

NALC AGM



The NALC AGM took place on Monday 19 May on a warm sunny day in the very smart surroundings of St Peter's Church, Eaton Square. This year about 30 members met in the church hall and enjoyed an excellent 'Waitrose' lunch before getting down to business. Attendees came from all over the country including Newcastle, Crawley, Derby and Glasgow. NALC President, Malcolm Babb, welcomed everyone and there was a minute's silence for 'absent friends'. Here are just a few quotes (or near quotes) from the meeting: I haven't tried to take detailed minutes as Vivien is much better at that!

- When I became President a year ago, I never thought Macmillan would plan to phase out NALC funding over the next three years. Not surprisingly, this has dominated the past year as we have had to come to terms with the new situation. Macmillan will give 70% of its previous contribution in 2015 and this is planned to reduce to zero over the following two years.
- In February NALC held a Patients' Day in Nottingham and over 100 attended. The reaction (to NALC Days) shows how important (Health Professionals) feel NALC's work is for patients. The next Day will be in Scotland on 5 June.
- The NALC website (www.laryngectomy.org.uk) has improved immensely – thanks to Andy Gage. It has about 100 downloads a week – including visitors from the US. You can now download 24 publications free.



Andy Gage thanks all those who voted for his re-election as Vice President & Webmaster, which means he can continue to work on the Site's development with our President, Malcolm Babb, and strive to make it one of the most visited self-help Charity Websites in the UK, as well as continuing with other NALC work!

- The NALC Education Programme has continued to grow with Bert Culling especially delivering many presentations
- A small subcommittee has been working with Macmillan to produce an Action Plan...we are seeking to reduce expenses and move to cheaper (or even free) premises with Martin Birchall's help when the current lease expires next March.
- CLAN has now been going for 33 years (general amazement was expressed at how the Editor could be old enough to have done so) and over 4,000 copies are distributed each quarter.
- Several clubs have closed (Pontefract, Glasgow Wide, Grimsby, Prescot and Salisbury) in the past year. Many younger laryngectomees now choose to join a general Cancer support group.
- The NALC bank accounts are both in good shape: over £50,000 in the Business Account and nearly £35,000 in the Savings Account.
- NALC is looking for fundraising ideas e.g. one charity asks its members to donate £1 a day: that's £365 a year (or £366 in leap years!)
- Why not have a collection box at all NALC events?
- The NALC website should soon have a facility for online donations. Please support it. It will also soon feature a "fun" page of cartoons and a page inviting laryngectomees to contribute accounts of their experiences.
- This year's Annual Lunch will be held in the Old Swan Hotel, Harrogate on

Sunday 7 September.

- The Central London Club continues to grow with 28 members listed and an average attendance of 9-12 members. They made a successful grant application to Macmillan which has helped them to buy a laptop, printer, iPad and personal Voice Amplifiers. They also benefited from Charity sponsorship in the London Marathon.
- The Cancer Laryngectomy Trust have funds which could help defray the cost of lunches etc.
- There was an election for the three Vice-President posts and Andy Gage, Ivor Smith and Tony Smith were re-elected.



The Arrival of the Country Bus

Len A. Hynds, our resident laryngectomee poet, has sent the following poem based on a true story of when his wife Tilly and he moved into an isolated bungalow on Romney Marsh, several years ago, and he had to make a bus trip into Ashford to collect his car. Only two buses a day, and it was raining.

At last it came, just an hour late,
I was wet, dishevelled and cold.
That hapless driver I did berate,
for being off-hand with the old.
I paid my fare and, sitting down,
continued to grumble at him.
Trips from my house to Ashford Town
began to look quite grim.
He stopped the bus, with an awful glare,
showing me his route to see.
"On time," he said, with again that stare,
tinged with sardonic glee.
"What time will we get there?"
I say in a quiet dismay.
"Can't say," he said, with a lofty air,
"You're going the opposite way!"

NALC Annual Lunch

This year's Lunch is on Sunday 7 September and will be held at The Old Swan Hotel, Swan Road, Harrogate HG1 2SR. The cost is three courses for £18.00. Further details can be found on the website or by calling Head Office.

