

# Newsletter September 2023

#### **Dear Friends**

We are very pleased to have been able to hold Summer Lunches in Blackpool and Scarborough and thank Sandra Waddington and Dawn Potts for all their hard work arranging and hosting the events. We are pleased that Wendy's widower Bill and daughter Sarah were able to attend the Scarborough lunch. Planning is progressing for Christmas Lunches in Blackpool, Halifax, Swindon and York for further details see later in the newsletter. We were also pleased to support the Speak Easy trip to the Dales and Lakes arranged by Ann Muir. If any group would like to arrange a lunch or outing on behalf of their members please get in touch for financial support.

We were sad to hear the news of the passing of two long-standing members, Peter Taylor and Phil Johnson. We thank their families for creating tributes to their loved ones indicating their help and support for fellow laryngectomees over many years.

Once again we enclose a Donation Form with the newsletter. Members have been very generous with donations in the past for which we thank you. We are very grateful for your support and look forward to receiving donations once again this year.

Best Wishes Carole Stainton, Trustee

#### **Summer Lunch in Scarborough**

#### Dawn Pott reports:

The summer lunch was held at The Crescent Hotel in Scarborough on 30th June. It was a thoroughly enjoyable occasion. We sat in the beautiful Brunswick Room at the hotel, a light and elegant room. The service and food were excellent. The conversation both interesting and entertaining. There was a lot of laughter.

The hotel excelled themselves in every respect. They even organised the delivery of the lunch to a member and his wife who were unable to attend at the last minute.

Regards, Dawn



#### Contact us:

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Address: CLT, PO Box 618, Halifax, HX3 8WX

Charity Registration No 326653





## **Summer Lunch in Blackpool**

Once again Sandra Waddington did a splendid job of arranging our Blackpool lunch at the beginning of June. The event was held at the Imperial Hotel and attended by 52 members, partners and guests.

Member David from the Oldham Quiet Ones group reported:



Hi Carole,

We all had a fantastic time at the Blackpool lunch yesterday.

As promised here are some pictures from the lunch. As you'll be able to tell there are lots of smiles as everyone had a great time.

Thanks again for a lovely day.

Kind regards David



## **Tribute to Peter Taylor**

Let me introduce myself. My name is Rosa Stones, daughter to the late Peter Taylor, who sadly passed away peacefully with all his family around him on the 7th of April 2023, aged 71 to cholangiocarcinoma (bile duct cancer).

Dad was born 17th June 1951 in Burton Upon Trent, Staffordshire. He was a husband of 48 years to Marie, a grandad and a great grandad. Dad was diagnosed with throat cancer in 1999 which he had radiotherapy treatment for. Then in 2004 it had returned, and Dad became a Laryngectomee at the age of 53. Dad never gave up and faced up to the challenges he had ahead of him. He was always able to take care of his stoma and change his own valve.

Over the years we as a family, we have supported the CLT along with a few other charities. We would sell the raffle tickets at work, at the local pub and through family and friends. We supported the race nights and named our own horses. My dad became an ambassador to the CLT. I also kept a CLT charity box at my workplace for spare change.

When dad became a neck breather, it inspired me to raise money for the CLT by taking part in a tandem sky dive with the Red Devils. This took place at Langar airfield 28th August 2007. Who would have thought jumping out of a plane strapped to one of the Red Devils at 13,000ft, would be so much fun! I managed to raise a fantastic amount of £742.50. See the photo of the presentation to Carole Stainton of the money raised.

