CLAN

THE NATIONAL ASSOCIATION OF LARYNGECTOMEE CLUBS NEWSLETTER

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Plus lots of other news, thoughts, poems, letters and views

A WORD FROM THE EDITOR

HAPPY NOVEMBER!

Welcome to our first ever November issue of *CLAN!* And let me be the first (perhaps) to wish you a very Happy Christmas and New Year! As we explained in the July edition, *CLAN* is now being published three times a year: March, July and November. We are still very keen to hear your news, of course. Are you in a club and, if so, what sort of activities are taking place? A search of the internet reveals several clubs' plans to celebrate Christmas whilst we learn that Chesterfield Club have been busy trying out new products from Severn Healthcare. And are any of you budding cartoonists? Over the years we've had some great ones like Andrew Staines but not any longer. Even if you're not so good at drawing, do you have ideas for cartoons? Just email them in and I'll have a go at a picture!

Still Continuing

Inside this issue, Malcolm Babb gives us the welcome news that most of NALC's activities are still continuing – especially online – even though Vivien and Kerry are now volunteers. We also learn that Head and Neck cancer is the eighth most common cancer whilst the Mayo Clinic has news of new genetic markers that brings non-invasive cancer screening ever closer. And there's an article by Malcolm on the importance of pre and post-op meetings and the barriers to being offered them. So, hope you enjoy this issue and see you again in February!

Ian Honeysett

Ian Honeysett (Editor)

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Notes from the President

12 months later

NALC has now been operating for a year without paid staff, so what has changed? The good news is that most of our usual activity has continued. We are still supporting hospitals with our information resources for their patients. We are supporting individual patients sending out our safety items on request, it just may take a little longer. We are very grateful that Vivien and Kerry, who worked in the NALC office, are now continuing as volunteers but they have competing demands on their time.

Our online work grows, as I mentioned in the last edition, not only for delivering presentations to students and professionals, but for providing individual support using the Zoom platform. Our website sees increasing visitor numbers and page views, as does our Youtube channel, which has replaced the dvds we used to share.

Our contribution to research work, a priority for me, continues. NALC members have responded well to requests for assistance from SLTs and others published in *CLAN*. On a sad note, the National Cancer Research Institute (NCRI) has been wound up. It played a pivotal role in organising the research programme across the country and promoted patient involvement so our voice was heard. Two former NALC stalwarts, Ethel Culling and John Bramhall, were founding members of the NCRI Head and Neck group. I followed in their footsteps and am hoping patient priorities will continue to influence studies and clinical trials.

Not The Christmas Edition

You will probably be reading this final edition of year of *CLAN* a bit earlier than usual. However, I am still going to share some reflections and hopes for 2024.

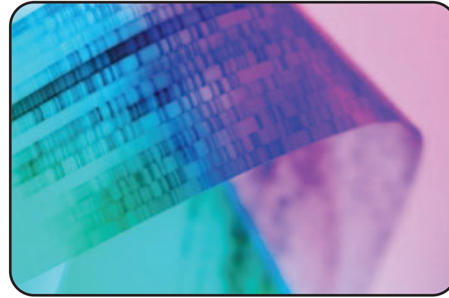
Like, I suspect, almost all laryngectomees I am eternally grateful for the ENT consultant who performed my laryngectomy, he saved my life. Of course, he was supported by a team of clinicians whose work I also appreciate greatly. In both my own care and in my other dealings with doctors and others I see nothing but dedicated and caring staff. I hope next year may see NHS staff get closer to the getting rewards they feel they deserve and the strikes can come to an end.

I wish all our readers a happy and healthy 2024!

Malcolm Babb

Mayo Clinic News

'New gene markers detect Lynch syndrome-associated colorectal cancer, Mayo Clinic' article by Kelley Luckstein, 20 September 2023



Researchers from the Mayo Clinic Comprehensive Cancer Center and Mayo Clinic Center for Individualized Medicine have discovered new genetic markers to identify Lynch syndrome-associated colorectal cancer with high accuracy. Studies are underway to determine if these genetic markers are in stool samples and, if so, how this could lead to a non-invasive screening option for patients with Lynch syndrome. Their research was published in Cancer Prevention Research, a journal of the American Association for Cancer Research.

