

A 'Forgotten Tribe'?

My husband had a laryngectomy in October 1993 and we have both attended Second Chance support group meetings since then. At that time, our knowledge of laryngectomees was very limited, not having met any beforehand. Fortunately, thanks to the marvellous support of our Consultant ENT surgeon at Walsgrave Hospital, Coventry, the staff and two laryngectomees and their wives, we received a lot of useful information and preparation before undergoing surgery; and later from the Speech Therapists.

As I was going to become a 'laryngectomy wife', I turned to my local library hoping to gain further knowledge of both the medical and, more important, the human aspect - all the 'little things' the inexperienced wish to know about. I hoped to be able to support my husband to the best of my ability in the trauma of losing his speech - as well as in the after-care. I was disappointed after searching the shelves to find dozens of books exploring every angle of deafness, blindness, strokes, etc., but not one book on the loss of speech through laryngectomy or similar. I came to the conclusion that laryngectomees are a 'forgotten tribe'. I wondered if other members have had the same problem. I mentioned it to a librarian friend who has promised to look into the matter in his own library.

We were delighted to hear that the 'Awareness Campaign' is going from strength to strength. We thought the tape aimed at the emergency services was excellent.

Mrs S. Ireland

FOREWORD

I have written this true story as the wife of a laryngectomee called Derek George Ireland, with the view that it may provide hope, encouragement and practical help to both carers and patients facing the daunting trauma of having a laryngectomy.

I have titled it “The Silent Mountain” because I felt that we were both, at the beginning, very inexperienced climbers, starting off on an expedition up a mountain, shrouded in fog and mist, full of crags, easy to fall down with despondency at the thought of the forth coming surgery, knowing that this would result in the loss of speech and silence.

We did, however, find also lots of sunshine on our journey during the endeavour to try and reach the summit as no doubt you find as you read this story.

I feel that we did progress towards the summit by coming to terms with our situation and Derek’s steady and positive efforts to achieve good oesophageal speech and mastering the art of using a “Servox”.

Second Chance (Coventry)

Gwen Daly is a new recruit to the club – she had her op only this June. However, she has been writing poetry for 40 years and has had five books published. The following poem is from her latest book entitled “Silver Lining” (available at £3.25):

Positive Attitude

*I walked the town today
And told my friends my tale of woe
Except that I was laughing
And my two eyes were aglow.
Each one in turn responded
With a happy, caring face
And that is how it should be
For cancer’s no disgrace.
So if you’re feeling down and blue
Then take a tip from me
If you’ve sad news to pass around
Then tell it gracefully.*

This book is dedicated to all cancer sufferers and carers and to members
Of the “Coventry 2nd Chance Laryngectomy Support Group”

My beloved husband
“A Laryngegtomee”



DEREK GEORGE IRELAND

1927 - 1996

THE SILENT MOUNTAIN

CHAPTER 1

Our trials and tribulations began during the Easter vacation of 1988 when Derek's voice became progressively hoarse. After about 6 weeks, I was concerned after viewing a programme on the television about early cancer diagnosis.

Unwillingly, due to my pressure, he paid a visit to our G.P. Doctor Garala, at Bedworth Health Centre. Derek was given a course of anti-biotics and was instructed to return in two weeks time. Unfortunately, he was still hoarse at the end of this period. Dr Garala looked around and down Derek's throat with a special mirror and spied a small nodule. We were to be eternally grateful for his speedy observations.

The very next day, much to my surprise, we received a phone call from the local hospital, arranging an appointment with Mr. Stansbie, an E.N.T. consultant surgeon, for Derek to attend the following week for an examination. I felt apprehensive about this as usually there is quite a long wait to see a consultant.

Three weeks later the nodule was removed and a biopsy taken under general anaesthetic at the Walsgrave Hospital in Coventry. Derek was allowed home after 48 hours.

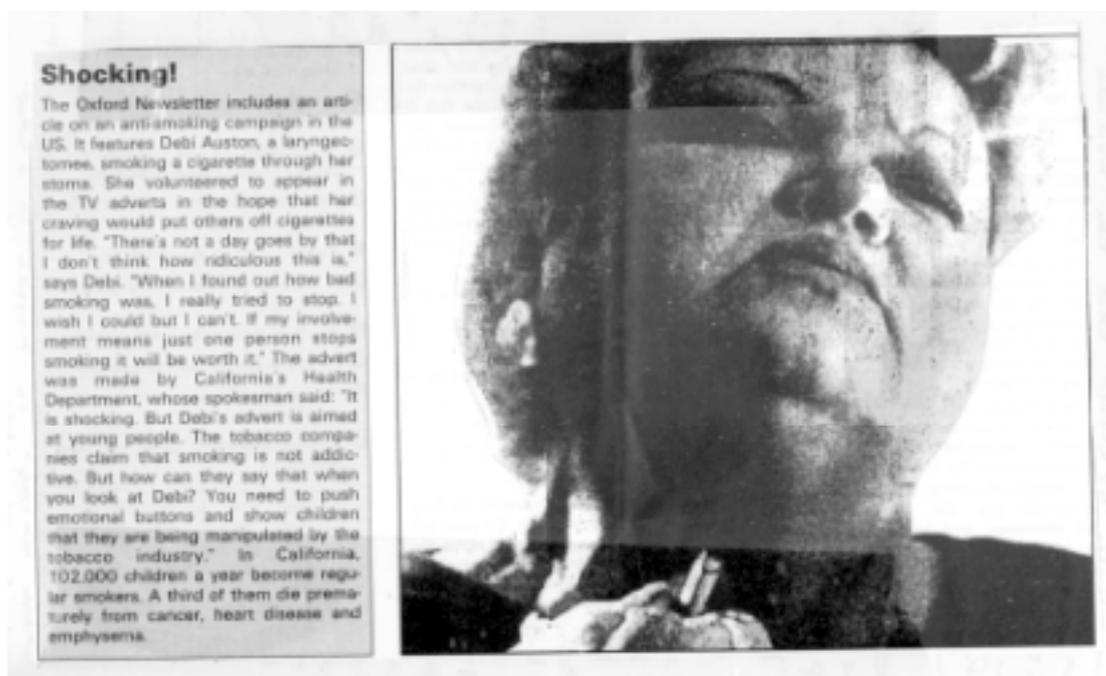
We really believed that the nodule would prove to be benign, however Mr. Stansbie, on looking at the laboratory report, told Derek that the biopsy had revealed that cancerous cells were present.

Mr Stansbie invited me in from the waiting room and very patiently explained all the details again for my benefit and answered any questions that I put to him.

He told us that he was going to arrange an appointment with a Dr. Das, a well-known local radiologist, with view of Derek having radiotherapy, in order to destroy the malignant cells present.

I felt numbed driving home and tried to hide my anxiety from my husband but could not help shedding a few tears over a pot of tea on reaching home. We knew so little about this treatment and its effects. We had a close relationship so we talked about it and decided, being practising Christians, to leave it in God's hands and support each other, come what may.

I must admit, I spent many sleepless nights due to the worry of it all, after all, we expect these things to happen to other people, not to ourselves!



Derek, many years ago, as a young man, ignorant of the dangers of smoking, had smoked about 20 cigarettes per day, 10 years previous to the diagnosis. Not succeeding to kick the habit, he had taken to smoking a pipe and had limited himself to 2 oz of St. Bruno tobacco a week. We feel it may have been the smoking factor that set off the malignancy. All the laryngectomees we have since been acquainted with had been previous smokers. I was amazed that after the initial phone call from the hospital, Derek packed up smoking immediately for good.

I felt that also that the stress factor could have been partly to blame too. Derek found it difficult to come to terms with being made redundant at 58 years old, after working for 43 years as a toolmaker. He had not been successful in finding another position. We had suffered two close family bereavements and I had been ill quite a lot during the that period, myself requiring nursing and extensive physiotherapy to recover.

On receiving Derek's appointment, we cancelled all our holiday arrangements and began to visit the radiotherapy department at Walsgrave hospital.



Taking Gypsy a walk in Smarts Road, Bedworth

CHAPTER 2

On our first visit to radiotherapy we found everyone so kind and reassuring. Derek was expertly measured up for a mask and the precise area, which was to receive the treatment, was decided on under the watchful eye of Dr. Das. He was prescribed a bottle of thick white medicine to coat the inside of his throat, to deaden any soreness likely to be felt after the treatment.

I, personally, was interviewed by a lady dietician and we discussed various types of soft food that I could prepare and cook which would be both nutritious and contain all the necessary vitamins etc, to help to keep Derek healthy during this period of treatment. I, laboriously, set about filling the freezer with homemade vegetable soup, chicken broth and spaghetti bolognese and many other tempting dishes. I was determined to keep him well nourished during the coming weeks.

Actually, although he did suffer from a sore throat, it was quite bearable and I found that he did not feel sick or lose his appetite. He found that he could eat most foods with care but not granary bread.

He even painted part of the outside of our home, with my help during this period of treatment.

I must admit, it was rather monotonous for me driving the 15-mile round trip daily. The weather was gloriously hot and sunny during that period and we both kept thinking of what we could be doing elsewhere.