Dad endured many hospital visits because of other illnesses, arthritis of the spine, where he had a metal plate inserted, three hand operations to combat Dupuytrens contracture and survived a cardiac arrest whilst being under anaesthetic

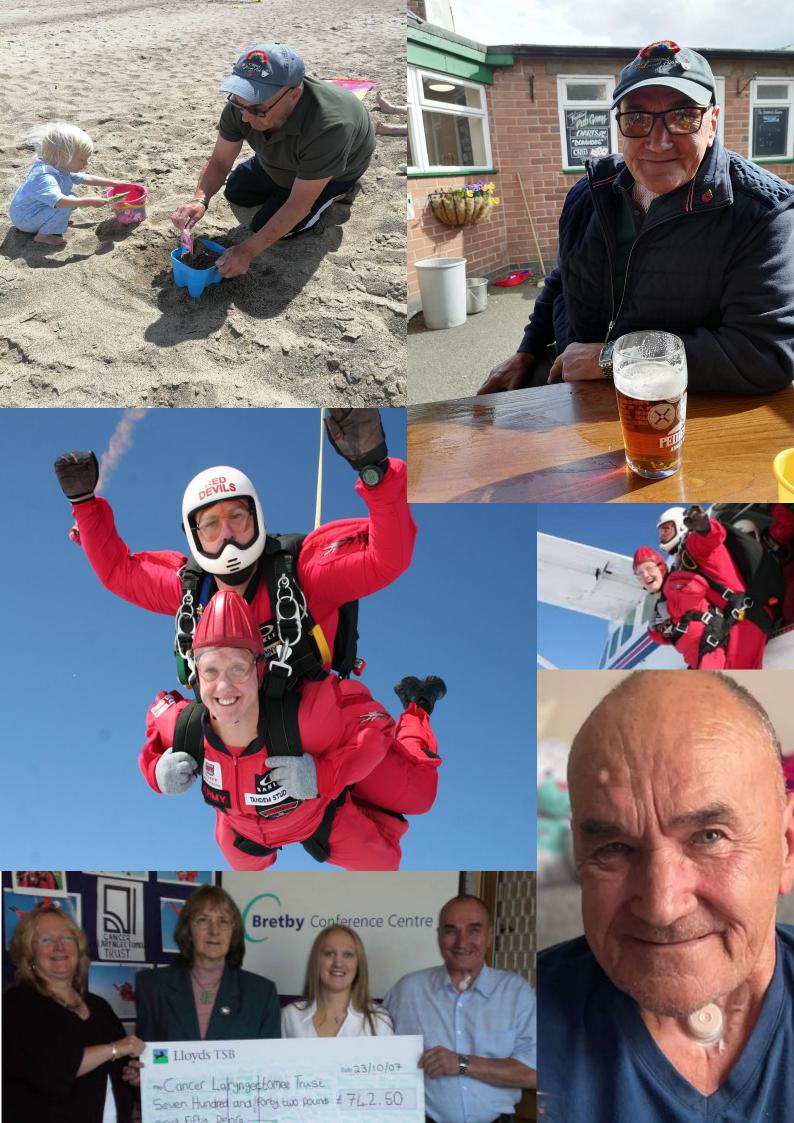
Dad was our very own bionic man.Dad loved his holidays abroad. The only downside once he became a Laryngectomee, was he couldn't swim or dive anymore which he loved to do. Dad used to always take myself and my elder sister swimming, when we were little. We will cherish these memories forever. Dad loved his gardening especially growing tomatoes and runner beans.

Dad started out as a drayman for Marston's brewery for 40 years and became one of the longest serving drayman in the brewery. He was made redundant from there at the age of 51.

He continued to work full time as a recycling driver. He came through all these difficult challenges and never complained. Dad finally retired at the age of 65. He was able to have one last holiday with my mum, Marie for 10 days in Lanzarote before Covid hit us. Then two more holidays in a caravan at Chapel St Leonards with his family. He loved to build sandcastles with my daughter Jessica who is 3. Dad was the strongest, bravest man I knew and was one in a million. He will be truly missed by all his family and friends.

We love you Dad, Pete, Pop Pop always and forever.





## **Tribute to Phil Johnson**

Hello, my name is Tina Johnson and my late husband Phil Johnson was the founder and Chairman of the charity 2020 Voice Cancer. He set up the charity after having been through the treatment for Laryngeal cancer himself.

Phil was first diagnosed with Laryngeal Cancer on 6/1/2010. He had both Chemotherapy and Radiotherapy which unfortunately didn't cure his Cancer. After an exploratory operation in the October of that same year he was given a Tracheotomy and told that he would need a full Laryngectomy. He had major surgery with a ten hour operation in the November for the removal of his Larynx and voice box and all the surrounding Lymph Nodes.