Novel Approaches to Communicating

John Oakley, from *Chesterfield*, had a laryngectomy three years ago. It became clear at an early stage that acquiring valve speech was going to be a problem due to the nature of his surgery. As a consequence John still has no 'voice' and has used some novel approaches to making sure he can communicate using new technology. His determination to communicate has aided his return to work. Here is his story:

I am a one of those few people who don't have an audible voice, but that has made my imagination much more active. From day one I had to learn new ways of getting my point across, or even just letting people know what I wanted or just that I was OK.

The first thing I tried was mouthing words, the secret to that from my point of view was to slow my speech down and exaggerate my lip movements. Of course this has to be done face to face.

The next thing I was given was a Magic Slate. This lets you write things down and then rub them out which saves paper but then I moved on to an iPad. Now this was a real help to me as not only can I use it as a Magic Slate but it connects to the Internet and that opens up a whole new world of applications that anyone can use.

Mostly Free

Applications downloaded from the App store can also be used on iPods and iPhones so making them very portable and this helps when travelling. Most of the apps I use are free to download and install.

Another little trick I learned from people who go abroad but don't know the language of the country they are visiting. What they do is take pictures of say a cup of tea or coffee or just put a tea bag at the side of the cup or a jar of coffee. In fact take a picture of anything that you buy or use regularly. Then just show them to anyone who you think can help you.

Applications can also be used on Android phones, which are cheaper than iPhones, and on any of the large number of tablets that are becoming very popular. In fact things to help people with disabilities are moving on all the time. I hope these few tips help some of your readers in their day to day life and never forget IF IN DOUBT, ASK! Someone will always help. GOOD LUCK!



One word of warning, there are some applications which are not free and also there is some speech simulation equipment on the market which proves frustrating to use. The free applications for phones and tablets are well worth exploring first.

John's specific recommendations for applications to start with are:

For writing notes and messages quickly – **MEMO**

For text to speech – **SPEAK IT**

Malcolm Babb

What Do You Recommend?

We have been asked if we can recommend a portable nebulizer. Do any readers have one they would recommend? Please send CLAN details.

A Matter of Taste

Ever since my laryngectomy, food just doesn't taste the same. You didn't operate on my tongue (did you?) so why is it that I don't taste as well as I did before surgery?

Taste is a complex special sense. What we know as 'taste', particularly the more delicate tastes, is really smell. The subtle tastes of eggs, certain cheeses, fruits, wines and the like depend on an intact sense of smell for their discrimination. Smell relies on our ability to move air containing certain molecules into the highest recesses of our noses. When we eat, the air with the odour-bearing molecules goes behind the palate up into the nose. Following your laryngectomy, you no longer breathe through your nose but through your stoma. This results in less air reaching the smell part of your nose. The bottom line to all of this is that with a decreased sense of smell, it naturally follows that your sense of taste will be less as well.

Some patients learn how to 'sniff' a little air up into the nose to enhance their sense of smell.

Another tip is to add a little extra spice or cook with pungent herbs to help the job that your tongue is doing for you. This may make your food a little more enjoyable. Bon Appetit.

*Glenn E. Peters, M.D.,
University of Alabama, Birmingham, Al, USA
(from the Still Talking newsletter of NSW)*

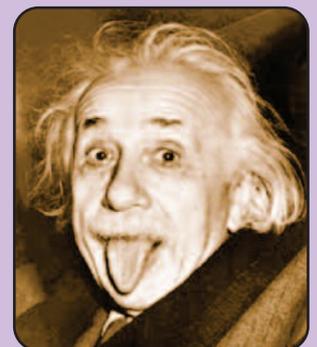
20-20 Voice Cancer Appeal

'20-20 Voice' Cancer (website: www.2020cancerappeal.org) has been registered with the Charities Commission (Reg No: 1156733) and have added a page to our website specifically for fellow lary's to tell of helpful tips or 'bonuses' they have found along the way which have made life easier for them. You will see, on the bottom right hand side of the website front page that we have added 'YOUR PAGE'. This is to highlight any helpful tips from fellow larys or, indeed, those in the medical profession itself! All people need to do is simply send in their tips on the e-mail form on the website and we will add them as we go along! Anonymity is guaranteed if preferred of course. We think that this will prove to be highly beneficial to all larys and their carers – for you never know what someone might know that you had never thought of!

Phil Johnson

Did You Know?

