with other conditions. They will also enable us to help us be as prepared as possible by training additional clinical teams who are not specialists in respiratory illness. We are reviewing these patients to ensure no harm will come to them by delaying their treatment."

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MyVoice Laryngectomy Webinars

We are all facing new challenges during the Covid-19 outbreak and it's important to try and remain as positive as we can. We want to continue to find ways to support the laryngectomy community during these unprecedented times.

Hosted by a Head and Neck Specialist Nurse, each month we will cover a different topics.

Previous topics covered:

- Staying safe at home
- Dealing with the unexpected

How to join:

All webinars are held virtually online, and if you would like to join a MyVoice Webinars, please email us on events.uk@atosmedical.com. Alternatively, you can find out about our latest events on our Facebook page at facebook.com/AtosMedicalUK



All are welcome to attend, and provides a great opportunity to learn something new and find support in these uncertain times.

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PET-NECK Study

The PET-NECK study set out to investigate if PET-CT scans could be used to monitor disease in patients after chemoradiotherapy, with neck surgery only used on those that still had disease or unclear results, rather than surgery as routine.

Traditionally it has been difficult to monitor the response of head and neck cancer to chemoradiotherapy using imaging scans. As a result, the standard care for patients with some kinds of head and neck cancer has included neck surgery after chemoradiotherapy. This is an invasive 2-3 hour operation and requires a hospital stay. It can be technically difficult for surgeons and carries risks of life-changing complications. However, other techniques to monitor the cancer in these patients were limited, and so surgery was necessary.

The NCRI Head and Neck Group identified this as an opportunity to transform the standard of care for this group of patients, in developing a less invasive way to monitor people with head and neck cancer. There was evidence from small retrospective studies that PET-CT scans could identify the absence of tumour in the neck following chemoradiotherapy, however there was a need for a definitive trial to provide the evidence needed to change clinical practice.

Head and neck surgery can be technically difficult for surgeons and carries risks of life-changing complications.

Largest Trial in UK

PET-NECK is the largest trial completed in head and neck cancer in



Head and neck surgery can be technically difficult for surgeons and carries risks of life-changing complications.

the UK in the last two decades, with 564 patients recruited. The NCRI Head and Neck Group was at the centre of the development of the study.

Professor Hisham Mehanna, lead researcher on the study, explained how the Head & Neck Group supported the study: "The Group was essential in developing the idea for PET-NECK, applying for funding, running the study and ensuring and encouraging recruitment".

"The study would have probably not happened if there had not been the input and coordination of the Group. Indeed, this Group is the envy of many head and neck cancer colleagues around the world"



Are you looking for support or advice during these challenging times?

The Severn Healthcare Forum provides postings which are being made by Clinicians, professional organisations, and fellow laryngectomees that we hope you will find helpful

We'd like to invite you to visit the forum

Instructions to navigate to the forum:

1. On any search engine type in 'Severn Healthcare'
2. Next click on 'FORUM'
3. Click the 'SIGN-UP' button in the top right-hand corner and create an account
Alternatively, if you already have an account then please sign-in
4. Once registered/signed-in please browse the forum posts and feel free to add any of your own comments

Recent topics:

1. Providing clean technique for stoma care
2. What is the right HME for you?
3. What to do if your valve starts to leak

Save the date – A webinar on Common Concerns in the Current Climate - a Question and Answer Session with the Severn Healthcare Clinical Specialist team and Malcolm Babb (President of NALC). Thursday 18th June. 2-3pm.

Email Julie.Lee@severnhealthcare.com for more

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The value of the NCRI Groups to studies like this is far-reaching; as explained by Professor Mehanna, the Group “originate new ideas, develop them, help others to develop their ideas, has significant expertise in obtaining grants, and is able to access the wider head and neck community and encourage recruitment and participation. This was my first major grant application and my first ever clinical trial – I needed help and could not have done it without the Group!”