The operation was successful and Phil was cared for brilliantly by the nursing staff during his recovery at The Leicester Royal Infirmary.

The operation was life changing. The adjustment time to what was to be a new life for Phil, as it would be for anyone whom has been through a similar experience, wasn't easy for him and those around him. He felt extremely vulnerable at first breathing through a stoma and worst of all was the fear and frustration of having no voice.

It was his gratitude to his surgeon and the hospital team and the difficulty that he first had to communicate without a voice that was the driving force for him to do what he could do to help others in a similar situation.

After a conversation with his Surgeon, Phil was told there was a shortage of much needed equipment for the ENT department which would play a vital role in early diagnosis. He described the Video-Electrorhinolaryngascope as being the one piece of equipment that would play a major role. It would give a clear and enlarged view of any change in the throat and surrounding area that could indicate the start of a cancer.

That was the beginning for Phil setting up his charity. First an appeal to raise funds to purchase vital equipment but then later he went one step further and founded the 2020 Voice Cancer charity.

Phil gained as much knowledge as he could researching the different types of head and neck cancers and set about not only organising events to raise funds but also to raise as much awareness of these types of cancers that he could. He worked tirelessly to help the hospitals and their patients despite the deterioration in his own health and was always looking for new ideas to further his cause.

He was also always grateful to anyone who would get on board to help as did his old friend the late Willie Thorne who became the Patron of the charity and gave much of his time to attend and host many of the events that were arranged such as fund raising dinners. Phil was a great net-worker and knew how to gain people's support for the charity.

Phil's last venture was to set up a support Group on Facebook for fellow Laryngectomees to share their stories and experiences. A place where they would have a voice, which was of great importance to Phil

Phil still had so much more that he wanted to achieve with many plans laid but sadly his mental strength couldn't be matched by his physical strength. After contracting Pneumonia for the fourth time, he finally lost his fight on 7th January 2022, after-overcoming many battles with his health during those last twelve years.

As Phil's wife and carer I am very proud of the legacy he has left behind and of all of the good work that he did. Tributes are still regularly made to Phil by his many friends and supporters.

Tina Johnson

Please note: the photos below show some of the many presentations which Phil made over the years to Leicester Royal Infirmary and Glenfield Hospital, Leicester.







## 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.

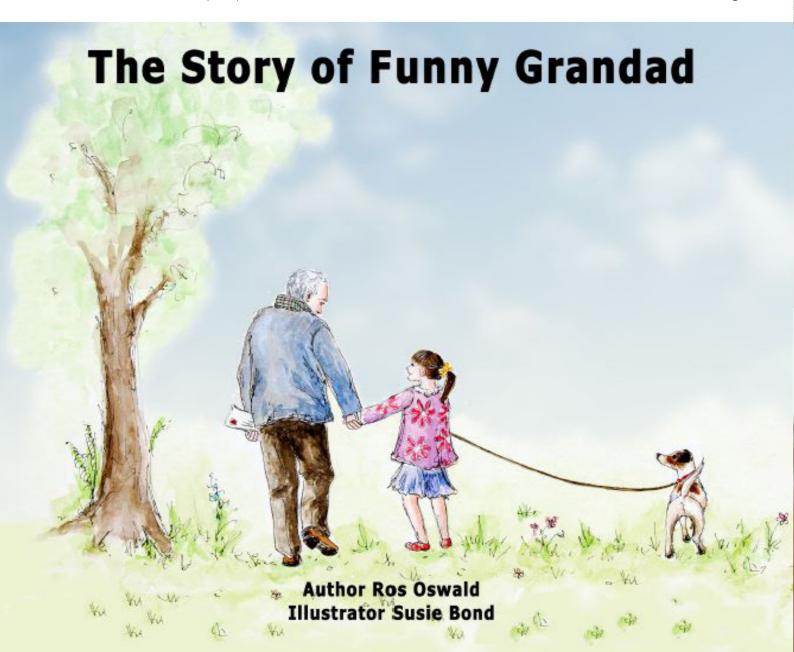
We were very fortunate to find an illustrator who understood what we were wanting to say. Jess and Pickle are fictional but Pickle

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

Alternatively, to download the PDF version of the book visit the CLT website at www.cancerlt.org



#### Speak Easy Trip to Lakes and Dales

Ann Muir reports on the Speak Easy Group Tour to Lakes and Dales. 12th June – 16th 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, & that was only the start of our journey!