- It would take more than 1,000 years to watch every video currently on YouTube.
 - Hippopotamus milk is pink.
 - Beer contains all 13 essential nutrients of life.
- Plymouth Club Newsletter*



Tony Smith: Life in a Day

I was born during the second year of WW2, which meant that I had a rather interesting childhood with memories of doodle-bugs, trams, trolleybuses and trips to the seaside, mostly to Brighton by steam train and to Margate and Southend by both train and paddle steamer (*The SS Royal Sovereign*) down the Thames from Tower Pier. My Primary school days seemed quite enjoyable and I was quite keen on all subjects, managing to get to a grammar school, taking the 11-Plus exam on the day that King George VI died and Princess Elizabeth became Queen. You don't forget days like that! During the rest of my schooling the academic side tended to take third place to my two main interests, music and sport, especially Jazz and cricket. Not sure whether I ever actually regretted that or not later in life – I suppose everybody wants to be more knowledgeable but the joy I received out of my two main interests were possibly more beneficial, if not always financially so!

Anyway, I left school at eighteen with some GCE 'O', and 'A' levels and went straight into a 16-piece orchestra playing at the Ritz Ballroom in NW London. I'd been playing the saxophone and clarinet since I was twelve, working at various venues, some more seedy than others, throughout London. This was mostly in Soho in the evenings and weekends. This first professional job with the 16-piece band was in 1959, which, unfortunately, was near the end of what was called the Big-Band Era. Therefore my residency only lasted a year, when the band was ousted for a small 4-piece rock band to replace it.

New York, New York

There followed various band work, some summer seasons and short residencies with bands such as Geraldo and his Orchestra, plus a period on the Trans-Atlantic liners, which enabled me to spend some time in New York. Whilst there, it gave me a chance to see and hear at first-hand some of the all-time great musicians, such as Thelonius Monk, Stan Getz, John Coltrane, plus the orchestras of Duke Ellington, Woody Herman, Gerry Mulligan and Count Basie. It was a wonderful time for this type of music.

I then spent a few years touring the UK and abroad backing many stars of the Rock and Roll era and in the bands of Little Richard, Bo Diddley, Ray Charles, Jerry Lee Lewis, and the Everley Brothers, plus doing a residency for a few months in Hamburg in the early 60s, then tours with the Rolling

Stones and several other bands of the time. However, my real interest was in playing jazz music so I then concentrated on that, playing around London in various clubs and, in fact, started a club of my own in the early 70s. I enjoyed that because it enabled me to play with some of the very top American jazz musicians whom I invited to the Club when they were in England.

Mid-Life Crisis?

However, by this time I was in my mid-thirties and married with three children so the responsibility of earning a decent regular living had become very important, not something that comes easily in the Jazz world. So, I started a sideline in teaching people to drive, which developed quite well in a relatively short time. I can't say I enjoyed it very much but it did give me the inspiration to write a book, called *Learning to Drive*, which in 1980 was published by Hodder and Stoughton and sold reasonably well for about 20 years. This was very financially helpful in those years.

I then decided to apply for a permanent salaried job with the Civil Service as I felt the need for a reasonable steady income with plenty of security, so I became a Driving Examiner in the Department for Transport. This I did for four years until I swapped over to the mainstream Government Department, still in Transport and Environment, where I continued working on Policy Development until I retired in 2008. I had kept up my interest in music, although in the early 80s I had virtually packed up performing. Also, my interest in cricket continued until the present day, and although I am now far too old to play I continue to umpire.

Back to Umpiring

I was diagnosed with throat cancer in late 2000, when I was just coming up to sixty, which resulted in undergoing a laryngectomy at Northwick Park Hospital in Harrow in January 2001. There followed a concentrated period of radiotherapy, three times a day for three weeks and then the period of recovery and learning to talk again using a non-in-dwelling prosthesis. I managed to get back to work after six months and back to umpiring cricket in the following year.

In the years since I have become heavily involved with NALC in trying to help other laryngectomees and their carers. This involves visiting and speaking at various laryngectomee clubs, hospitals and emergency services. I am also involved with various Head and Neck Cancer

bodies, such as NICE, currently sitting on the Guidance Development Group for Cancer of the Upper Aerodigestive Tract, which will publish the new guidelines in early 2016. I also

sit on the London Cancer Pathway Group based at University College London Hospital.

The change of life-style following my laryngectomy only really relates to the necessity of preparations and considerations of always being equipped with emergency items. Whereas before my operation I went to appointments and functions without needing to carry anything, now I always have spare filters, tissues, a mirror, brushes, water-bottle and all the other paraphernalia required to keep me going. Mind you, it certainly is much easier now, after 13 years, than when I first ventured out in the months after the operation. Such things as clearing my throat and changing a filter I can do very quickly and surreptitiously, without attracting attention to myself.