I recall the department having a cheerful, comfortable lounge with armchairs and pleasant pictures on the walls. There was a friendly cafeteria and jigsaw puzzles for all the patients to have a go at, whilst waiting for their turn on the machine.

I think I read every magazine available whilst waiting for Derek. I also became quite knowledgeable about different types of cancer. People would ask “What are you here for” I would explain to them about my husbands larynx and thus they would proceed

to tell me all about their problems and types of cancer that they had or that their relations had. I found it quite therapeutic and always came home thinking how lucky I was and said a prayer for them all, especially the young children and teenagers I encountered there.

Do You Qualify?

Did you know that Macmillan Cancer Relief provides grants to people with cancer or who are still affected by their illness or treatment? This may help with increased fuel bills or fares for hospital appointments. Every week they help some 300 people.

To qualify for a grant, you must not have capital savings of more than £6,000 (single person) or £8,000 (for a couple). Individual members of the household must not have more than about £80 to spend each week, after allowing for some basic costs. Macmillan do not award grants for medical costs or for items that have already been purchased. Applications come to them from Macmillan nurses, community nurses, health and social workers and local voluntary organisations. They do not accept applications direct from patients themselves.

Of course, they are also looking for donations in order to continue this work. One in three of us get cancer at some stage in our life and, by 2015, that figure is forecast to be one in two.

Their address is:
*Anchor House, 15-19 Britten Street,
London SW3 3TZ
Tel: 0171 351 7811.*

I can always remember a notice on a door as you entered the radiotherapy department reading

“One in three people will have cancer at sometime during their lives”.

All the staff were marvellous, supportive and very cheerful. One plus point was that Derek could not wash his neck for seven weeks.

August 24th 1988 was Derek's 61st birthday. For a joke, whilst laying down, being placed in his position for his weekly shot, he produced a paper party hat and they all responded by singing "Happy Birthday to you".

Derek had 30 shots of treatment so we attended the department for seven weeks, as on a few days equipment had to be checked and serviced.

After the final treatment, we felt like excited children, let out of school for the holidays.

I went ahead and booked an autumn holiday in a large luxury caravan in the Lake District area between Windermere and Grange-over-Sands for 2 weeks. We really enjoyed that holiday after being confined for most of the summer. We walked with our dog, Gypsy, in the nearby woods and visited all the Lake District beauty spots in spite of a lot of rainy showers and thanked the Good Lord for seeing us through this difficult period in our lives.

We had had so much support and encouragement from neighbours, friends and family and the members and clergy of St. Lukes Church in Coventry of which we were regular communicants, which brought joy into our hearts. The high spot of this period was when Derek's voice returned as clear as could be. It was unbelievable!! It felt like a miracle had happened.

CHAPTER 3

Life passed by fairly uneventfully for the next three years. Derek still had his three months check up with Mr. Stansbie and a more thorough check up once during that period under general anaesthetic in Walsgrave E.N.T. ward. We accepted the fact of forced early retirement and led full lives together. We enjoyed our summers walking and cycling in the Derbyshire Peak District, which was our favourite area.

From March until October we left our two-berth caravan on a farm situated half a mile from the River Dove. We spent our time commuting the 60 miles between the farm and our home, which has a large garden, which had to be attended to as well.

We had four married sons and daughters with two children apiece, living within a five-mile radius of our home, also a family of four in Australia.

In the winter months we enjoyed rambling locally with our dog, some ballroom dancing and having a bar meal in a country pub. We attended our church and its various functions so as you can imagine, there were not enough hours in the day for us in our retirement.

During the summer of 1991 after a routine check up and biopsy under a general anaesthetic, unfortunately to our disappointment another small area of malignant cells had been discovered. The larynx was too delicate an organ to receive any more treatments of radiotherapy so it was decided that laser treatment should be used.

This was a one-off treatment and was performed under general anaesthetic by a Mr. Currie, another E.N.T. surgeon at Walsgrave Hospital. This treatment was successful. Derek suffered the inevitable sore throat afterwards for a few days but once again there was a price to pay for this success. He talked once again with a permanently hoarse voice but at least he still had his voice box intact. We resumed the three monthly check ups with Mr. Stansbie at George Eliot Hospital Out Patients department and life returned to normal again until June, 1993.

CHAPTER 4

After the laser treatment, we both had begun to feel more confident after two years had passed by uneventfully. After all, five years after the very first diagnosis, we were still enjoying life to the full. I personally, always had this fear at the back of my mind that one day Derek could have to face having a laryngectomy but had never voiced my fears to anyone including my husband who had always said that losing his speech would not be bearable to him.

However, in July, 1993 Mr. Stansbie decided it was time to have another check up in Walsgrave Hospital, just to be on the safe side, so once again Derek spent 48 hours in the E.N.T. ward. By now he was an “old hand” and was known by most of the staff.



One nurse called Eileen had even put a teddy bear in his bed before he was admitted.

Will I never forget the date of 18th August, 1993? It was a boiling hot day and we had decided to spend a week in our caravan in the Peak District. We decided to pack the car and call into the George Eliot Hospital to keep Derek’s appointment with Mr.

Stansbie, on the way to the caravan, to find out the result of the check up. We parked the car in the car park but owing to it being so hot, I had to stand outside the car with out dog, Gypsy, unable to accompany Derek into the hospital as I usually did. For some reason, I felt a sense of qualm and uneasiness.

Derek, obviously, did not have these feelings as he was totally unprepared for the shock of being gently told that he was to have his larynx removed and be rendered speechless. He reported later that his reaction was to feel hot and cold all over and said so to the consultant. Mr Stansbie, who is an extremely understanding man, later told him that it was a perfectly natural reaction to such bad news. He asked if I was in the waiting room as he would like to speak with me. Of the times that I was most needed, I was not able to be there with Derek. Mr. Stansbie tried to explain about the operation procedure to Derek but he was too shocked to absorb it. Mr. Stansbie was very sympathetic and told him:-

“Still go on your holiday in your caravan. The operation is not urgent. Talk it over with your wife and bring her with you in two weeks time and I will reserve an half hour appointment and discuss it with you both present.”

Afterwards I thought how lucky we were to be involved with such a kind, understanding consultant.

I can vividly remember Derek returning to the car park. By then he was portraying a calm that he obviously did not feel and I thought “Great, everything is fine”. He then said “Well it has finally got to go”. I felt nauseous, numb and shaky inside. We both sat there dazed, trying to decide whether to return home or continue on our journey to the Peak District. We thought that we might as well go on as it would give us a breathing space away from friends and family, in tranquil surroundings, to try and come to terms with the news we had just been presented with.

The field in which our caravan was situated, was in a beautiful spot of unspoilt scenery, surrounded by picturesque hills with the adjoining fields, full of grazing sheep and cows. There were lovely walks to be taken in whatever direction one took. Our site was situated between Beresford Dale on the River Dove and Hulme End in

the Manifold Valley. Several other families left their caravans here each year. They were all friendly people who came from the north of the region. In the nearby farmhouse lived the farmer Dennis and his young son Nick who were very obliging to us all. It was good to share our problem with these kind, sympathetic people and try to get things into the right prospective before returning home.



Relaxing outside our caravan at
Beresford Lane Farm. "Peak District"

I, personally, found the greatest problem, being in the confined space of the caravan, trying to hide my sorrow from Derek. I desperately wanted to be strong for him yet I felt so vulnerable emotionally and could not sleep at night. Derek was acting so bravely and putting on a good front. I wrote a letter to our vicar at St. Lukes and the congregation and asked for their prayers. Derek and I decided to join a coach trip with the church planned for September 4th 1993 to visit the shrine of Our Lady at Walsingham to pray for a healing of body, mind and spirit. We both somehow felt more at peace after making this decision.

During and after this trip, the Vicar, the Rev. John Twistleton requested that we done a write up in the church newsletter. (This can be found below)

JESUS IS BIGGER THAN CANCER

Fr. John writes:

It says in the Scriptures that we can "do all things in Him who strengthens us" Phil 4:13 for "nothing is impossible to the Lord" Luke 1:37 and we as Christians are "partners with Him" 1 Cor 1:9.

This is true since God has said it and it applies whether we are up against a financial crisis or a marriage problem, whether we are facing temptation or death itself. Christ has drawn the sting of all evil, this means that any evil that throws itself against someone who has Jesus in his life loses its power.

All of this is true not only in principle but also in experience for faithful believers as Derek & Sylvia give testimony below.

Anyone who meets Derek or Sylvia will see a witness to the above: Jesus is bigger than cancer. As things stand Derek is set to go into hospital this coming Wednesday to have his voice box removed. Regular St. Luke's folk over many years, Derek & Sylvia entrusted Derek's cancer to the Lord at Walsingham and with our readership to know the situation. It is not one of loss, a trial of faith rather than a problem to them. All the same they earn our admiration and ongoing prayer that God will be glorified. If Our Lord grants a physical miracle the operation (set for around the 27th) will not take place.

Sylvia writes:

September 4th 1993 was a special day for Derek and myself when we decided to join the pilgrimage to the Shrine of Our Lady of Walsingham. About 19 of us from St. Luke's joined a coach of people from other local churches, all with a special purpose, different needs, worries and requests to lay, in faith, at the foot of the cross, at this very holy village.