The driver & coach had come from Aberdeen picking up passengers along the way – Perth, East Kilbride, Lothian & finally us at Hamilton.

As the tour company hadn't factored in a break for the driver,

he had to improvise, & we ended up travelling 15 miles in the opposite direction from expected & 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 & this time headed south, & 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, &

we saw a couple about to get married – complete with their dog all dressed up in attendance!

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 & 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 3.45 am!! 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 & a 13th castle - a bit far to walk to in our allotted time. We once again boarded the coach & travelled through beautiful country side to a lovely town with cobbled streets. Grassinaton, surrounded by wonderful views of the Dales. After wandering around admiring the views, exploring the shops & enjoying coffee & 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 & 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.

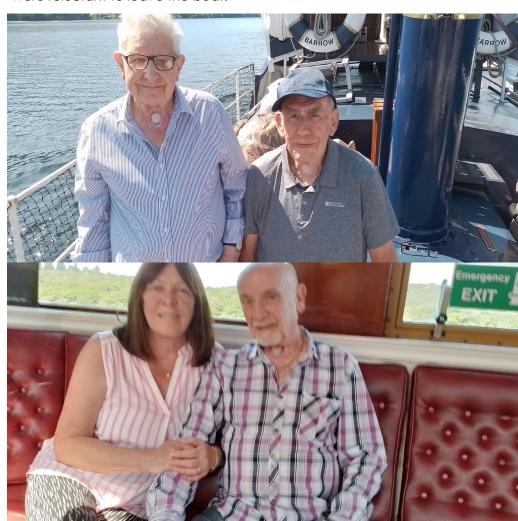
We took a vote & decided this wasn't going to happen as it was really hot even with air con on & some were tired of sitting. So, we continued on to picture perfect Ambleside, again some retail therapy, more nice coffee shops & a 2nd century Roman Fort.

I wandered towards the fort, but the heat was intense 34 degrees, & going uphill seemed not a good idea, so I turned around a 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 two 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 & water records in the same year 1964! It is also the lake where his last trial took place & his boat aeroplaned, hit the water & 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 & everyone enjoyed it, & I managed to take photos of our members while on board. We were reluctant to leave the boat! After this we headed towards Ulverston a bustling market town, which we all explored! There is also a Laural & Hardy Museum, birth place of Stan Laural, & the John Barrow House & 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 & the beautiful Morecambe Bay. The last stop was Cartmel, famous for its 12th century priory, a racecourse & 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 & leave the Dales & Lakes for another time.



### **Emergency Care for Laryngectomees**

# Prof Itzhak Brook introduces his recent publications to aid laryngectomee care.

Laryngectomees and other neck breathers are at great risk of receiving inadequate care when they experience breathing difficulties, require cardiopulmonary resuscitation (CPR) or need anesthesia.

Unfortunately, many medical personnel who care for laryngectomees are not familiar with their unique anatomy, how they speak, and how to manage their airways. These include nurses, medical technicians, surgeons and even anesthetists. This can

lead to devastating consequences, which can lead to depriving the patient from the oxygen needed to survive. The links below explains how to administer respiratory care to neck-breathers, including laryngectomees.

You are welcome to inform your laryngectomee support club about this information, so that they can educate those who care for you. This is especially important to share with their local EMTs, doctors and nurses prior to

any procedure, surgery, or hospitalization.

Itzhak Brook MD, MSc, Professor of Pediatrics Georgetown University

Laryngectomee care manual https://bit.ly/3k1iRO5

Laryngectomee airway care video https://www.youtube.com/watch?v=YE-n8cgl77Q





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