Help

The help given to me by the Speech Therapists at Northwick Park and Mount Vernon Hospitals had been crucial to my returning to full-time employment and umpiring because they persevered in teaching me to change my valve and to use hands-free speech. This, I found, was very liberating.

I still have a deep interest in music, both classical and jazz, and try to keep reasonably fit by going on longish walks every day, when I'm not umpiring. I live with my wife, Lesley, in Harrow and have four grandchildren whom I visit quite often.

All this is fine, of course, while I stay reasonably fit and my eyesight remains good (although most batsmen and bowlers seem to think differently when I make a decision they do not approve). I realise that it can be a very different matter for a person with ill-health and impediments. This is where I think NALC can be so important by giving help and guidance to laryngectomees who are having such difficulties. With the marvellous job done by the specialists, speech therapists and nurses it can help to point people in the right direction to make their life more bearable.



My Story

I have been a regular recipient of *CLAN* since my laryngectomy in 1995 at Aberdeen Royal Infirmary and have read with interest the many stories of Clubs and their members. The Clifford Hughes obituary in issue 128 inspired me to share my story with your readers which I hope may give those who have just been through the procedure hope that their future will be very much what they make it.

I turned 65 in July 2013, a little over 18 years after my laryngectomy. I remain in the employment of the company I joined three years before my procedure and who fully supported me through my absence and recovery. Although I had reduced my working week from five to four days a week last July, unless my health significantly deteriorates – a possibility I must face with my history – or am no longer required by my employer, I plan to work on for as long as I continue to enjoy coming to the office.

Preceding my laryngectomy, I suffered a heart attack in 1991 which required me to undergo a triple heart bypass that September. Some years earlier in 1986 I was dismissed by my employer of nearly 11 years due to a personality clash with a new General Manager. This led to two years of unemployment and temporary jobs leading to a relatively poorly paid position which was very stressful and, in my view, contributed to my heart condition. By then my wife and I and our two sons had lost our detached four bedroom house and had been living in a two bedroom council flat for some 18 months. After recovering from heart surgery, I succeeded in finding my current employment in April 1992.

Voice Problems

During the Christmas/New Year festive break of 1994/5, I started to notice problems with my voice and began suffering excruciating earache. Towards the end of February 1995 and after several courses of antibiotics had done nothing to resolve the symptoms of earache – and, by then, suffering from what appeared to be constant laryngitis – I demanded a referral to an ENT Consultant and used my employer's medical scheme to obtain a prompt consultation. The Consultant discovered a growth on my larynx at the first consultation and referred me immediately under the NHS for a biopsy at Aberdeen Royal Infirmary.

I will never forget my second consultation after the biopsy: I entered the Consultant's office and was introduced to a Speech Therapist and a Radiographer and was then asked to sit. I was on my own – my wife was disabled with emphysema and was at home and our sons were at school. The Consultant picked up my folder, looked me in the eye and said: "Well, Mr Bush, I have some news and it is all bad! You have carcinoma of the larynx!"

Plan of Action

He went on to explain his plan of action: to remove the larynx and follow up with a course of radiotherapy and speech therapy so that I might try to learn oesophageal speech. Did I have any questions? I had, of course, known the purpose of the biopsy but had clung to the idea that the growth might have been benign. Confirmation of cancer was like being punched in the solar plexus. I was speechless. All I could think of was how my family would cope without me? My legs felt like jelly and I sorely wanted a cigarette. I felt the tears sting the back of my eyes and sat in shock. All I could say was that it was my job to negotiate contracts and how could I do that if I was mute? The Speech Therapist

carefully explained the options from electronic devices to learning oesophageal speech.

The Consultant was kind but firm. He said my only option was surgery. If I needed time to decide, he could understand but time was of the essence and he could fit me in for the operation the following week. I gave my consent immediately and left a dull consulting room into a bright sunshine of an early March day. I stopped on the pavement and lit a cigarette, stood and just silently cried. Then I walked like an automaton to my car and drove home. I could not face going back to work. My wife was watching telly and knew just by looking at me that the news was bad. I explained as best I could and she reacted angrily: what were the chances of survival? Would I lose my job? What caused the cancer? What was she going to do if she was left on her own with our sons? Why us?

