

"To help improve the quality of life for all neck breathers"

Newsletter March 2021

It is with great sadness that we wish to let you know that Wendy passed away peacefully on Monday the 15 February after a short illness. With the approval of her husband, Bill, and her daughters, Sarah and Helen, we have left her words exactly as she wrote them, looking forward as she was to 2021. Our next Newsletter will include our reflections and those of her family on her major contribution to the work of the Charity. If you have any photos or memories you would like to share please let us know.

Carole and Ros, Trustees

Dear Friends,

First of all I hope you have all managed to keep well and that 2021 will see us back to some sort of normality. We don't expect that this will come in time for Summer Lunches but fingers crossed that we can hold Christmas Lunches later in the year. Surprisingly last year seemed to go quite quickly despite having to self-isolate for most of the year. We did manage to have a short stay on the coast near Whitby in late summer.

Thank you for all the Christmas Greetings and for the donations sent in response to the September newsletter.

We were very pleased to be able to meet up with our two daughters separately at Christmas. As a health care worker the younger one had to work on Christmas Day so we met up with her on Boxing Day. We are missing seeing the younger members of the family but keep in touch on the phone. Before Christmas our youngest great-grandson was asking his grandmother "When are you going to put up Christmas lights like all the other houses on your street?" He was very disappointed to find out that she didn't have any lights. Our youngest grand-daughter has returned to Bath University to continue her studies. She lives in a 4th floor flat close to the Jane Austen Museum in the city.

Our grandson has returned to his RAF base where he has recently completed his training. As members of the Over 80's Group we were very pleased to get a phone call inviting us to attend for our Covid vaccinations at Beverley Race Course. The session was held in the Owners & Trainers Area which brought back happy memories of our visit there with our father Sydney who had a horse running there. We will be returning there for our 2nd vaccination in 9 weeks.

New members might be interested to know about how our charity came to be founded. Sydney Norgate was the founder of the charity following his laryngectomy in 1979. At that time speech valves were not routinely inserted during surgery and therefore he set about learning to speak using oesophageal speech. Having successfully achieved that he decided to write the book Laryngectomy is not a tragedy and founded The Cancer Laryngectomee Trust to support fellow laryngectomees. He worked tirelessly for the last 15 years of his life promoting the work of the charity.

Working with fellow Trustees, Carole Stainton and Ros Oswald, we are all proud to continue our late father's work.

This newsletter is sponsored by Atos Care

Best Wishes, Wendy Thompson, Trustee

Use of a Mobile Phone in Emergency

The emergencySMS service lets deaf, hard of hearing and speech-impaired people in the UK send an SMS text message to the UK 999 service where it will be passed to the police, ambulance, fire rescue, or coastguard.

Simply by sending an SMS message to 999 you can call for help and the emergency services will be able to reply to you. You will need to register your mobile phone before using the emergencySMS service.

To register using SMS text messages you must:

- 1 Send the word 'REGISTER' in an SMS message to 999.
- 2 You will then receive SMS messages about the service.
- 3. When you have read these SMS messages reply by sending 'YES' in an SMS message to 999.
- 4. You will receive a SMS message telling you that your mobile phone is registered or if there is a problem with your registration.
- 5. In an emergency contact the service by texting 999. Your message should i include Police Service required + details of incident + location

For further information consult www.emergencysms.net or RNID, 9 Bakewell Road, Orton Southgate, Peterborough, PE2 6XU

Telephone: 0808 808 0123 Textphone: 0808 808 9000

SMS: 0780 000 0360

Donation Form 2020

2020 has been a difficult year financially for all charities and we are very grateful to all our members and supporters for their continuing support for CLT. The Trustees would like to thank everyone who responded to the appeal for donations in our September 2020 newsletter.

We have also received donations through Virgin Money Giving and donations from Amazon Smile when supporters nominate CLT when purchasing online from Amazon.

These donations will help us to provide support to laryngectomees throughout the UK. Thank you all.



https://uk.virginmoneygiving.com/giving



https://smile.amazon.co.uk



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Trustee Ros Oswald shares her Lockdown Hobbies

Lockdown has been very difficult for many people, particularly those who live on their own. However, some people have been able to use the time to revisit old hobbies or discover new ones. Here are some ideas you might like to think about.

Our garden has seen much more of me that it is used to! I have always felt rather embarrassed that despite being brought up on home grown vegetables, I had completely failed to grow anything worth eating. In the past, my cabbages were eaten by very grateful caterpillars, the carrots

tasted good but were tiny and the green beans were very curly. However, in lockdown I had no excuses about being too busy so decided to make more effort. I was shielding at home so had to start with seeds and a lot of optimism. I discovered that parsley takes a very long time to germinate but green beans seemed more successful. The good news is that we did actually eat our own lettuce and tomatoes and the slugs loved the beans!