Exciting Finding

"This is an exciting finding that brings us closer to the reality that clinicians may soon be able to offer a non-invasive cancer screening option to patients with the highest risk of getting cancer," says Jewel Samadder, M.D., co-lead author of the paper and gastroenterologist at Mayo Clinic Comprehensive Cancer Center. "I look forward to the day when I no longer have to remind patients with Lynch Syndrome to schedule their annual colonoscopy and complete the prep, when they will instead be able to provide a stool sample to screen for cancer."

Lynch syndrome is an inherited genetic condition that significantly increases the risk of multiple cancers, most notably colorectal and uterine cancers. Approximately 1 in 300 people have Lynch syndrome, many of whom are unaware of it. Patients with Lynch syndrome undergo colonoscopies annually to detect and remove pre-cancerous lesions that can form colorectal cancer, in addition to undergoing invasive tests or prophylactic surgery to prevent uterine cancer.

For this study, the researchers evaluated a panel of methylated DNA markers (MDM) for sporadic colorectal and endometrial cancers in people with Lynch syndrome (LS). Sporadic cancer is cancer that occurs randomly in people with no family history or known predisposing risk factors. The researchers also included control groups with no cancer. For colorectal cancer, there were 23 LS cases, 48 sporadic cases, 32 LS controls, and 48 sporadic controls. For endometrial cancer, there were 30 LS cases, 48 sporadic cases, 29 LS controls and 37 sporadic controls.

92% Accuracy

"We found that a marker panel composed of three biomarkers (LASS4, LRRC4, PPP2R5C) could effectively differentiate Lynch syndrome-associated colorectal cancer from Lynch syndrome controls, with 92% accuracy. This three-marker panel also performed similarly in distinguishing sporadic colorectal cancer cases from controls," says Dr. Samadder. This three-marker panel is being tested in a multi-site clinical trial in patients with Lynch syndrome as a non-invasive screening option.

"Our findings support the feasibility of cancer detection in stool and lower gynecologic genital tract samples in the setting of Lynch syndrome and warrant further testing," says Dr. Samadder.

The research was funded by the Mayo Clinic Center for Individualized Medicine and Gerstner Family Career Development Award. For a full list of funding, authors and conflicts of interest, see the paper.

NALC STILL NEEDS YOUR SUPPORT

The easiest way to donate to NALC is via the Justgiving page: www.justgiving.com/laryngectomy-clubs Typing 'Justgiving NALC' in Google also works well

Do your medications and supplements affect your blood pressure?

Article by Laurel Kelly, Mayo Clinic Newsletter, 2 October 2023

If you've been diagnosed with high blood pressure, you're in good company. Nearly half of the adults in the U.S. have high blood pressure, and many don't even know they have it, according to the American Heart Association.

Your healthcare professional likely has provided information about the dangers of high blood pressure and lifestyle changes you can make to control it. And if lifestyle changes aren't enough, your healthcare team may recommend medication to lower your blood pressure.

You also should know that some common medicines, supplements and other substances can affect blood pressure. Some raise your blood pressure. Others make medicines you take to lower your blood pressure less effective. Some medicines that affect blood pressure are prescribed by your healthcare team. Others are available without a prescription.

How medications can affect your blood pressure

Pain medications

Some medicines that relieve pain and swelling cause the body to hold onto water. Too much water in the body may create kidney problems and raise blood pressure.
Examples of these medications include:

- Indomethacin (Indocin).
- Medicines available without a prescription such as aspirin (multiple doses a day), naproxen sodium (Aleve) and ibuprofen (Advil, Motrin IB, others).
- Piroxicam (Feldene).

Cold medicines, also called decongestants

Decongestants make blood vessels smaller, which makes it harder for blood to flow through the blood vessels. Sometimes that raises blood pressure. Decongestants also may make some blood pressure medicines not work as well.
Examples of decongestants include:

- Pseudoephedrine (Sudafed 24 Hour).
- Phenylephrine (Neo-Synephrine).

Antidepressants

Antidepressants work by changing the body's response to brain chemicals that affect mood. These chemicals also may raise blood pressure.
Examples of antidepressants that can raise blood pressure include:

- Monoamine oxidase inhibitors.
- Tricyclic antidepressants.
- Selective serotonin reuptake inhibitors.