A Cup of Tea

I made a cup of tea and we waited for the boys to return home. They took it better than their Mum had. They accepted the high chance of survival and nothing else mattered. It was just another operation their Dad had to have. Cool! It was not until admission the following week that the full truth dawned on me: that I would be a neck-breather for the rest of my life. I had accepted that, without a larynx, I would need to find an alternative 'voice' but the mechanics of the operation had not been explained to me. I saw my first neck stoma on arrival at the ward. When my family visited that night, I explained the mechanics of the operation and saw my wife visibly cringe. "Do you mean you will have a hole in your neck for the rest of your life?" I can say she was never comfortable with my appearance afterwards. The stoma had to be covered in her presence. It did affect our intimacy thereafter. Later on, small children though were fascinated by my speech and asked to 'see your hole'!

For me the worst part of the procedure was being fed by tube for six days, pending the healing of the oesophagus. I had plenty of nutrients but felt starved and salivated as my fellow patients tucked into three meals a day. After favourable results from a barium meal swallow on day six post-surgery, the nurse told me my tube would be removed and I could drink 'sloppy foods'. I really enjoyed a roast chicken dinner that night! The nurse went ballistic when she saw what I was eating and reminded me about the 'sloppy food'. I assuaged her concern by ordering porridge for breakfast but, as I was discharged the following day, she didn't see the Chinese takeaway I stuffed down my throat later that night!

Speech!

I went back to an understanding employer a month later, using only my computer to communicate but, within three months, I had mastered oesophageal speech and was using the telephone, albeit warning each caller of my 'impediment' (which I continue to do today). My speech is passable but not as good as I've heard in other laryngectomees. Amplification by telephone or microphone aggravates the roughness and, without the ability to inflect emotion into my speech, I can sound aggressive so a warning is needed to prevent alarm or offence to strangers.

I used to be a heavy smoker until my heart by-pass when I reduced my smoking. For many years after the operation, I was my wife's carer – she suffered from emphysema – and she had to use a wheelchair outside, much to her disgust. In 2007, she was diagnosed with carcinoma of the throat and died in 2008. Compared with her suffering, I consider myself very fortunate

indeed and I'm again in a loving relationship with my partner of over four years. She is a retired professional care assistant and is blind to my disability.

My Christian faith is fundamental to my will to live and not fear death – though I worry for those I would leave behind. I thank my Creator daily for what I have been provided with. My life has always been fulfilling. I have never had to ask: "Why me?" Rather, I constantly ask myself: "Why not me?" I have no answer to that question. There is no good reason I can come up with as to why my life has been so relatively free of pain and suffering – other than it has been so very full of love.

Alan M. Bush, Inverurie, Scotland

Bychance Emmanuel

CLAN readers will know about Bychance Emmanuel, a poor, young Ugandan laryngectomee born to a single mother.

He has recently been interviewed by Dorothy Nabwiru about his life and here are some extracts.

Why are you called Bychance as your surname?

No doubt, and I can testify that, my real life has been about chances. But the best person to answer that is my mother.

How do you speak to people in your community of work?

Very easy, I pass my messages to them by action, just like I say "Action speaks louder than words". And this has encouraged me to work harder for the better success of my life and be like others in the community; also people have loved me for that.

What do you call that cloth around your neck?

Oh! That's my beautiful stoma cover that protects me against dirty air like dust from entering through my neck stoma. In fact, I give a lot of credit thanks to my friend Kerry and NALC-club for a heartfelt support have done to my life for these materials. Otherwise, I wouldn't have been studied or socialise myself in different communities like churches, God should bless these people.

Lastly, what is your best moment?

The 3 June celebration of Uganda Martyrs each year. As a Catholic Christian, this day means a lot to me because I normally prepare myself to come closer to God and perceive the holy spirit of our beloved Saints

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Hope for New Throat Cancer Treatment

A newly discovered gene linked to oesophageal cancer holds the promise of new treatments for the notoriously difficult-to-fight disease. Cancer of the oesophagus is an uncommon but serious type of cancer that affects the long tube that carries food from the throat to the stomach.