Research into Practice

The PET-NECK study successfully showed that PET-CT scans could be used as a monitoring technique, and that neck dissection surgery could be avoided in over 80% of patients*. This has great cost-saving potentials for the NHS – for each person that avoided neck dissection during the trial £1,492 was saved. The avoidance of invasive surgery and its potential complications is also a huge improvement in the care of patients, avoiding the risk of complications, reducing hospital stays and ensuring quicker recovery times.

This work has translated into new recommendations in clinical guidelines at a UK, European (e.g. Germany, Italy) and global level (US), with tangible changes seen in clinical practice in the UK and internationally. As a result of this study, PET-CT guided surveillance has now become standard care in the NHS. This research will benefit around 2,500 patients in the UK every year, estimates Professor Mehanna.

* The results of this study can be found in the publication: Mehanna, H et al. (2016). PET-CT surveillance vs neck dissection in advanced head and neck cancer. New England Journal of Medicine, 374;15 1444-1454.



Our grandparents were called to war. All we're being asked to do is to practise self-isolation and stop hoarding toilet paper.

This May Save Your Life!

We all know too well the ignorance surrounding laryngectomies and the importance of being aware of neck breathing. We have all heard the stories of unknowledgeable medics who want to stick oxygen in the wrong place! Action is always needed to raise awareness. None more so than at this time of uncertainty during this worldwide pandemic.

With this in mind, as Trevor's 'carer' and knowing that unlike normal times I may not be at his bedside to ensure all was being done correctly to care for him. I could not be his 'minder' when he might need me the most. I needed something to remind the medics about his condition if in an emergency he was admitted to hospital with suspected COVID-19 virus.

It is one page, will be laminated, with the intention of attaching it to him so that it can be clearly seen by all once in hospital.

I have kept it general and I am sure there are lots of others things that we could add but I wanted the most important stuff to be at the fore. If medics need more info then hopefully they will go and find out more. Please adapt it as you see fit.

It might just save one of our much loved Larys lives.

Sally Hutson



My name is

I am a LARYNGECTOMEE. This means I am a NECK BREATHER.

I may NOT be able to talk.

A LARYNGECTOMY is different to a TRACHEOSTOMY, it is not reversible.

Please contact the ENT TEAM and be VERY AWARE of the following:

- * **BREATHE IN AND OUT** through the hole in my neck (the stoma) **NOT** through my nose or mouth. I do not have a larynx.
- * Ensure **NO LIQUID** goes into my stoma. This will go directly into my lungs.
- * Testing for COVID-19 may mean testing my nose, throat and **NECK** stoma.
- * Always place an oxygen mask over my **NECK STOMA**.
- * **DO NOT** place an oxygen mask over my mouth and or nose.
- * Laying me completely flat may cause me breathing problems.
- * If I am laid on my front it is imperative that my airway in my neck is kept clear **AT ALL TIMES**. If my neck stoma is covered or restricted in any way, I will **NOT** be able to **BREATHE**.
- * If I need to be ventilated you **MUST USE MY NECK STOMA**.
- * I may have a tracheo-esophageal (TEP) valve fitted at the back of my stoma. It helps me to speak and stops food and liquid entering my lungs. Please **LOOK** in my stoma.
- * **DO NOT REMOVE** the TEP valve as saliva will leak into my trachea. If the TEP valve comes out it can block my airway.
- * I may have a filter button on the outside of my stoma fitted into my laryngectomy tube or baseplate. This is **REMOVABLE** if oxygen is being given. It acts as a nose does, warming air and filtering germs to prevent them entering my lungs.
- * I need my hands to press the button to allow me to speak to you.
- * If I cannot speak, I will mouthe, use gestures, diagrams or write.
- * I need to access my button at all times where possible.
- * I remove the button to cough and clear my lungs. I may cough more than others.
- * You may save my life by following the above.



We're on Channel 4!

Hello everyone and we hope you are all keeping well and safe from this virus. Probably going stir crazy by now, I know we are! Anyway, it was probably the boredom that caused us to get involved in a project a month or so ago that you might like to hear about.