Birth control with hormones

Birth control pills and some birth control devices contain hormones. These hormones may raise blood pressure by making some blood vessels smaller, which makes it harder for blood to flow. Most birth control pills, patches and other devices carry warnings that high blood pressure may be a side effect. The risk of high blood pressure is higher if you're older than 35, overweight or a smoker.

Caffeine

Caffeine can cause a short-term spike in blood pressure in people who don't use it all the time. It helps to keep blood vessels open, which allows blood to flow easily and may raise blood pressure for a short period of time. There isn't enough evidence to prove that caffeine raises blood pressure long term, though.
Examples of medicines and products with caffeine include:

- Caffeine pills (Vivarin, NoDoz, others).
- Coffee.
- Energy drinks and other beverages.

The amount of caffeine in coffee varies widely, so it's difficult to say how many cups of coffee you can safely drink a day. Check your blood pressure about 30 minutes before and about 30 minutes after drinking a cup of coffee or another beverage that has caffeine. If your blood pressure goes up by 5 to 10 points, you may be sensitive to caffeine's effect on blood pressure.

Herbal supplements

Herbal supplements may not be safe just because they're natural. Check with your healthcare team before taking any herbal supplements. You may need to avoid supplements that raise your blood pressure or make your blood pressure medicines less effective.
Examples of herbal supplements that may affect your blood pressure or blood pressure medicines include:

- Arnica (Arnica montana).
- Ephedra (ma-huang).
- Ginseng (Panax quinquefolius, Panax ginseng).
- Guarana (Paullinia cupana).
- Licorice (Glycyrrhiza glabra).

Biological therapies

Powerful medicines used in biological therapies can have side effects. One of those side effects is high blood pressure. Some of these medicines target specific cells. Others use the body's own immune system to fight some autoimmune diseases and cancers.

Angiogenesis inhibitors and some monoclonal antibodies may raise blood pressure. Examples of these medicines include:

- Bevacizumab (Avastin).
- Gefitinib (Iressa).
- Imatinib (Gleevec).
- Pazopanib (Votrient).
- Ramucirumab (Cyramza).

Immunosuppressants

Most people who've had an organ transplant take immunosuppressants. These medicines help keep the body from rejecting the new organ. Some immunosuppressants can raise blood pressure. This may be due to the ways immunosuppressants affect the kidneys.
Examples of immunosuppressants that can raise blood pressure include:

- Cyclosporine (Gengraf, Neoral, Sandimmune).
- Tacrolimus (Astagraf XL, Prograf, Envarsus XR).

Stimulants

Stimulants, such as methylphenidate (Concerta, Ritalin, others), can cause the heart to beat faster or unevenly. This may raise blood pressure.

A caution on illegal drugs

Illegal drugs can raise blood pressure. They may narrow the arteries that supply blood to the heart. This raises heart rate and damages heart muscle.
Examples of illegal drugs that may affect your heart include:

- Amphetamines, including methamphetamine.
- Cocaine.
- Ecstasy (MDMA).

If you're using illegal drugs, it's important to stop. Ask your healthcare professional for information on counseling or drug treatment programs.

Next Steps

Talk with your healthcare professional if you have concerns about the medications or supplements you're using affecting your blood pressure. Have your blood pressure checked on a regular basis. If your blood pressure goes up or isn't well controlled, ask about other medications or supplements you can take. Your healthcare team may recommend lifestyle changes or additional medications to control your high blood pressure.

Connect with others talking about managing high blood pressure in the Heart & Blood Health Support Group on Mayo Clinic Connect, an online patient community moderated by Mayo Clinic.

Speak Easy Trip to Lakes and Dales

Ann Muir reports on the Speak Easy Group Tour to Lakes and Dales. 12 June-16 June inclusive.

Our tour started off at the pick-up point at Hamilton Bus station, 13 miles from home for me that is. The coach was 15 minutes late and that was only the start of our journey! The driver and coach had come from Aberdeen picking up passengers along the way – Perth, East Kilbride, Lothian and finally us at Hamilton. As the tour company hadn't factored in a break for the driver, he had to improvise and we ended up travelling 15 miles in the opposite direction from expected and ended up at McKinnon Mills in Airdrie, where we spent an hour wandering around while the driver had his break. Once again, we boarded the coach and this time headed south and, after driving 91 miles, we arrived at our next stop – Gretna Green where people from all over the world come to get married. We had another hours stop here and we saw a couple about to get married – complete with their dog all dressed up in attendance!