After a very pleasant and amicable journey through some lovely countryside, we gathered after lunch, outside the Shrine Church to walk in procession to St. Mary's Church along leafy lanes, singing the Pilgrim Hymn together all the way. I am sure, as we sang, we all had a great feeling of expectancy of

the power of God to heal us in body, mind and spirit. Personally, I went the whole hog, and asked for a miracle. I prayed for a complete healing of my husband's voice box so he would not have to face having it removed and also for the return of clear speech.

I believe Jesus does have the power of sudden healing, but having read the Bishop of Durham's book concerning miracles, I realise it is not always the way Jesus works, and why, but that if you pray in faith, he answers your request in his own way and in his own time and for his own reasons.

We had a marvellous, uplifting Mass in St. Mary's Church. At the end Fr. John offered Derek and I the opportunity, due to our circumstances to

receive the Sacrament of Anointing with Holy Oil in St. Mary's Church, which we gladly accepted, hoping to receive strength in our trial together. One of the most momentous moments was when a group from St. Luke's, both young and old, chose to stand behind us, praying and supporting us, sharing in our hopes and fears. I personally very much felt the "welcoming Church" and a sense of peace.

We then walked to the Shrine Church and gardens. We drank the Holy water, received the sign of the cross on our

foreheads from the priest who then poured water in our hands. I poured mine over my head and Derek poured his over his throat.

I sensed a "Challenge" at Walsingham, I felt we were very inexperienced climbers getting a wonderful send off at base camp on an expedition up a mountain full of crags, easy to fall down in our weakness but to be re-climbed with God's encouragement. Sometimes there will be mists, fogs, streams but hopefully some sunshine along the way. We may even one day reach the summit with God's help. Thankyou, St. Luke's for all your prayers, letters and support.

Derek writes:

We left St. Luke's at about 8.15 am on Saturday 4th to begin our trip and I really enjoyed passing through places which I had visited with my wife



when touring in the van. The weather forecast was to expect rain in East Anglia and as we approached Walsingham through the tiny lane there was a sprinkling of rain on the coach windscreen but on arrival at the car park it had stopped. We the pilgrims assembled outside the shrine church to walk in procession to the parish church singing the Pilgrims' Hymn. Arthur was in fine voice and kept our section at the right verse and right time during the walk. We attended Mass at the Church, and at the end Fr. John invited Sylvia and myself to a small side chapel to be anointed with Holy Oil.

As we both knelt at the altar a small group of our friends from St. Luke's stood in a semi-circle at the back of us to watch. It was there in the company of my friends knowing that they were watching and praying for me that I felt the presence of God and I knew that He was going to strengthen me and give me the will to persevere and also to look over my wife in the days ahead.

Later in the afternoon we visited the shrine to be sprinkled and drink the holy water. For me the village of Walsingham, despite the many pilgrims, gave me a feeling of peace and serenity which is sometimes hard to find. On the way home different thoughts were going through my mind of how I was going to cope without a voice but the further we travelled towards home the clearer my mind became and by the time we arrived at a Pub for refreshments I was feeling good.

I really enjoyed my trip to Walsingham and I know there are folk who are sceptical about visiting a shrine and look at you with a little grin on their faces. I say to them,

"When you have a headache, take aspirin, when you have a headache take in Jesus!"

CHAPTER 5

On returning to our own home we told our close family and friends who were naturally very upset and concerned. We wrote also to our family in Australia. We were totally overwhelmed with the love and kindness shown to us by all. We received letters and phone calls and had bunches of flowers left on our doorstep from unexpected people. Our sons and daughters offered us financial support for any aids needed for later on if necessary. We had a visit from the vicar to talk things over and support from the congregation. It warmed our hearts to see how much good there still was in the world. We began to feel more positive and able to cope. Of course we had days when we felt depressed but we would try and dispel these feelings by walking our dog in the countryside or treating ourselves to a bar meal.

Derek and I went to the hospital and we had a long talk with Mr. Stansbie, our E.N.T. surgeon. We had quite a few questions to ask (which I had written down) which he patiently answered. He explained why he had decided to perform a laryngectomy. He explained to us that he could not rely on the small areas of malignant cells not spreading further afield. Possibly they could remain dormant but if they did decide to move, this could interfere with Derek's breathing. It appeared to us that it was a case of "Better be safe than sorry".

He basically explained about the surgery in laymen's terms, which we could understand. There would be an external incision to the throat needed approximately 24 stitches. The larynx (voice box) and Adams Apple would be removed. There would be a repair to the top of the oesophagus (food pipe) and the wind pipe detached at the top end and brought out and grafted on the chest forming a stoma (hole) through which Derek would breathe.

I must admit, it all seemed rather daunting and secretly I worried in case he would feel suffocated on waking up after the operation. I was pleased to say my fears were unfounded as you will read later on in this true account. However, after the interview, we both felt more positive and knowledgeable about the surgery to be undertaken.

The operation date was fixed for 27th September, 1993.

As you can imagine, waiting for those weeks to pass put an enormous strain on us both.

We had great moral support from far and wide. Many letters arrived including one from a church friend Val Bryan, who had lost her husband recently with cancer. A lady called Lillian Cox phoned whose husband Cyril was fighting cancer of the oesophagus offering her prayers and sympathy. I remember being greatly moved by people's concern and shedding tears of gratitude. Neither of us, strangely, felt bitter about our situation. We did not say "Why us?" but said "Why not us?". We were not the only ones suffering in the world. If I felt tearful or panicky I would disappear and upstairs and pray and then felt calmer and able to cope. Derek put on a brave face and kept his fears to himself.

Suddenly, the phone rang and a lady introduced herself as Kathy Dadley. She was the wife of Ernie Dadley. Ernie had had a laryngectomy 15 years previously. They were both members of "Second Chance, Coventry Laryngectomy Support Group". Evidently, they had been contacted by phone the moment after we had left the George Eliot Hospital Out Patients Department. She asked if Derek and I would like to meet Ernie and herself for a chat. She sounded so nice and friendly, I jumped at the chance to meet them. We must have chatted on the phone for half an hour discussing my fears and questions. I cannot express how wonderful it was to have contact with people who had actually experienced what we were about to face up to. Kathy invited Derek and I to her home in Cheylesmore, Coventry for afternoon tea on 15th September, 1993. We were delighted to accept as we had never met a laryngectomee. Neither had we heard anyone talk with an oesophageal voice. Like most people, we had only heard about the famous film star Jack Hawkins who had been a laryngectomee.

Mr. Stansbie had informed us that basically there would be a chance of three ways of communication other than pen and paper and lip reading.

1. Learning to achieve oesophageal speech, with the help of a speech therapist, by learning to use a valve situated near the top of the oesophagus

2. Using an electronic device usually a SERVOX

3. By having a further operation to have a valve fitted near the top of the stoma

On arrival Kathy Dadley introduced Derek and I to Ernie who had his laryngectomy 15 years previously. Ernie greeted us by saying “How do you do” in a good oesophageal voice. It was a bit of a shock to us both hearing this type of voice for the first time. I can’t think why but it reminded me, personally, of the sound of hot air balloons and initially we found it very strange and a very different sound to what we had expected. We felt rather despondent coming face to face with reality.

A car drew up outside the house and we discovered that Kathy had kindly invited another couple called Len and Flo Hudson. Len had been a laryngectomee for ten years and had an excellent oesophageal voice and we were informed that he had returned to his job, two years after surgery and could talk on the phone really well. Derek and I began to feel that this diagnosis was not a death sentence after all.

After talking to these two couples, our confidence increased when we realised these long-term laryngectomees and their wives were leading happy, normal lives in spite of their speech difficulties.

Over tea and cakes, these fantastic people, patiently answered our many questions, some quite trivial, which to us were important. Some were to do with surgery and others to do with every day living. I also received valuable advice from the two wives, which helped me psychologically. After all as I later discovered, wives need to be extremely involved to encourage their husband with speech therapy practise and to deal with and receive a certain amount of flack at first, due to the frustration caused by loss of speech. It is not an easy task being the partner of a laryngectomee! Fortunately, having had a close relationship throughout our married life helped us to survive but it can put an enormous strain on a partnership especially in the early months after the operation.

No longer can you have a heated yet rewarding discussion about politics, religion or anything else or have sweet nothings whispered in your ear! It is important to realise that a partner will have to adjust to this fact of life for a long period of time until an alternative method of communication can be worked out.

Often, a partner will find, a lot of the time, he or she will seem to be conducting a one way conversation which can feel very sad and lonely at times. It is important that both of you mix with other company sometimes and have a hobby to indulge in. Personally, I received a lot of pleasure striving to play the piano and keyboard. Derek enjoyed wine making and reading.

Towards the end of a very enjoyable and rewarding afternoon, Ernie Dadley invited Derek and I to become members of “Coventry 2nd Chance Laryngectomy Support Group”. Ernie was the treasurer and Len was the chairman. They explained to us both that several laryngectomees and their partners or family members meet on the second Thursday of every month (except August, January and February) in the conference room at Coventry and Warwickshire Hospital at 7pm. Nurses and speech therapists also attend this Meeting at times.