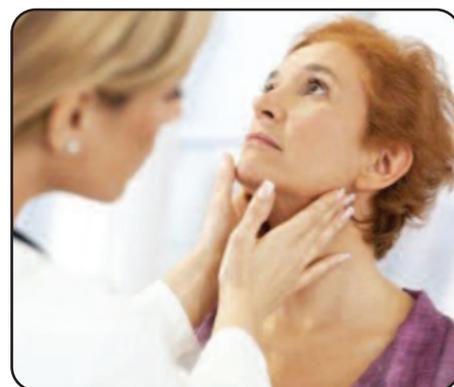
The strain of cancer, which can cause difficulty swallowing, currently affects 8,500 people a year in the UK, but the discovery of a new gene could help treat this potentially deadly disease.

Researchers believe drug therapies based on their discovery could help up to 15% of patients diagnosed with this rare form of cancer. With the advance of DNA sequencing, researchers are increasingly able to identify genes associated with diseases. More often than not the function of the gene is unknown, making it difficult to develop a treatment based on the discovery.

But this study, by scientists from the University of Cambridge, not only found that the TRIM44 gene plays a key role in the development of oesophageal cancer but also discovered how the gene drives the disease... *meaning they can make advances towards treating it.*

New Treatments?

Professor Rebecca Fitzgerald, lead author of the research from the MRC Cancer Unit at the University of Cambridge, said: "We know how effective treatments targeting the over-expression of genes can be... just look at the success of Herceptin for breast and stomach cancer. As there are already a number of drugs which target mTOR, we are hopeful that our discovery could lead to new treatments within the next five years." The researchers have already found that when they treat tumours in mice which are over-expressing (producing an increased



amount of) TRIM44 with mTOR inhibitors, they reduced in size. Interestingly, they have also performed the same experiments with cells from human breast cancers, and found the same results, indicating that these findings could also be applied to other cancers.

Professor Fitzgerald added: "For cancer of the oesophagus, and other cancers such as breast cancer, when the TRIM44 gene is overexpressed, it can also be used to indicate the likely response of an individual to an mTOR inhibitor drug. By tailoring the treatment to the individual, we increase the chance that it will be effective at fighting the disease."

Oesophageal cancer is the ninth most common cancer in the UK, and the sixth most common cause of cancer death. Many people are unaware of cancer of the oesophagus and symptoms, which include difficulty swallowing, weight loss and throat pain, are often ignored.

As a result, the disease is frequently at an advanced stage when it is diagnosed. Only around 15% of people diagnosed with oesophageal cancer are alive five years later.

This article was published in the Daily Express on Friday, 9 May 2014 by Laura Mitchell and also appeared in the Plymouth Club newsletter, The Voice of PLC.

The Ramblings of an Enfeebled Mind

This is not our judgement but the title of a booklet of poems by 'The Speechless Poet' Len Hynds. Len has explained that he and another laryngectomee, Peter Malling, have a half hour slot at the East Kent Seminar on Head and Neck Cancer for GP doctors, District Nurses and Dentists on 7 March at Canterbury Hospital. He says it's usually an hilarious affair – which we can well believe. His booklet will be freely available there. We feature one of his poems in this issue of CLAN and you can see more on his website at: thespeechlesspoet.co.uk

Len went to Canterbury University and graduated in Creative Writing, poetry and writing for stage and screen at the age of 78.

News from the Clubs

Speak Easy Club, Cornwall

Their visit to Cornwall's Living Aviation Museum on 2 April was a great success, and members were very grateful for being so generously allowed in just two days before their official opening for the season, for them providing refreshments and giving them their time for the full guided tour. They even made planes such an interesting subject for everyone, not just the men! On 13 May Speak Easy were invited to the official unveiling of a bench with engraved plaque donated by the Recovery Club for the Clinic Garden. On 14 May, their Annual General Meeting was to be held at the Carclaze Tavern, Treverlyn Road, Carclaze but this had to be postponed. On 4 June they were due to visit the Shipwreck & Heritage Centre at Charlestown – Europe's largest private collection of artefacts from over 150 shipwrecks plus collections from Cornish mining and china clay, and scenes from village life in days gone by. On 2 July, they have planned a summer afternoon tea with Janet and Martin at their farmhouse.

One of their members, Bob Brewer, sadly has died. Here is an obituary by Rev. Colin Salter:

Bob died, I think, at the ripe old age of 90 years. He said himself, "I am a visual aid to anyone who cares to see that a laryngectomy operation is not the end of life." His operation was during September 1987 in Plymouth. Afterwards Bob was taught and he used oesophageal speech. He spoke gently and wisely.