Imposing Hotel

So far, I'd had two stops for an hour each and taken 4.5 hours to travel 78 miles from my home! Anyway, we got on the road again and made it to our hotel Cumbria Grand in Grange-Over Sands in the Lake District. A very imposing hotel, with 124 bedrooms. It was a little tired – in need of sprucing up, but more than made up for it with the great food, and magnificent views from our rooms. Mind you no one told us before hand that there was a male peacock who wanders around and usually starts calling at 3.45am! Still, it was lovely to see him fan out his tail while calling in the hope a female would turn up. Sorry to say none did! Our first tour was to a bustling market town Skipton, which is known as the gateway to the Dales. Lots of unique shops to browse and a 13th-century castle – a bit far to walk to in our allotted time. We once again boarded the coach and travelled through beautiful country side to a lovely town with cobbled streets, Grassington, surrounded by wonderful views of the Dales.

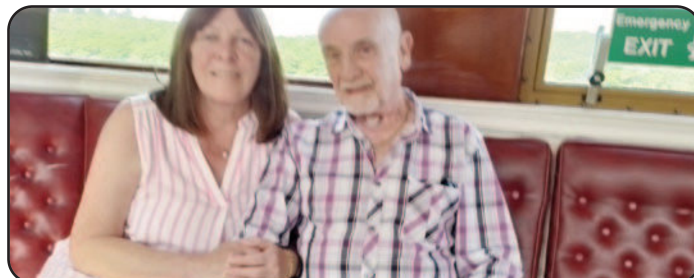
Dove Cottage, Grasmere

After wandering around admiring the views, exploring the shops and enjoying coffee and cakes we travelled back to our hotel in time for evening dinner. The next morning, we set out for a full day tour to Grasmere to visit Dove Cottage, the newly opened Museum dedicated to the poet William Wordsworth, then the plan was to visit Ambleside and Bowness. Unfortunately, after driving for a couple of hours – the driver had to inform us the tour company had altered the time of our tour at Dove cottage till the afternoon, from a morning slot. this would mean he had to drive us to Ambleside then double back then go on to Bowness. We took a vote and decided this wasn't going to happen as it was really hot even with air con on and some were tired of sitting. So, we continued on to picture perfect Ambleside, again some retail therapy, more nice coffee shops and a 2nd-century Roman Fort.

Bowness

I wandered towards the fort, but the heat was intense 34 degrees, and going uphill seemed not a good idea, so I turned around and visited the Bridge House which spanned a large stream. I suspect it would have been used as a toll house hundreds of years ago as it was too narrow to live in, but interesting to see. There were some lovely views over Windermere.

After our time was over, we travelled to Bowness, a very popular tourist hotspot, again with some amazing views of the Lake. Our last day of touring included a cruise in a steam gondola on Lake Coniston, where some may recall Donald Campbell broke the world speed land and water records in the same year 1964! It is also the lake where his last trial took place and his boat aeroplaned, hit the water and exploded, in 1967. His remains were found by divers working to bring up the wreckage in 2001 and then an inquest could finally be held. The cruise was very relaxing and everyone enjoyed it and I managed to take photos of our members while on board. We were reluctant to leave the boat!



Sticky Toffee Pudding

After this we headed towards Ulverston a bustling market town, which we all explored! There is also a Laurel & Hardy Museum, birth place of Stan Laurel and the John Barrow House and Monument. The house was built in 1850 in honour of John, a naval explorer who was also Second Secretary to the Admiralty. The monument stands 450 ft on the high summit of Hoad Hill overlooking Ulverston and the beautiful Morecambe Bay.

The last stop was Cartmel, famous for its 12th-century priory, a racecourse and is the undisputed home of sticky toffee pudding. I think I may have been one of the few who doesn't like this pudding! So, our coach headed back to the hotel for our last meal, time to pack and leave the Dales and Lakes for another time.

Article by Ann Muir in the Cancer Laryngectomee Trust Newsletter

Increase In Head And Neck Cancer: it's the 8th most common cancer in the UK

Press release, 3 July 2023: Medical experts and researchers team up to highlight increase in head and neck cancer:

Experts from the University of Derby, University Hospitals of Derby and Burton (UHDB) and University Hospitals Leicester have joined forces to raise awareness of head and neck cancer.