Their aims were to support each other, to offer any advice to new patients before or after their surgery and to visit them in hospital if they so desired.

Occasionally, if it could be arranged, there would be a speaker, video or demonstration and a visit by a consultant. There had, in the past, been fund raising activities and the odd social outing organised or if funds were high enough, an extra item of comfort had been purchased for the E.N.T. ward. This group appealed to Derek and I and we requested to be put on the mailing list as we felt being members could be a valuable experience for us both, which it later proved to be.



Socialising with members of
“2nd Chance Laryngectomy Group”

After our visit to Kathy and Ernie’s house, we had only seven days to wait before the operation. We pondered about some of the questions we had asked and the answers we had received.

I have listed a few which maybe could be helpful to anyone facing a laryngectomy operation:-

- a) What do you actually find when you come round from the anaesthetic in intensive care?

Answer

This answer will be dealt with later in this book.

- b) Is there anything you can’t do or find difficult to do after the surgery?

Answer

You will be able to do most things. You may be inclined to get more puffed out, e.g. mowing lawns. Bending over can be a nuisance as sometimes, due to more excessive secretion from the stoma, especially in cold weather, it may run down your chest and need mopping up.

c) Any special diets or eating problems on returning home?

Answer

No, not usually. Occasionally a bit of steak or a capsule will temporarily stick on the scar tissue but will eventually move with no ill effects. You will not choke as you will be breathing through your stoma!

d) What dressing will I wear to cover the stoma?

Answer

Usually, a light, white cotton bib for summer use or a thicker white winter bib with a filter in. Some people prefer a laryngeal cover especially the ladies. It is important to cover the stoma day and night as the windpipe does not like the cold and is inclined to secrete too much lubricant in cold conditions and this can be a nuisance. Also the cover acts as a filter (similar to the nose) against dust, fumes and insects! One lady had a centipede creep down! Bibs are obtained free on prescription.

e) Do you have to have a tube in at night?

Answer

A few people do, according to the width of their windpipe. Derek did not have to have one.

f) Do you have to clean out the stoma every day?

Answer

Yes, this is done with the use of a syringe and sodium chloride for irrigation and thus any debris is easily coughed up. You will receive instruction on how to do this before you leave the hospital.

g) What about if you get a cold?

Answer

Anti-biotics often are needed if the cold is severe. The stoma can get clogged up as the nose does with non-laryngectomees. However, as inhalement of steam or Friars' Balsam will help. Sometimes the catarrh will dry and stick a little or maybe a little blood will be coughed up, but not to worry as it is only because it has pulled on the delicate lining of the windpipe a little.

Of course, any serious breathing difficulties and you must immediately contact your E.N.T. ward, which will admit you and have special equipment available for such an emergency.

h) Can I be affected during the hay fever season?

Answer

Derek found his stoma got rather clogged up instead of his nose, but an inhalent helped.

i) Can I sneeze or cough?

Answer

Yes, but not with the nose or mouth but through the stoma.

j) Are you more prone to infections?

Answer

Yes. Avoid people with colds if possible!

k) Can you go to a normal dentist?

Answer

Yes, no problem.

l) What about speech therapy?

Answer

This will commence four weeks after the operation. Usually, you will be seen twice a week. No one can tell you how long it will take to achieve oesophagael speech. Every one varies. This will be dealt with further on in the book.

m) A delicate question. Will my sex life be affected?

Answer

Not at all.

n) How will the public act, hearing me talk with an oesophageal voice or Servox?

Answer

Almost always showing an element of surprise, but acting in a sympathetic manner. Usually people try to be very helpful and show an interest and nearly always mention JACK HAWKINS!. Derek and I had no problem meeting strangers in holiday hotels, bars, etc. once the ice had been broken. If a person cannot handle it, it is their problem, not yours!

o) What if I need artificial respiration?

Answer

Derek always hung a special card around his neck if walking alone, produced especially for laryngectomees with special instructions which can be obtained from the speech therapist. He also had one stuck on the car dashboard whilst out driving. Oxygen has to be administered through the stoma and the kiss of life can be performed by placing the mouth over the stoma after it has been wiped clean. Emergency services should have had special training in this matter.

p) Can I fly in an aeroplane?

Answer

Permission should be obtained from the airline concerned as special equipment has to be on board in case of an emergency. Consider taking a long flight with careful thought. Check on medical insurance.

Advice

Be determined to live life to the full. Don't look back and cry over spilt milk. Always carry plenty of tissues in your pocket, not to cry into but to clean your stomal

P.S. For special occasions, different coloured bibs (very strong and machine washable) can be ordered from "Kapitex" for approx. £4 each.

Pure Gold!

We receive quite a few letters about making stoma covers more attractive. Well, here's a gem of an idea - or precious metal at least! The photograph shows a neckpiece that can be worn as an addition to the normal cover - fitting securely over the essential laryngof foam filter cover or a Blom-Singer valve. The filtering and humidification of the air around the stoma cover can be maintained via a finely pierced design in the metal and/or gold or silver plated stainless steel fine mesh. The piece shown is made from 23 ct gold plated silver and can be worn with or without the additional side pieces. It is worn around the neck by means of a ribbon and is fixed securely by velcro, allowing for comfortable wear and quick, easy removal.

The jewellery can be made from a range of metals and surface designs, depending on the preference of the customer. So each piece will be unique and hand-crafted. Obviously the degree of complicity used in the surface design technique and the type of metal used will determine its cost. To give you an idea of the price, though, the one shown was sold to a laryngectomee for £120 plus p&p. The price could be lowered by using other metals.

Ultimately, the neck piece is intended to provide an alternative to the usual practice of wearing a scarf or high neck clothing worn by the majority of female laryngectomees. It will hopefully go a long way in restoring morale by giving a sense of worthiness in one's appearance.

For more information, please contact the designer, Caroline Manders, direct at



28 Wood Green Road,
Wednesbury,
West Midlands WS10 9AX
or ring her on 021-556 6874.

CHAPTER 6

There was just one week to go until the planned day of admittance to Walsgrave Hospital to prepare for the operation. Unfortunately Derek developed an excruciating pain in his back and waist during those last few days which caused me much concern. Everything seemed to go wrong. I had to take to my bed with a severe attack of diverticulitis, then Derek's waist broke out in blisters three quarters of the way round and I suspected shingles. The day before his admission our exhaust pipe gave up the ghost on our Montego 1600 and we made a desperate dash to an exhaust centre knowing that I would be dependant upon the car for daily visits. We both felt a tremendous build up of pressure these last few days. September, 22nd 1993 arrived and although we felt very sad as I drove him to Walsgrave, we also felt a sense of relief. We sat in a small waiting room on arrival and eventually we were taken onto the ward and into a side room with an armchair and a T.V. It was nice and private and a nurse came in with a tray of coffee and biscuits. A lady doctor entered and immediately diagnosed shingles. She contacted Mr. Stansbie the E.N.T. surgeon and we were informed that no way could he perform the surgery as it would not be safe to do so in case the virus entered the neck glands. What a let down! However it really was for the best as on returning home Derek became quite ill and had to take to his bed. We realised that the correct decision had been made after all.

My next door neighbour Pam bought me a lovely bunch of red carnations to try and cheer me up. We had lots of encouraging phone calls from "2nd Chance Support Group", friends and church members.

Every week I had to phone Mr. Stansbie to give him a report on the progress of Derek's shingles which slowly improved although he was still in a great deal of pain. Eventually the date of the operation was fixed for October, 18th, 1993. On October, 7th, 1993 we celebrated our 32nd Wedding Anniversary at a country pub called "The Four Counties" with a bar lunch. I began to have negative thoughts wondering if it might be our last. I remembered all the former happier anniversaries we had celebrated with tears in my eyes. We both tried to make an effort to fill the last waiting days with cheerful activities and positive thinking.

On October, 14th 1993 Derek was once again admitted to hospital. We were given coffee and counselled very thoroughly by a nurse called Mary Fisher, who was very kind and friendly. We visited a gentleman who had had a laryngectomy previously so we could see for ourselves what a stoma looked like. Mary went into every aspect of having a laryngectomy and we both felt more relaxed as I said goodbye to Derek.



FRIDAY, 15TH OCTOBER – I visited Derek again and we both had a long talk with Mr. Stansbie. He wished to impress on us both the implications of how it would be having no speech. I was allowed to drive Derek home for the weekend. It was great to have him home on this temporary basis but in a way I felt it would have been easier if he had remained in hospital that weekend. On Saturday we drove out to the “White Lion” pub at Pailton and had lunch. Our youngest son, Bern, paid us a visit to say ‘goodbye’ and became very upset on leaving. We attended church on Sunday morning and the vicar asked me to read the lesson and we came away strengthened. My son-in-law Robert came with his family unexpectedly to drive Derek back to the hospital so we could say our goodbyes at home to make things easier for me. We

were all in tears, I decided to drive myself to St. Lukes where by chance a healing service was taking place that very evening. Hence this article which was written by myself two years later for St. Lukes newsletter during October, 1995.