I have always enjoyed cross stitch so this was something else I could turn to. I looked through

some old books and found a cross stitch pattern for wild flowers so spent the time whilst I was inside sewing the flowers I hoped to see in the future.

Once shielding was over, I started to take our Labrador for her walks. She really prefers my husband as he is more fun and energetic. Whenever I fetch her lead she looks at him, then looks at me and sighs deeply. However, she would rather go with me than not walk at all. Her favourite hobby is swimming so we have been looking for suitable places without strong currents. She has been taught not to shake all over me when she gets out but becomes so excited she often forgets.

Reading has also become a popular hobby and one book I have enjoyed is Molly the Pet Detective Dog by Colin Butcher. Its a true story of a dog that

has been trained to find lost cats. Our dog lives fairly harmoniously with our very strong willed cat (who is the Boss) but I am not sure how much effort she would put into finding him if he went missing. However, Molly the Pet Detective has had some remarkable successes and the story is truly heart warming as well as being entertaining.

I hope you have managed to find some enjoyable activities during lockdown. it would be lovely to hear from you about anything you have been up to







Trustees Report to the year end January 2021

It's difficult to know where to start when I look back on the last twelve months. The world seems unrecognisable when it is compared with our circumstances just one year ago. No doubt, in years to come we shall gain a sense of perspective on the pandemic that is keeping us in lockdown for the third time since last March. However, at the moment the sense of uncertainty and danger is very real.

For me, two events stand out from the past twelve months. The first is the decision by the Chief Medical Officer that people who had had a laryngectomy should not automatically be included in the shielded patient list. This decision was opposed by the leading surgeons who carry out these complex and challenging operations. We worked with Cancer 52 to bring about a change in the list. This proved impossible and the best we were able to achieve was this confirmation from NHS England.

Yes, someone who has had a laryngectomy is likely to be considered extremely vulnerable as the upper airway cannot be protected as well as usual. Patients should discuss directly with their cancer care team and GP, who will have discretion to add them to the vulnerable list. In the meantime, if they are concerned about their risk of infection they should follow the shielding guidance.

The second and far more positive event was the publication of our book for children, The Story of Funny Grandad. Fortunately, lockdown gave us time to focus on this and we are very pleased with the result. It has been a difficult and time consuming project. However, it is so good to know that there is now a resource available for any family that is facing the uncertainty that an operation brings. The book is beautifully illustrated and will be an ideal way to introduce the topic of a laryngectomy in a comforting and positive way.

As there are now vaccines available let us hope that 2021 will prove to be a significant improvement on 2020 for all of us.

Newsletters

Sometimes we like to send out our newsletters by email to those members who have agreed to receive them in this way. This saves us postage and other costs. If you would be willing to receive email copies in future please contact info@cancerlt.org to supply your email address. Thank you.

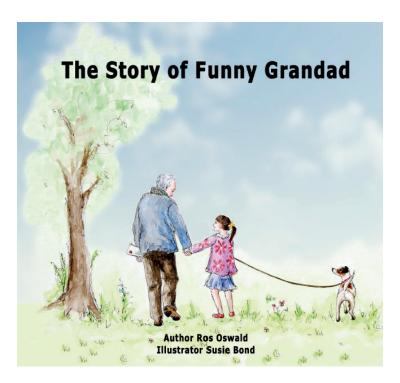




The Story of Funny Grandad

Some time ago we were asked if we had any information to help young people to understand what was happening if a friend or relative was to have a laryngectomy. We soon realised that although there were books about cancer diagnoses and about some of the more usual cancers, there was nothing specifically for laryngectomees.

We decided to produce a suitable short publication which would be informative and would have suitable illustrations. It was not a simple task but with care and not a little effort we have been able to put together a book we think will be extremely helpful.



As a family, we remember only too well when Sydney became aware he had to have a laryngectomy for throat cancer. We were pitched into a completely new world which ultimately resulted in the founding of the Cancer Laryngectomee Trust. My children grew up assuming having a Grandad with an unusual voice was just part of everyday life. However, it would have been so helpful to have a book explaining more about the operation and the implications.

We were very fortunate to find an illustrator who understood what we were wanting to say. Jess and Pickle are fictional but Pickle does bear more than a passing resemblance to Brandy who was Sydney's constant companion.

We do hope you enjoy the book and we would love to hear from you if you find it helpful.

To receive a copy of the book please send a SAE (size at least 230mm x 230mm) and bearing a Large Letter stamp to CLT, PO Box 618, Halifax, HX3 8WX. Alternatively, to download the PDF version of the book visit the CLT website at www.cancerlt.org

A voluntary donation of £10 to CLT to support the work of the charity would also be appreciated.