The teams, which included clinicians, nurses and scientists, as well as representatives from two national charities – The Swallows and the Oracle Cancer Trust – are on a mission to highlight the rise in these cancers. As part of their campaign, they offered advice and information and free head and neck screening at a recent event in the Derbion Centre in Derby. The aim was to help people spot the symptoms of these cancers, which are seeing a sharp rise.

Dr Elizabeth Marsh

Successful Screening & Vaccination

Dr Elizabeth Marsh, Senior Lecturer in Biomedical Sciences at the University of Derby, explained: "A lot of these cancers are caused by human papillomavirus (HPV), which also causes cervical cancer. It's good to see the prevalence of cervical cancer falling as a result of successful screening and vaccination programmes, and we need to ensure that there's the same level of awareness for its ability to cause head and neck cancers.

"Treatment for head and neck cancer, if not caught early, can affect an individual's ability to eat, breathe, smile and speak, so it's really important that we make people aware of what to look for."

Around 80 people were screened at the session, with around 10% referred for further tests.

General Lack of Understanding

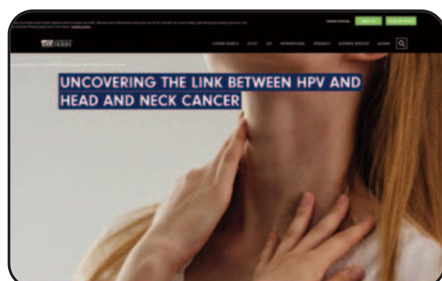
Mr Bindy Sahota, Consultant Ear Nose and Throat (ENT) and Head and Neck Surgeon at UHDB, said: "We believe there is a general lack of understanding and knowledge in the wider public when it comes to oropharyngeal cancers, but they are rising sharply and are now one of the most common forms of head and neck cancer, especially in men.

"The numbers of people smoking are decreasing and there is an increase in awareness of alcohol-related issues, but we are still seeing a large growth in the numbers of cases, driven by HPV."

Dr Marsh and her team used the day to gauge awareness levels of head and neck cancers. The information gathered will help evidence the need for head and neck screening in the fight against this cancer, which they plan to raise this with health ministers.

Common signs and symptoms of head and neck cancer can include new and fast-growing lumps, persistent issues with your voice, pain when eating, ulcers that don't heal, and lumps that bleed, but symptoms can vary.

If you are concerned about head and neck cancer symptoms, please speak to your GP as soon as possible.



Find out more about the University of Derby's research into head and neck cancer by visiting www.derby.ac.uk/research/showcase/hpv-and-head-and-neck-cancer .

Take a look at the video: www.youtube.com/watch?v=QCaoMOkUrYQ .

Experiences after (chemo)radiotherapy for throat (oropharynx) cancer

I am a PhD student at Oxford Brookes University interested in hearing about peoples' experiences after treatment for throat cancer. My name is Sara Matthews. I would like to better understand what it is like for patients and their caregivers (the main person supporting them outside of the hospital) after treatment has finished.

The results of this study will be used to develop the support available for future patients and caregivers after treatment for throat cancer. Participation would include an interview by videoconference or telephone, whichever is preferred.

Three Questions

1. Have you recently been diagnosed with throat cancer?

   Or have you been caring for someone diagnosed with throat cancer within the last two years? *Yes or No.*
2. Was (chemo)radiotherapy treatment in the UK the main treatment? *Yes or No.*
3. Would you be interested in discussing your experiences of being a patient or caring for a patient to help us develop support for others in the future? *Yes or No.*

If you have answered *'Yes'* to all three questions, please complete the contact form: docs.google.com/forms/d/e/1FAIpQLSeGy7ylVcY34B2c0G9TkgeSMRlpxarlZKJm5vmsc0Wy9DLF1g/viewform?pli=1

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Peer Support

Peer support has an invaluable role to play in the care pathway for cancer patients. The consequences of the disease and the effects of treatment given make this especially true for head and neck patients. I have been involved with peer support on a one to one basis or as a member of a peer-led support group for nearly 20 years. I was prompted to write this article by a couple of recent events

I saw by chance a laryngectomee that I first met more than ten years ago. He was about to have the operation and I spoke to him at the request of my local hospital. I have been supporting patients in this way since my laryngectomy and it is one of the most important things I do. A laryngectomy can be a terrifying prospect which a few will decline, but it is a life-saver. Seeing what it is like on the other side, after surgery, can be a source of strength in deciding to proceed and provide reassurance when it is most needed. It is also helpful to family members who may be present at some meetings.