God Answers Prayer! 

I know that we all enjoyed the visit by Roshini Chandi to St. Luke's and appreciated the fact that she shared her experiences with us of the spiritual renewal in her life and the culture of arranged marriages in India. She was also a great asset in her assistance and prayer during the laying on of hands at the healing service at which I am sure that most of those who were present received a strengthening of body, mind and spirit and the Lord's mercy.

Whilst sitting there on Sunday evening, my mind flashed back to the healing service which took place two years ago. I attended this service one hour after my husband had been admitted to Walsgrave hospital to have a laryngectomy, because of cancer, which would result in total loss of speech. Life looked very bleak but with the encouragement of Mary Chitty, I plucked up courage to go down and kneel at the altar to be administered to by Fr. David Urquart from Holt Trinity Church. Feeling very stressed and suddenly tearful, I had difficulty telling him and the Lord what I had come to ask for which was to pray for strength and healing for my husband and myself. Eventually he understood my request and we talked about it and he prayed to the Lord and laid his hands on me. A sense of calm and renewed strength came over me and I felt able to cope.

Looking back since that evening, the Lord has bestowed many blessings on us both, too numerous to name, but in spite of many difficulties of communication etc. our lives have been enriched in many ways and we have been led down many new paths by the Lord. Some examples are, an awareness of good neighbours who collected money and stood on our door step with a large basket of flowers for me, a bottle of rum for Derek and a signed card from the whole street wishing us both well.

We are constantly supported by the E.N.T. ward at Walsgrave and the surgeon, who on every visit, reminds us we are only a phone call away if we have any worries or a crisis. We have a wonderful speech therapist at the George Eliot Hospital Nuneaton who has, and still is, teaching Derek to obtain an oesophageal voice and to use a Servox and has been a good friend to us both and made our visits very enjoyable. eventually with more experience we would like to counsel others.

New friendships have been formed through attending Coventry "2nd chance" Laryngectomy Group who have been brilliant in their support and management of the condition. We have social occasions and fund raising and the chance to attend various conferences with other types of cancer group and staff, to improve services.

We have received a feeling of a deepening of family relationships at St. Luke's and our caravanning friends in the Peak District and many other blessings the Lord has bestowed on us since that healing service two years ago. Whatever the future holds I pray that the Lord will continue to strengthen us.

Ask and ye shall find.

Sylvia Ireland

CHAPTER 7

OCTOBER 18TH 1993

I have to say that this was one of the worst days of my life.

Derek phoned me up at 10am in his own voice for the last time. His last words to me were 'I love you'.

After that there was no news for hours. I worked myself into a state of exhaustion, polishing our home from top to bottom. I was on edge, but also felt a sense of relief that it was at last happening so we could get cracking with our new way of life. There was complete silence in my house but I needed this in order to face those few hours alone with my thoughts and prayers.

I could not bring myself to pick up the phone and dial the ward number that I had been given. My son Bern arrived at 5.15pm and he phoned the hospital. He was informed that Derek had just come out of theatre after a 6½-hour operation and that Mr. Stansbie was in the room attending to him and setting up the equipment needed in readiness for his 24 hours of intensive care with a nurse continuously at his bedside. I phoned again at 9pm and was told that he was comfortable and sleeping. What a relief! Fortunately, I received no urgent calls from the hospital during the night.

OCTOBER, 19TH 1993

Diane, my daughter-in-law insisted on accompanying me on my first visit to Derek in hospital after the surgery. I was feeling very apprehensive about what I was likely to encounter. My son-in-law Robert was already standing vigil at the bedside. Derek was very tired but I noticed he had a good colour. He had a hole (stoma) in his upper chest wall with stitching around it. It made me think of a big black spider! This was the top of the windpipe grafted out onto the chest through which he breathed quite easily. He had an incision across his throat with 24 clips and stitches and also a few drainage tubes in the top of his chest and a drip. He also had a tube through his nose

going down into his stomach through which he would be fed liquid food to keep him well nourished for the next few days. I could hardly find a space to give him a kiss. Nether-the-less in spite of all this he seemed O.K. The only problem, due to a long period of being under anaesthetic he could not pass water even with the encouragement of a nurse and the threat of a catheter being inserted. Much to the nurse-in-charge's amusement he ordered her out of the room saying 'I want my wife to do it'.

Gingerly, I got him out of bed worried about all the tubes and ironmongery but with the help of a running tap and a bit of encouragement we finally got results. I only stayed for an hour but visited again in the evening with my two sons and daughters.

OCTOBER, 20TH 1993

There was some improvement. Derek kept writing on his magic children's pad. "Talk to me". I found it extremely difficult to conduct a one way conversation once all the day's news had been told. We certainly felt the impact of having no speech. The nurses on the E.N.T. ward are all brilliant at lip reading but I was particularly hopeless at it. I experienced the first taste of his frustration and felt quite useless. However, I was so relieved that he had survived the surgery and could breathe easily through his stoma with the help of an atomiser, which moistens the air entering the windpipe, which has to adjust to being exposed to direct air for the first time.

OCTOBER, 21ST 1993

I became really worried today, as Derek was not well at all. He had a headache and a high temperature. I spent the whole afternoon holding his hand and applying cold compresses to his head. He wrote a heartbreaking message on his magic pad 'Will I ever get well again?' I returned home feeling very depressed and dejected.

OCTOBER, 22ND 1993

Today I could not believe the change in his condition. He was so much better and he even walked to the bathroom adjoining his room, trailing all his equipment along with him. They had removed two drainage tubes.

I met Mr. Stansbie in the corridor and he told me that Derek had had an infection the previous day but was now O.K. after a liberal course of anti-biotics. He reassured me that all had gone well during the operation. I felt I was walking on air after that meeting.

Father Wilf, a priest from our church St. Lukes had visited him that morning. He had enquired about the food drip and was greatly amused when Derek had written on his pad that he was enjoying 'pheasant and chips'.

We spent a pleasant afternoon together with the cheerful banter from the nurses and I was introduced to Derek's physiotherapist. We also had a visit from a very charming lady chaplain who was interesting to converse with and supportive.

OCTOBER, 23RD 1993

Derek was slowly improving I allowed myself to be treated out for lunch by my son Keith and his wife Diane at the local pub called the 'Mount Pleasant Inn'. I had hardly eaten the past few days through tension.

OCTOBER, 25TH 1993

Today, Sunday, all the tubes have been taken out of his chest and Derek was doing fine. Derek had learnt how to disconnect the food pipe himself and was walking about quite a lot. He was getting very spoilt by the nurses, fussing around him, cracking jokes. They appreciated his wicked sense of humour. In spite of his continued improvement I still felt his exasperation and frustration concerning my feeble attempts to lip-read. Everyone else, especially my young grandson James seemed able to do it quite well, which did nothing for my ego. I felt, somehow, that I was letting him down.

OCTOBER, 26TH 1993

Derek had his 24 clips removed from his throat. He had his first attempt at drinking black currant juice and proceeded then to drink three cups of black coffee. Father John Twistleton, vicar at St. Lukes visited with his two sons who were fascinated to view a stoma for the first time. A friend called Alma from the church had made Derek lots of sturdy cards to use after his operation with different instructions on such as 'I want a drink please', etc. etc. The Vicar and sons were highly amused when Derek held one up saying 'Sod off!' The vicar raised his eyebrows whilst one of his favourite nurses gave him a passionate kiss for devilment much to my embarrassment. I began to feel he would be sorry to leave. He was particularly fond of the Irish nurse Eileen who had sat with him all night in intensive care. We still exchange letters and Christmas cards to this day. He had a wall covered in Get Well cards and that small room in Walsgrave hospital had become like home. I cannot praise the care and kindness enough of the staff of the E.N.T. ward.

The chaplain Rev. David Robinson arrived and we both received our communion and offered prayers of thanksgiving for the care and support that we had received.

OCTOBER, 27TH 1993

Derek had been visited by a dietician and could now eat liquid foods such as soup and ice cream. We had a visit from Kathy, Ernie, Len and Flo representing the 2nd Chance Laryngectomy Group who had counselled us both previously. This visit was very helpful and encouraging for Derek.

OCTOBER, 28TH 1993

Derek was progressing in leaps and bounds. Lots of friends were now allowed to visit besides family members. A nurse spent time instructing us on how to daily clean and look after the stoma using a syringe and sodium chloride solution for irrigation. Also how to apply Vaseline to the top of the stoma to prevent soreness.

OCTOBER, 29TH 1993

Today we both had a visit from a speech therapist. She began by giving Derek tips on doing lip expression and sounding hard “T’s” to help me to lip read. I had felt a bit useless, not being able to communicate with my own husband very well. I felt excited when I was told to expect him to come home on Saturday. They had removed his stoma stitches earlier that day.

OCTOBER, 30TH 1993

Derek was now feeding on solids successfully and Eileen his Irish nurse had even bought him in a Guinness to drink. I still worried a great deal at my poor attempts to lip read. Probably in my imagination I felt that it was putting up a barrier between us and I wondered how we would cope at home. To cheer myself up I treated myself to a lunch at the local pub. I felt I deserved it.