As a member of 'the 40 Club' for laryngectomees in Cornwall, and later as the chairman for eight years, Bob was active in meeting patients and their partners in hospital a day or two before their operations. He tried to help them see that a good life was still possible with no voice box, with a stoma to look after instead. "Adjustments had to be made by everyone, patient, family and friends," he warned, "but small changes could make big improvements." He urged the Club to encourage people to share their own experiences to help one another. Bob also visited folk in their own homes where possible.

Bob was also passionate that the Club, the forerunner to today's mainly social Speak Easy Club, could help the hospital by fund-raising for especially needed equipment. He and his wife, Millie, presented City Hospital, Truro, with a laryngoscope and TV monitor, after 18 months of hard, but successful, fund-raising.

In researching for "Our Story" book, I discovered that several laryngectomees who came along after Bob expressed how much his pastoral care in using his time to visit them, and sharing his life experiences, had helped them living through their own traumatic times. Many of us are truly thankful to have been touched by Bob Brewer's life.

Ashford Club

Caroline Mackenzie, Club Chair and Ward Manager, Rotary, reports that Ashford Laryngectomy Club have just introduced a new initiative for those who cannot or have trouble speaking – after a bit of investigating, their clinical nurse specialist discovered a useful emergency service that has been developed by Royal National Institute for the Deaf. The leaflet has details on how to register your mobile phone which enables you to contact 999 by text message. As a club, they have realised that a lot of people only have mobile

phones now so this therefore is a very useful service to have. They already register all our laryngectomees as non-speakers with the ambulance service but they only respond to a landline, therefore this is a step forward and will ensure that emergency services can be contacted wherever the person texts from. At their club meeting, they felt that they should share this awareness as it could benefit others that may need it. Their club members found this to be very useful and are all busy registering.

Len A. Hynds reports that Caroline Mackenzie and Sue Honour (MacMillan

Plymouth Club

On 8 April they had an outing to the Donkey Sanctuary at Ivybridge followed by a Cream Tea. On 24 April, members attended a Networking & Information Evening for Cancer Self-help & Support Groups. On 13 May they planned a talk by Mr Bob Stacey about his work at the HM Prison Dartmoor. Then on 10 June was a visit to Badgers Holt including a Cream Tea and delightful views of Dartmoor.

Their newsletter includes the following on one of their members, Rose-Marie Stephens, who has recently died.

Mourners are expected to pack a church on Friday for the funeral of the founder of a Plympton support group for dementia sufferers. Rose-Marie Stephens, who was known to her friends and colleagues as Rosemarie, died aged 70 on Monday, 17 March 2014 at St Francis Care Centre, Plympton. She was the driving force behind the launch of the Plympton Memory Conservatory in 2006, which



provides help and support for people with dementia, and their carers. Her friend Mrs Karen Wellard, Secretary of the Group, said: "Rosemarie was a former matron of the Mutley Lodge Care Home in Elburton, and founded the Memory Conservatory in October 2006. Although she had had a stroke and was retired, she was asked if she would consider running a memory drop-in. She was passionate about it. She thought that there was a special way to look after people with dementia by keeping them busy. She worked tirelessly to help dementia sufferers, and the people who care for them too. Sometimes the carer can be more isolated than the sufferer. At that first meeting, there were just three of us. It is thanks to Rosemarie and all her hard work and commitment that the group is still going now."

Mrs Wellard said that Rosemarie suffered from throat cancer and had her voice box removed in 2011. She said: "Rosemarie had been ill for the last three years, and had been in hospital since last July. She was transferred to St Francis Care Centre in November of last year. Even then all she would think about was others. She helped so many people. There will be a lot of people there on Friday who will want to say thank-you for all the support and help she gave. It is a fitting tribute to her that the group she founded will continue in her memory. She was inspirational and it took over her life."

clinical nurse) organised a one day seminar at the East Kent University Hospital Trust Theatre, Canterbury Hospital in March for 70 delegates: GPs, District Nurses & Dentists from Kent and Sussex on Head and Neck Cancers. Top Consultants spoke and all the medical supply companies were present with their stands and goodie bags. MacMillan asked Len to do a booklet of poems to be given to everyone attending. He was also given a 40 minute spot talking about life as a laryngectomee which he split with Ron Haden, another club member who did very well.