The outcome for my friend was not the best. He has no voice as a valve was not an option, due to the nature of the surgery required, and he cannot use an electrolarynx. Additionally, he has swallowing problems and cannot eat a normal diet. Despite all of this he has no regrets about having the operation. Whenever we meet he thanks me enthusiastically, the pre-op meeting was of massive significance for him. He took out his phone and showed me pictures of his young grandchildren who he would not have lived to see without the treatment he was given.

The second event was a request to have a meeting with another patient facing a laryngectomy, who this time was accompanied by family members. I was especially struck by the reaction of the family members who I think got as much from the meeting as the patient. NALC has always sought to provide the chance for caregivers to meet other caregivers, as their needs are different to those of the patient.

For me, the pre-laryngectomy meetings with patients don't make great demands on my time, the challenge is to respond appropriately to someone you are meeting for the first time. Since the publication of Improving Outcomes In Head and Neck Cancer in 2004, the value of such peer support meetings has been widely recognised in peer review measures and cancer strategy documents, including the NICE Guideline for Head and Neck Cancer (2016). However, not all patients are offered the chance of such a meeting, so what are the barriers preventing this?

The COVID-19 pandemic had a serious effect on peer support, and I think is still a factor. I recall, in late 2020, meeting a patient and caregiver online for a pre-op meeting, so there are ways around any concerns.

Safeguarding is an issue of importance. At the time of my early meetings with patients I was working as a teacher. Since my retirement I have not had any background checks but this has not been an issue, I usually meet patients in clinic or on the ward, alongside a clinician.

I made mistakes in my first couple of meetings and would have benefitted from training for such work. Later, at the request of my local hospital, I attended a course provided by Macmillan. Such face to face activities have been affected by COVID-19 but it is now possible to receive training online.

I am sure we are all aware of the pressures on NHS staff as a result of unfilled vacancies and consequent effects on the workload of current staff. Organising peer support takes time which may not easily be found. Nonetheless, I would hope that clinicians will place support meetings high on their list of priorities, the benefits are not in doubt.

Laryngectomees will also benefit greatly from having a support group available to help them recover after their surgery. Breathing through a neck stoma and maintaining a new method of speech pose challenges for life. An examination of many research studies indicated participation in a peer-led self-help group leads to many perceived benefits including sharing experiences and learning from and helping others. Clinicians have a vital role in promoting and supporting such groups but the groups also depend on having a number of patients wanting to give something back after their cancer journey.

Malcolm Babb

Supportive Care: Its Importance in Patient Care

The term "supportive care" and "palliative care" are used interchangeably in healthcare (Lo & Buss, 2019). They both focus on improving the quality of life for patients and families with serious illnesses. According to the Multinational Association of Supportive Care, supportive care is defined as care delivered to patients with any serious illness at any point along the trajectory of their disease (Berman et al., 2020). It is meant to improve the quality of life of the patient by addressing all domains of care such as physical, psychosocial, spiritual and social aspects (Ferrell, 2019).

It is also important to note that supportive care can be used simultaneously with all current therapies a patient may be on and is not limited by their current treatment plans. Therefore, supportive care is holistic care delivered to patients by a care team comprising of medical providers such as physicians and advances practice professionals, social workers, chaplains and nurses with the aim to improve or preserve quality of life at any stage of an illness (Ferrell, 2019).

Greater Acceptance

Over the past decade, patients and providers have been found to gravitate to the term "supportive care" as compared to "palliative care." This is because many patients associate palliative care with hospice care and end of life (Lo & Buss, 2019). Therefore, many healthcare systems with palliative care teams have now rebranded themselves as "supportive care teams" to enhance their images and deliver much needed care. This has led to greater acceptance by patients and clinicians to include supportive care as part of the treatment team whereby improving patient outcomes (Lo & Buss, 2019).