OCTOBER, 31ST 1993

Great joy and excitement. I drove to the hospital and brought my husband home. I could not believe how well he had progressed. He even took our dog a walk to a nearby park on his own for some fresh air. He was managing really well to handle the coughing up of debris and cleaning out the stoma himself with no help. He put on his first laryngectomy winter type bib, which at first made him feel hot around the stoma. He had only lost five pound in weight since the operation, which was to be expected.



NOVEMBER, 1ST 1993

We were nearly back to normal. We even managed to attend church together and received a great welcome. We came home to a tasty roast beef dinner, which he ate with no difficulty.

NOVEMBER, 2ND 1993

We received a visit from our two local district nurses who introduced themselves as Etta and Winnie. They explained how they would supply any syringes needed and what to order from the Chemist. They advised us both to have an influenza injection as laryngectomees are more susceptible to cold and flu infections and can develop breathing difficulties. Often anti-biotics are needed to clear up persistent infections. We had been told that should severe breathing problems occur we must phone and go straight to the E.N.T. ward bypassing our G.P.

NOVEMBER, 3RD 1993

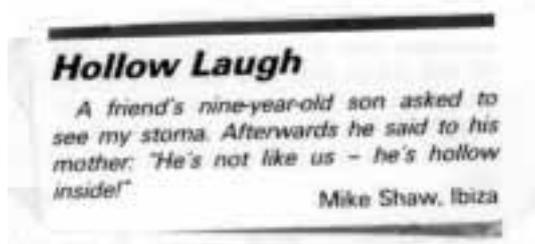
Our first social outing. I drove my husband to Ryton Pool Country Park, Warwickshire for a walk around the lake to feed the ducks and swans. We stopped for a pub lunch at the Three Horse Shoes at Bubbenhall. The landlord looked at my husband suspiciously as Derek was scribbling messages to me in his small notebook. I think he thought we were from the Brewery checking up on him. What a marvellous day out we had, savouring every moment after all the stress we had suffered lately.

NOVEMBER, 5TH 1993

We visited our G.P. Dr. Garala who had diagnosed Derek's illness 5 years previously. He was extremely interested to inspect Derek's operation as cancer of the larynx is not so widely publicised as other types of cancers. We had been told that many doctors and nurses had not seen a laryngectomee before in the flesh. More awareness of this condition and information is needed. We visited the local chemist to arrange about a regular supply of bibs that we would need to have on prescription. He seemed reluctant to order many, as they are quite an expensive item. We got the impression

that he thought Derek would not be here for that long. This was a typical example of the widespread ignorance surrounding the survival of laryngectomees.

Derek now felt strong enough to potter in the garden, sweeping up the autumn leaves and twigs ready for the bonfire to be held that night at my daughter-in-law Diane's



riding stables. This was the first annual bonfire event we had missed since our marriage because we considered it unwise to expose Derek's windpipe to the smoke.

We ended up with a crowd visiting us afterwards with a pile of muddy boots, to drink coffee and thaw themselves out by the gas fire.



The same evening, we had a lovely surprise visit from three neighbours. The whole street of River Close had subscribed to a collection for us. We were presented with a

basket of beautiful flowers for me and a large bottle of rum for Derek, plus a signed card reading 'from your friends in River Close'. We felt overwhelmed with their kindness.



Can still join in !. Doing the “SLOSH” at Grand Hotel, Whitby 1996



Derek and Sylvia and Gypsy .

Walking in the Derbyshire Peak District after the operation.

CHAPTER 8

On the second Thursday in November we nervously attended our first meeting of “The Second Chance Laryngectomy Support Group”. We were introduced to all the members and given a welcoming cup of coffee. Everyone was very friendly and supportive. We were introduced to Frances Bate who was to become Derek’s permanent speech therapist at the George Eliot Hospital.

Mr. Patel E.N.T. consultant surgeon at Walsgrave hospital was to be the speaker that evening. He discussed the advantages and the down sides of having a Provox valve fitted or a Blom Singer. We were shown a videotape concerning this. We also watched on video a tape of a complete laryngectomy operation. We found this extremely interesting and we all greatly admired the skill of modern surgery.

Derek, at 66 years of age decided he did not want to risk having a valve fitted. Maybe it would be a good decision for a younger person to go ahead who needed to return to work to earn a living. However, this valve sometimes has to be changed every few weeks and can sometimes cause a thrush infection or other complications. Some people on the other hand think it is well worth it, to have this further operation, to regain their speech.

We enjoyed the company of the “2nd Chance Group” . We appreciated their helpfulness, advice and encouragement. One of the ladies called Peggy, had had extensive laryngectomy surgery over twenty years before and had survived having had the operation in Birmingham in an age when the survival rate was low. There were several long-term laryngectomees present which raised our hopes and spirits. A few days later, we attended Derek’s first speech therapy session with Francis Bate. Francis was only in her twenties but very good at her profession and we hit it off straight away. This was the beginning of many enjoyable sessions we were to attend over the next 2 to 3 years. Frances told us that it was important for me to attend too as I was to be very much involved in encouraging and helping Derek with his homework. We had an extremely helpful hour’s session practising hard sounds of the alphabet such as “T’s” “C’s” ”P’s” etc.



Members of “2nd Chance Laryngectomy Support Group, Coventry”

Enjoying a Christmas dinner at “The Toll Gate”.

This was to help me to lip read. I came away feeling much more confident. We decided to set aside half an hour daily to practice together at home.

We also went ahead and purchased an answering machine and installed it in case I was out since Derek, as yet, was not able to answer the phone himself.

Everyday, Derek walked Gypsy, our dog, in the fresh air and carried a card reading ‘I have no speech’ in his pocket in case a stranger spoke him to. He also hung a card around his neck explaining that he was a laryngectomee and which gave instructions how to perform artificial respiration in case of an emergency. These cards are supplied by speech therapists. There is also one required to stick on the car dashboard in case of an accident. We had our first visit to George Eliot Out Patients, to see Mr. Stansbie the E.N.T .surgeon who had performed the operation. He viewed down Derek’s stoma with a torch, poking out a few bits and bobs with his tweezers and was very pleased with his progress. Every visit, he made a joke, asking me if I had felt any lumps in Derek’s neck. I used to reply “How would I know?”. This check for lumps and swollen glands always seemed to be a priority. Derek was still suffering

quite badly from post-shingles pain but there was little they could do for him, only prescribe painkillers.

● EMERGENCY ●
I AM A
LARYNGECTOME
(I have no Vocal Cords)

I breathe through an opening
in the **NECK**

**NOT through
the NOSE or MOUTH**

If **ARTIFICIAL RESPIRATION** is
necessary:

1. Keep neck opening clear
of all matter
2. Don't twist head sideways
3. Apply oxygen only to neck
opening
4. Don't throw water over
head or neck
5. Mouth-to-**OPENING** treat-
ment is effective

PTO

WITH COMPLIMENTS

**National Association
of Laryngectomee Clubs**

Ground Floor
6 Rickett Street, Fulham
London SW6 1RU
Tel: 0171 381 9993

My name, address and telephone
number are:

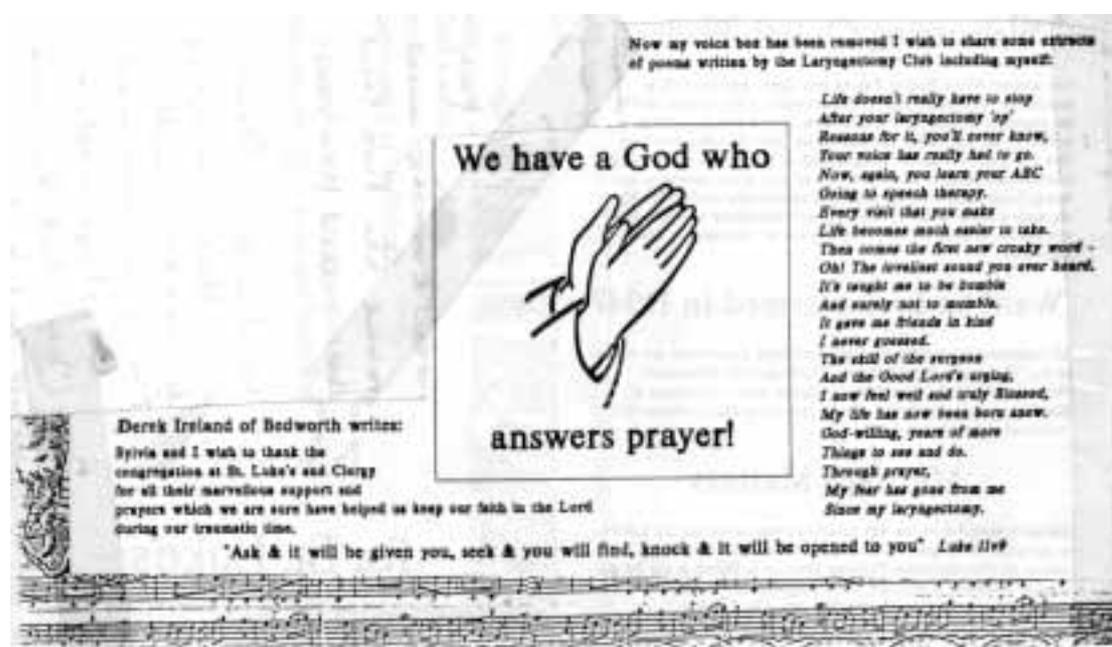
CHRISTMAS 1993

A group of us from St. Lukes church, one evening went singing carols around the two local working mens clubs called “Hen Lane” and the “Unicorn”. It raised money for the charity “Christian Aid”. Derek came along as a collector mingling amongst the club members with his collection tin. The vicar announced a sob story from the stage explaining our collector had lost his voice box due to cancer and had come along to sing “Silent Night!”



