

Lymphoedema help for my big brother by Sandra Bradburn

"In June 2020, during the worst health crisis of our lives I picked up the telephone to hear my big brother breakdown and cry.



Brother and Sister, Steve and Sandra Bradburn

Sandra desperately wants to help her big brother Steve manage Lymphoedema at home and improve his quality of life

At only 58 years old, he had just been told that he had extensive cancer of his larynx (voice box) and lymph nodes in his neck and without surgery he may die within 3 months. If that was not bad enough, they then told him that even if he chose to have the significant life changing surgery it may be too risky to operate as he would not survive if exposed to covid. He still braved to ask, "how life changing?" The reply, "you will never speak again, you may not be able to eat or drink normally, you will have to breathe through a hole in your neck, you are likely to lose your teeth and your hair, and you may also lose the ability to raise your arm!"



My independent, hard-working brother who had learnt from a very young age to cope with every challenge that was thrown at him, suddenly was at a complete loss, how could he decide...how could he go on... will he be given the opportunity to decide.... how can he be there to support those he loves? So many fears and it felt like such an impossible decision to make, the surgery could kill him, covid could kill him, but so could the cancer so eventually the decision was made and with love and support of family and friends he went for the operation in July 2020.



Steve with sister Sandra, Charlie, and Jan and giving his sister away

The surgery removed a considerable amount of his neck, including his voice box and lymph nodes and he then spent the next 4 weeks recovering in a covid secure room, with so much scary medical equipment and the terror of not being able to breathe or even vocalise his fears. However, he remained strong and could not wait to get back to his wife, Jan and his 2 dogs, Loki and Foxy.

He has had to learn how to live a different life. He cannot speak normally but has shocked all the clinicians by how quickly he has adapted to using an electrolarynx to speak with so he can be understood. Despite many setbacks he has been able to eat and drink again and is keeping his diabetes under control. After the initial fear he has now realised that he can breathe through his neck and is caring for it really well, as well as learning how to use the

medical equipment that is required. He was determined to support himself and his family financially and has returned to work even doing a lot of the manual labour himself.

BUT the nightmare for him is **LYMPHOEDEMA** – a common complication caused by the removal of the lymph nodes where an excess of fluid collects in the tissues causing excessive swelling.

"In head and neck cancer, lymphatic and soft tissue complications can develop throughout the first 18 months post-treatment, with greater than 90% of patients experiencing some form of internal, external, or combined lymphoedema.

Over half of those patients developing fibrosis."

Ridner SH, Dietrich MS, Niermann K, Cmelak A, Mannion K, Murphy B. A Prospective Study of the Lymphedema and Fibrosis Continuum in Patients with Head and Neck Cancer. *Lymphat Res Biol.* 2016 Dec;14(4):198-205. [PMC free article] [PubMed]

For Steve this swelling:

- Reduces the effectiveness of the electrolarynx making it difficult for his speech to be understood
- Presses onto his throat making swallowing really difficult and painful and so reducing how much he can eat and drink
- Reduces the size of the hole which he breathes through – can you even begin to imagine how scary this is?
- Reduces his movement in his shoulders and arms and causes significant pain when even doing the smallest of tasks

Lymphoedema cannot be cured but it can be very effectively managed!

How – by the use of DEEP OSCILLATION®



DEEP OSCILLATION® [1-25] is internationally patented electrostatic massage therapy – it is safe, gentle and effective and it has quickly become the treatment of choice in first line management of Lymphoedema

Steve was fortunate to have been loaned one of these units when he was first diagnosed, which Jan then used twice a day to massage the areas of lymphoedema making his life so much more bearable. Sadly, he has now had to return this to the lymphoedema clinic as there is only one machine available in the whole of the area Steve lives. He was then offered just one 20-minute session per week and the swelling; pain and complications listed above are becoming increasingly problematic. Now they have said that due to lack of resources and funding even this is to be stopped. He is scared and it is a horrendous situation to be in.

The DEEP OSCILLATION® plus attachments, which is purchased through a company called PhysioPod (<https://www.physiopod.co.uk>) costs £3,145.00

Steve has done so well and has been told by his lymphoedema nurse to try raising money to buy himself this as it is the only effective way to manage his lymphoedema, but as always Steve will not ask for help for himself, but I will, as he is my big brother who I love very much.

Throughout our lives, even as children, we have been involved in fundraising for various causes and now I ask for your help to see if we can make Steve's new, very life changed life, a little more bearable.

Thank you"

Sandra Bradburn



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