We were contacted by a neighbour who has contacts with Channel 4. They were looking for people who would be interested in being involved in a television programme about what it is like for, shall we be kind and say the older of us, who are trapped indoors during this lock down due to health issues: *Old, Alone and Stuck at Home*. Always willing to push the awareness of laryngectomy interests and of course NALC, we agreed to take part and C4 accepted our circumstances. Because of social distancing this programme would be filmed in an experimental way with us doing most of the filming with our iPhone. They wanted to see our day to day life in lock down and record our thoughts and experiences through this most strange time.

And indeed, it was a strange time for us. As well as me being a laryngectomee for the past 4½ years, we are also in the middle of a move from our home of 28 years in Stony Stratford to a new home in Worcester, to be nearer our daughter Esther and grandson Finley. The plan was to exchange contracts just before the Easter weekend – plans, ha! We all laugh in the face of plans now! We are surrounded by packed up boxes, cleared out lots of stuff to go to the tip and the charity shops. Already in our minds we have the furniture placed in the new house and know exactly where the Christmas tree will take pride of place. They say that moving is one of the big stress factors in anyone's life, after 28 years in the same house, in the middle of a worldwide pandemic – yes, it's certainly stressful. We also have the added stress that our son James works in the care sector. He lives at home at the moment but goes into work everyday to care for people with profound disabilities who live in a residential home. As a key worker he could contract the virus at anytime and of course bring it home to us. But of course, he has to do his job, we would expect nothing less of him, he is doing much appreciated and valuable work. Another worrying factor we have is that Sally was diagnosed with breast cancer at the very start of lockdown, stage 2 so treatable but still a great worry. Concerns over an operation being carried out with the virus all around was, as you can imagine, fraught with panic and fear.

The Channel 4 producers thought the challenges we faced would fit perfectly for the social documentary that they were making. Sally investigated the production company to find that it was reputable and *bona fide* and had made some important programmes for *Panorama* and *Horizon*, programmes that had helped to highlight issues about social care in this country. As raising awareness about neck breathers is important to us, we agreed that this was an excellent way to bring to the fore the life of a laryngectomee.

We both made what seemed like many hours of filming little videos and sending them to the director, Nick Green. Strange, as we were both not into 'selfies' before this. We did not even look through the videos never mind edit anything. It was sometimes quite emotional reflecting on our situation and a few tears were shed.

After a couple of weeks C4 sent along the film director, Nick and camera man Charlie, risk assessed for our safety and theirs. They arrived dressed like astronauts fully booted and suited and explained that due to the virus and C4 guidelines they would socially distance themselves and only be filming from outside and into the



house. It was uplifting to see and socialise with real people even though we couldn't give them a cup of tea. They interviewed us both and we talked a lot about our concerns and worries. It was good to be directed by experts and we are sure they got some better shots of us than our inept filming attempts.

We have tried to be open and honest in all our ramblings and hope that we got across the plight of the vulnerable whilst staying at home. Although we have opened our hearts to the world it never really felt intrusive – we might think differently once it is aired on the telly! We hope that it has shed some light on being a laryngectomee and lets people know that there is life after all this.

The programme was shown on Channel 4 Wednesday 20 May at 9 o'clock. It will be available on catchup Channel 4 for some weeks. Also on the website roganproductions.co.uk.

It will be interesting to see how much has been edited out but we got NALC and its plight in as much as possible. Oh and by the way we never realised we were old until we saw the programme title!

Trevor Hutson

Chesterfield Club

We look back with affection to an earlier year, shown in the photograph above, when we were able to enjoy each other's company, many miles from home. The NALC Annual Lunch in York was very memorable, not least as it marked the start of the work to become financially independent from Macmillan Cancer Support.

In the meantime we are keeping in touch and supporting each other via email, phone and texts. Like many others we are examining how we can use digital platforms, like Zoom, to get together in the months ahead.