After this all the ladies were saying to Derek “Are you alright me duck!” and were dropping one pound coins into the tin instead of a few pence. I think we doubled the collection that evening. In spite of extensive speech therapy, two months had passed and Derek could not utter one word. He had practised using his diaphragm muscles and trying to use certain tongue movements to push a little air pass the valve situated near the top of the oesophagus without success. This lead to Derek feeling both frustrated and despondent.

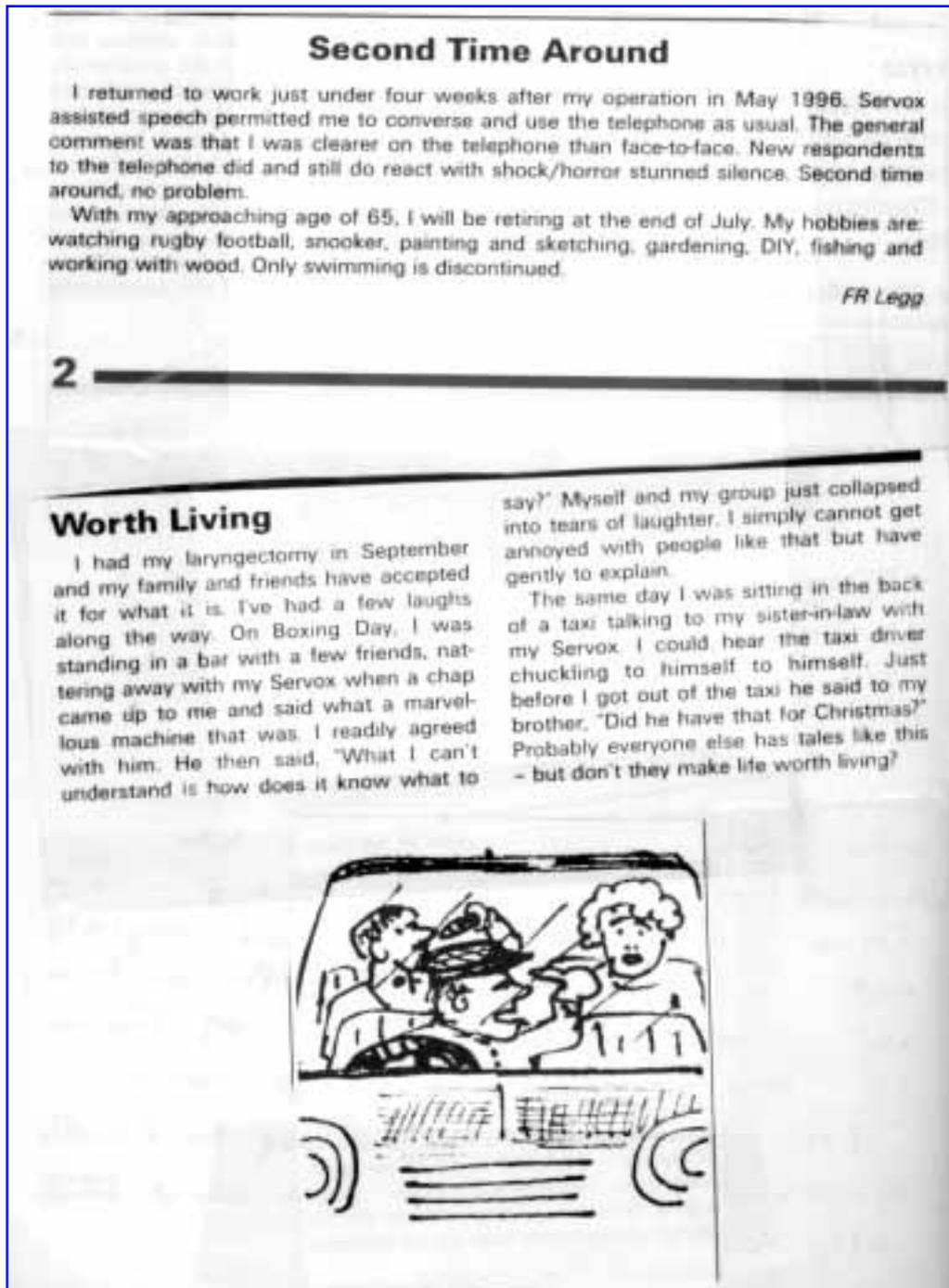
Frances, although herself an excellent, qualified speech therapist decided that we should all have a session with a more experienced and mature Coventry speech therapist called Bernadette Larkin who by chance was also the secretary of our support group. Derek, Frances, Bernadette and myself sat in this small room for an hour all sweating with the tension of trying to make Derek say the word “pop”. To our great relief he finally succeeded. We still joke about that afternoon to this day. Evidently, a third of people obtain the knack of oesophageal speech quite quickly, a third are like Derek was and have to struggle for a long period and a third never achieve it at all. Nobody can predict at the start, how any one person will progress.



During February, 1994 an electronic device called a “Servox” became available. Frances was amazed that Derek was able to use it straight away. He pressed it to the side of his neck and started speaking like the “dalek” space character. Evidently, the sound comes about from pressure on the base of the tongue. This device was brilliant.

At last, Derek and I were able to communicate with each other instead of relying on pencil and paper or lip reading. I remember that day as being a “high spot” of being a laryngectomy. He was still determined in spite of this aid, to achieve oesophageal speech. He became an expert at using a Servox and sometimes Frances requested that Derek came into the hospital to demonstrate and encourage other patients who for some reason were having difficulty in using a Servox. Derek had a special x-ray to

see if the valve at the top of his oesophagus was normal because of his slow progress to obtain “belly talk”. It was normal and to our great joy, slowly but surely Derek started to say two syllable words, then three syllable sentences such as “boy and dog” or “cat on mat”.



To this day, I still have pages and pages of words, sentences and paragraphs that Frances gave us to practise at home, day after day, until after two and a half gruelling years, he achieved oesophageal speech. He also used to practise whilst walking the

dog. People he encountered must have thought he had a screw loose, talking away to himself into thin air.

■ Phrases/sentences with *five syllables*

- ① Return to London.
- ② Say that again, please.
- ③ Please may I change this?
- ④ Is this seat taken?
- ⑤ In the hospital. •

- ⑥ The kitchen is full.
- ⑦ Make a cup of tea. •
- ⑧ Fill up with petrol.
- ⑨ Replace the lightbulb. •
- ⑩ Practice makes perfect.

- ⑪ Are you pleased with it?
- ⑫ Can I go with you?
- ⑬ Open the bottle. •
- ⑭ On your own again?
- ⑮ Behind the station.

- ⑯ Go on holiday. •
- ⑰ Open for business. •
- ⑱ Go out for a meal.
- ⑲ Book a holiday.
- ⑳ Is it ready now?

- ㉑ How long does it take?
- ㉒ Will you drive the car? •
- ㉓ Watch the performance.
- ㉔ He just can't see it! •
- ㉕ Play a game of chess.

Samples of
Speed Therapy
Home work.

I felt so proud of him. He became vice chairman of the P.C.C. at St. Lukes church and his “Servox” machine always awed everyone into receptive silence. Father John Twistleton appointed Derek to be a chalice assistant with special permission from the

Bishop of Coventry, Simon Barrington-Ward. As he had administered the wine to communicants he was able to say “blood of Christ” from the belly quite well.



Derek and Sylvia socialising on a coach holiday at Whitby in March 1996.



Derek riding the “Tissington Trail” in the Peak District in 1994

Life still goes on!

CHAPTER 9

As time passed, Derek's confidence increased. Gradually, instead of sending me up to the bar to order drinks or a meal, he would go himself and order using his "Servox". I can honestly say that people, after the first shock of hearing the unusual sound, were very accommodating and understanding. Some have even been interested enough to approach us and ask questions. We had more conversations since he had his laryngectomy than we ever had before.

We began to venture forth on short coach holidays and trips. On the first evening in a hotel or sitting with strangers I always broke the ice by saying "you will have to excuse my husband as he has no speech and has to use an electronic device". On every single occasion, people have rallied around and gone to great lengths to be friendly with us both. We have obviously been lucky as one or two other laryngectomees have occasionally met rejection. I have always personally held the view that if anyone cannot handle it, that is their problem not ours!

Derek became very well known locally in our town Bedworth as "the man who uses that thing". Acquaintances would stop him in the street and ask how his speech was progressing and have the patience to listen to his attempts at oesophageal speech.