Geoff's New Life Chapter



Background. I spent 25 years in the British Army before taking up a second career with British Aerospace in the Kingdom of Saudi Arabia where my wife Jean and I spent 15 years or so. I was out there for both Gulf Wars. I then spent some years doing various bits of voluntary work before spending a year in Baghdad helping to open a private security company for VIP protection whilst under contract to the US Embassy at Saddam's palace in the Green Zone of Iraa.

I had my laryngectomy in Plymouth in January 2009 and was later referred to the Royal Sunderland Hospital in 2014 for a major pectoral flap operation.

I was a co-founder and committee member of the Plymouth Regional Head & Neck Cancer Support Group for ten years. Unfortunately, this group has recently disbanded due to a lack of volunteers to run it. I was also a co-founder of the Plymouth Area Cancer Support Network and that is still a fledgling organisation growing its feathers. To find out more, please click on this link https://plymouthcancersupport.com/

Jean, my wife of 52 years. Jean was diagnosed with Ovarian Cancer on Christmas Eve in 2018 and subsequently died in the February. It was like losing

my right arm. Jean was my wife, my best friend, my confidante, my carer, my everything.

I bought Scruffy, our White West Highland Terrier, some years previously for Jean but now I was to become her master. Scruffy kept me sane for the months that followed. The following Christmas I decided to escape for a few days with a friend. King Arthur's Castle at Tintagel in Cornwall was one of the few places that accommodated dogs as well as humans and we all had a wonderful time and met some really wonderful friends who we remain in contact with.

Seeing the light. It was only when I returned home and I locked the front door that I realised how alone I really was... apart from Scruffy that is.

I knew that I couldn't exist in this state of isolation... and that was before the pandemic! I missed companionship, friendship; simply, I missed company. I mulled things over for a few months and eventually decided to apply to become an in-pensioner at the Royal Hospital Chelsea where I could at the very least enjoy some camaraderie. I applied just before the first lockdown of February 2020.



For any queries, please contact CLT on: 01422205522.



Preparation for a change. Most of 2020 was taken up with cleaning and clearing the house from the attic downwards including the courtyard and the office outside. It's amazing what you accumulate in 52 years of marriage. And I had to be brutal in getting rid of things. There's only so much one can pass on to relatives, friends, and neighbours. The rest goes to charity shops or the tip. I could only take a carload to Chelsea. And of course, I had to rehome Scruffles. I found her a home with grounds, woods, and gardens; with a lovely lady who already had a couple of dogs. And I'm pleased to say that Scruffy has settled in there with her new friends... much to my relief.

Joining the Royal Hospital Chelsea. The joining process is vigorous and thorough. Having applied in February 2020, I eventually received a notice inviting me to have a four-day visit in September to ascertain whether I liked the idea and, perhaps more to the point, whether they liked me. I later received a Letter of Offer inviting me to become an In-patient. I joined the RHC on 2nd November. I wanted to be in situ before Remembrance Day if at all possible but unfortunately, as we all now know, the pandemic didn't allow for such niceties and we were all placed in lockdown and, at the time of writing, we still are, although we were one of the first care homes in the UK where the inmates received the first Pfizer vaccinations. At the time of writing (Mid-January 2021) we are still in lockdown and confined to the hospital. And the whole place, normally buzzing with thousands of visitors is still closed to the public

The future. It's taken me a while to sort my berth and get it the way I want it. I had to purchase a desk, a smart TV and a few other odds and ends but the bulk of furnishings and accoutrements are all supplied. A walk around the vast grounds abutting the River Thames keeps us reasonably fit but we're all looking forward to the lockdown being lifted so we can take part in public engagements once again and lead a normal life once more. That may be some time off yet. My medals are still in for silver-plating so I am unable to provide the photograph that everyone is screaming for. In the meantime I will provide this one which shows me wearing our daily casual wear in the grounds of the RHC.



I hope to provide another update in a few months' time when things have improved for us all. In the meantime, if you would like to know more about the RHC and look at some amazing pictures, can I suggest you take a look at www. chelsea-pensioners.co.uk

IP Geoffrey N. Read

Sunday, 17th January 2021

Royal Hospital Chelsea, Royal Hospital Road, London SW3 4SR



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HME

- Four newly designed adhesives for a wider range of skin types and stoma contours with improved materials and new SecureFit[™] coupling.
- HMEs that are compatible with all adhesives in the Provox Life[™] range to offer you a personalised routine.
- Colour coded products and packaging for improved easy identification.



HME





HME