In addition, as there continues to be an exponential growth in our aging population, as well as advances in immunotherapy and targeted therapies for numerous chronic ailments such as cancer, supportive care is becoming an everimportant aspect in patient care (Berman et al., 2020). However, despite these advances in therapy, many of these novel treatment options have resulted in significant toxicities to patients. This has led to increased symptom burden and overall poor quality of life for patients. Therefore, in order to improve survival rates and obtain better outcomes, there has been a global movement to include supportive care as an integral part of treatment pathways. This would enhance care coordination, and quality indicators for patients (Berman et al., 2020).

Recent Studies

In fact, recent studies have shown that patients who have supportive care or palliative care integrated early on in their disease trajectory, had overall better patient outcomes when compared to standard care (Temel et al., 2017). Other factors such as mood, trust and rapport with their providers were positively impacted (Temel et al., 2017). Supportive care is not only aimed at symptom management for patients to tolerate their current treatment plans but to also improve the overall quality of life for patients by utilizing a holistic approach to care.

This care addresses the psychosocial, spiritual and physical aspects of suffering (Ferrell, 2019). However, many patients continue to have limited access to this type of service despite its importance to patients' care. Future healthcare policies and provider goals should be directed at increasing access to palliative care for all patients despite their type of disease or physical location.

Jessica Latchman
MSN, APRN, AGACNP-BC, ACHPN, AOCNP
webwhispers.org/wp-content/uploads/2023/06/WotW-June-2023.pdf

No Money, No Money!

Curtis Weeks, laryngectomee, says patients in British Columbia, are left to pay for expensive medical supplies after surgery.

Four years ago surgery took away Curtis Weeks' voice, but he is still determined to make himself heard by the provincial government. The Chilliwack man says B.C.'s PharmaCare program isn't covering essential medical supplies for a group of people he calls 'Larys'. "They keep telling me there's no money, no money, no money," he said.

Larys are people who've had a laryngectomy, a surgery that removes some or all of the larynx (or voice box). Weeks had the operation to get rid of cancer, leaving him with a hole in his throat, called a stoma. The 81-year-old had a voice prosthesis inserted during his operation that lets him speak in a raspy whisper-like way. When he wants to talk, he pushes a finger into a valve/air filter (HME or Heat Moisture Exchange) that is inserted into a base plate that covers the stoma.

The voice prosthesis needs to be replaced every two to six months. The base plate is held in place with adhesive backing, and both the plate and HME need to be replaced at least once a week. Usually more. Therein lies the problem because currently none of these is covered by PharmaCare.

Expensive

For people who have coverage through work? Not a problem. For Larys who aren't so fortunate, it's an out-of-pocket expense that can range from a few hundred dollars a month to more than $1,000.

"If I didn't have this, I couldn't be talking to you," the retired mortgage broker said, pointing to the HME. "And I'd be breathing right through the open hole. The cold or hot air and all the fine particulates that are out there like viruses and dust, you name it, it would go straight into my lungs because there's no way to filter it. My life depends on this."

It seems like a slam dunk that all of it would be covered, but Weeks said that, as soon as you leave the hospital after a laryngectomy, "the government is done with you." Over the last two years he has tried countless times to get the attention of someone in B.C.'s Ministry of Health. He's fired off dozens of emails to Health Minister Adrian Dix, Premier John Horgan and others, and he's spent countless hours on the phone. All of it fruitless.

No Response

"I sent them one email and I said, 'You guys put masking tape over your mouth and go around like that for one day, just one day, and see what it feels like," he said. "They didn't respond." After weeks of increasingly terse communication, Weeks received an email from Noah Treacher, director of patient and client relations for the provincial government. Dated 18 January, 2022, it reiterated the 'no money' theme, with Treacher noting there was a review completed in 2019 that decided laryngectomy supplies would not be added to the government's list of eligible benefits.

"The ineligibility for coverage of voice prostheses and associated laryngectomy supplies is not a comment on the value of this treatment, but rather reflects PharmaCare's ability to cover such

Eric J. Welsh / Chilliwack Progress

treatments within the limits of available resources," he wrote. The final paragraph in the letter was even more discouraging.

"While I recognise your continued concerns, I must advise that we have provided all available information at this time. We are unable to respond further on this issue. If you have new questions or concerns, our office would be happy to assist you."

That's effectively saying, "go away" without saying, "go away." But Weeks isn't going away.

Where's that Money Going?