We spent a lot of time in our caravan in the Peak District and received great support and friendship from our fellow caravaners. We found that Derek and I could still cycle on the flat cycle tracks in the area, such as the "Tissington Trail" and "the High Peak Trail", and also do some gentle hill walking.

We also found, we could still go ballroom dancing together. The greatest difficulty was making ourselves heard in a noisy room or whilst music was playing. We joined in the social occasions with the Second Chance group, going out for a meal or for the annual Christmas dinner in a restaurant or the odd celebration with food or wine in the conference room where we meet at Coventry and Warwickshire hospital. On another occasion Derek and I were invited with Peggy and Gerald Scott, another couple from "Second Chance" to attend a conference in Coventry with other types of cancer sufferers, carers and Macmillan nurses to confer with hospital managers about

good and bad treatment received and suggestions for improvement. This was very interesting and productive for all parties concerned.

Use Your Loaf

I had my laryngectomy about four years ago. For the first two years I was without a voice of any kind so I had to use a note pad to ask for anything I wanted. I was in a shop one day and needed a loaf of bread so I wrote on my pad: "Please could I have a thick, sliced loaf?" The shopkeeper took my pad, read it and wrote: "White or brown?" and handed it back. It made me mad so I wrote: "I can't talk - I'm not deaf." I found that, just because a person can't talk, people assume they are deaf. When they do talk to you they do so slowly and loudly. They also point to whatever they are talking about.

Still Got the Accent

For the last two years I've been the proud owner of a Blom-Singer valve which has changed my life. I can now answer the phone and ask for anything I need. I have been told that people can't tell that my voice has changed at all - and I still have my Hereford accent. I had the valve fitted at the Queen Elizabeth Hospital, Birmingham and haven't looked back since then. A few weeks ago, my local hospital asked if I would go and speak to a man due to have a laryngectomy. I said yes and when I got there, found he was someone I used to work with. He said that if he ended up talking half as well as me, he would be very pleased: which made me feel great!

Peter Walker, Hereford

Silence

A new laryngectomee visiting his Speech Therapist for the first time, wrote the following wry observation: "If silence is golden then I'm Fort Knox!"

IAL News

Cindy and Robert, my daughter and her husband, are cub leaders and after hearing that “Second Chance group” funds were rather low, attempted to raise money through their cub group doing a sponsored silence. They raised £60.



Meanwhile, Derek and I were requested to attend their meeting and we nervously attempted to give a talk about the club, laryngectomy and the dangers of smoking to 28 small boys aged between 8 and 11 years old. The interest and the intellect shown by them during question time astounded us. They had great fun queuing up for a turn on Derek's Servox! Robert plus two of the cubs joined our next meeting for the presentation of the cheque to our treasurer Ernie Dadley.



The National Association of Laryngectomees (N.A.L.C.) have been conducting an awareness campaign to counteract the widespread ignorance of the condition. The emergency services have been educated about the special needs of patients such as administering oxygen and performing the artificial respiration procedure. British Telecom have also been informed and sent tapes demonstrating how a person using a Servox or using an oesophagael voice sounds when making a 999 call. N.A.L.C. are fighting for our rights as after all, having no speech is definitely a disability and should be treated as such.



We will not pretend that being a laryngectomee or the wife of one is easy but with a lot of love, patience, good humour and determination, there is no reason that most difficulties cannot be surmounted and a near normal life lead.

I felt that Derek and I had at last reached the summit of "The Silent Mountain".



Still enjoying life to the full at a family barbeque.

PROVOX 2

A significant development has taken place in the last two months within the voice restoration field in that a new version of the Provox valve is now available.

We have called this valve PROVOX 2. Although there are a number of improvements to be seen in the new valve the most important point is that it is now **FRONT LOADING**.

Since its introduction into the UK six years ago, Provox has established itself as the Indwelling Voice Prosthesis of choice for many patients who have had a total laryngectomy. Its use has brought about a number of improvements for patients, compared with non-indwelling devices, such as easier maintenance, longer valve life and also, favourable results have been reported regarding the quality of voice. The placement of the valve has normally been carried out by the doctor, either in clinic or even under anaesthetic. The reason being that to remove the old Provox prosthesis and replace it with a new one has often been uncomfortable and, on occasion, even traumatic for the patient.

Work has been carried out between the Department of Head and Neck Surgery at the Netherlands Cancer Institute in Amsterdam by Dr Frans Hilgers and his team, and The Department of Biomedical Engineering and Development, at Atos Medical in Sweden headed by Jan-Ove Persson both to improve the Provox Prosthesis and to develop a method of placing it into the fistula which does not have the disadvantage of it having to be placed into position via the mouth.

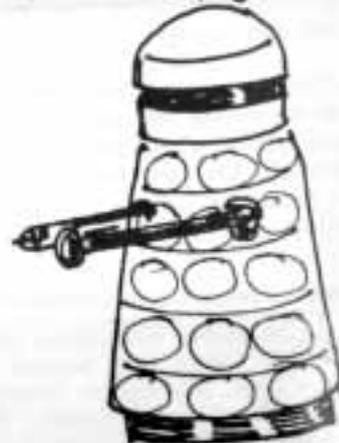
As a result of this work, the next generation of the Provox valve was recently launched in the United Kingdom.

PROVOX 2, whilst enjoying the same characteristics as the original prosthesis, differs in that it is now loaded from the front without the use of a guide wire. For many patients this will mean the end of the discomfort associated with changing the original Provox voice prosthesis. In addition there is the added advantage that the valve can be changed not only by the doctor, but also by the nurse or speech therapist with the appropriate training.

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"They keep telling
me I sound just
like a laryngectomee"



THE EPILOGUE

Sadly, Derek George Ireland died suddenly in Walsgrave Hospital on June, 28th 1996 aged 68 years. His death was not connected with him being a laryngectomee. A post mortem disclosed that he was completely free of cancer and that his death was due to congestive heart failure due to a long-term condition of mild angina diagnosed in 1981.

DEREK IRELAND IN THE LORD'S PEACE

Derek's death at 68 after an 8 year battle with cancer is a grievous loss to Sylvia & St. Luke's. Ironically his death certificate certified his victory over cancer as it confirmed his sudden & unexpected death came from heart failure.

It is a great test of character, determination and faith to have your voice removed, to use the "Servox" and to achieve "belly talk". Derek's character rose to all of this. He was able to serve as a Eucharistic Minister and as PCC Lay Chairman despite being clinically voiceless, so to speak. In recent months he was able to say "The Blood of Christ" quite well from the belly as he administered the Sacrament we shall celebrate on his behalf on Monday morning (11.a.m.).

The kids off River Close used to queue up to use his voice machine, the famous "Servox". Derek always got a hearing, that's for sure, at PCC for example. The machine awed everyone into receptive silence.

How we shall miss him - the resilient, courageous and ever humorous Derek Ireland, such a loving, caring man. Amazing and sobering to think that 10 days ago he was ripping down the bunting from the Fete with the other Church men. "In the midst of life we are in death.". One of his neighbours wrote on a sympathy card to Sylvia, "We shall miss Derek's happy smiling face". Indeed we will!

In September 1993, possibly a turning point in his battle with cancer, Derek and Sylvia joined our Annual Pilgrimage to the Shrine of Our Lady of Walsingham after which Derek wrote these words in the newsletter under the heading, "Jesus is bigger than Cancer":

"As we both knelt at the altar a small group of our friends from St. Luke's stood in a semi-circle at the back of us to watch. It was there in the company of my friends knowing that they were watching and praying for me that I felt the presence of God and I knew that He was going to strengthen me and give me the will to persevere and also look after my wife in the days ahead.

"When you have a headache, take aspirin. When you have a heartache take in Jesus".

As we his friends gather around his coffin at Requiem Mass we should take heart from Derek's words - that our prayers will strengthen Derek on his last journey and Sylvia in her bereavement. Jesus, who has proved Himself bigger than cancer, is also the Risen One we proclaim to be alone bigger than man's last enemy. May Derek rest triumphantly in peace with Jesus & rise to share the Lord's Glory. Amen.



I hope this book will continue to provide practical help and encouragement to all patients and carers.

Thank you from Sylvia Ireland
I wish to thank all the members of St. Luke's and clergy, wholeheartedly, who have given me such support and donations during the last few weeks following the sudden death of my husband Derek, not forgetting the organist for his musical contribution at the Requiem Mass.

I am pleased to say that ^{£450} ~~£425~~ was handed to the "2nd Chance Laryngectomy Support Group" and, hopefully, an item of comfort will be purchased for the E.N.T. ward at Walsgrave.

Yesterday I was delighted to receive a letter to inform me that Derek's corneas had been successfully transplanted into two blind patients completely restoring their sight enabling them to lead a normal life. One recipient was an 80 year old female and the other a 69 year old male.

Thanks be to God for his infinite mercy.

Sylvia Ireland



**Presentation of money collected to E.N.T. Ward and Macmillan Nurses
At Walsgrave Hospital, Coventry**

MINES WITH ORANGE SAUCE PLEASE!



GYPSY

A good listener and aid to speech therapy who sadly died 6 weeks after Derek.