"Premier (John) Horgan was going to lay out $800-million to redo the (Royal BC) Museum, and then he cancelled it. So, where's that money going? Give part of that to the laryngectomy community," he said. "All I want is to have dialogue with them and say look, there's got to be a solution. "Don't just shut it down, because there has to be some way to do this."

Weeks feels like one voice crying in the wilderness. The community of Larys is small, about 600 in B.C., and so far he's the only one standing up to fight. The Facebook group he created (facebook.com/groups/335653219842829/user/100052721924599/) is full of posts pleading with others to get involved, but so far, he's alone.

"I'm just one guy mouthing off in B.C. about laryngectomies, and I guess I'm not making enough noise," he said. "The laryngectomy community is discouraged because they know the government doesn't want to do anything and won't do anything. So, they figure, 'why beat our heads up against the wall.' "Well, I'll do it for them."

The Chilliwack Progress

NALC has a New Website

NALC's website is over ten years old. So much has changed that it does not work well with social media or when accessed using tablets or phones.

A brand new site will be launched during September which will allow for better access to our information resources, as well as being an easier and more enjoyable resource to use.

Getting to the site will use the same link as before:
www.laryngectomy.org.uk

News from the Clubs

Chesterfield Club

In recent months members have been trying out new products from Severn Healthcare. Having been disappointed last year when the Romet Electrolarynx range was released members were delighted with the latest model, which is very competitive. Paula Barnes, SLT and Severn representative, joined us at our October meeting and we were able to share our experiences using the latest HMEs from Severn. She also joined in our discussion of a wide range of laryngectomee topics.

One topic was the support for female laryngectomees. In Chesterfield, there are many, many more male laryngectomees than female. This can be a problem when accessing help from a support group. Paula told us that in her locality some separate meetings were being considered for the female patients. She knew of another locality where there were separate support groups in operation. We have always had many caregivers attending our meetings and this can help in having a welcoming group for all.

We are now planning our Christmas celebrations to end the year in our customary style!

OLDHAM

On 1 October, they showed the film *Can You Hear My Voice?* which features the amazing Laryngectomy Choir, Shout at Cancer.

Belfast

They plan to celebrate New Year with a 'chilly dip' at Crawfordsburn Beach at noon to raise money for Cancer Focus NI. Fancy dress is encouraged and there will be a prize for the best outfit. They do advise bringing a change of clothes and a towel for after the dip. Especially a hat to help prevent heat loss! After the dip, there are toilets, changing facilities and a café at the Visitor Centre. For more details call 028 9068 0741 or email: events@cancerfocusni.org . Visit the website: cancerfocusni.org/event/daretodip24 .

Christmas Lunches 2023

The Cancer Laryngectomee Trust newsletter gives details of Christmas Lunches planned for Blackpool, Halifax, York and Swindon. The September 2023 Newsletter is now available for download: http://www.cancerlt.org/assets/news/newssep23.pdf

The Blackpool lunch at the Imperial Hotel on Sunday 3rd December is being arranged by Mrs Sandra Waddington, 76 Rutland Avenue, Poulton-le Fylde, FY6 7SA Tel 01253 899531 email: waddington46@yahoo.com

The lunch in Halifax which is planned for Wednesday 13th December at Windmill Court is being arranged by Carole Stainton contact at CLT, PO Box 618, Halifax, HX3 8WX email: info@cancerlt.org

The lunch in York at Fulford Golf Club, Heslington Lane, York, YO10 5DY will be held on Friday 8th December and is being arranged by Dawn Potts, The Granary, Hull Road, York, YO19 5LE, Tel: 01904 489360, Mobile: 07947624421, email: dawn.potts@hotmail.co.uk

A lunch for Swindon area members is to be arranged by Ros Oswald. For further details contact Ros at 17 Kandahar, Aldbourne, Wilts SN8 2EE, Tel: 01672 540619 email: rospiano@yahoo.com

In English pubs, ale is ordered by pints and quarts...

So in old England, when customers got unruly, the bartender would yell at them, "Mind your pints and quarts, and settle down".

It's where we get the phrase: "Mind your Ps and Qs".

Many years ago in England, pub frequenters had a whistle baked into the rim, or handle, of their ceramic cups.

When they needed a refill, they used the whistle to call for service.

"Wet your whistle" is the phrase inspired by this practice.

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