

My story

Hello darlings...

By Lucy Laing

When Phyllis Yates lost her voice more than 13 years ago she despaired of ever being able to say hello to her beloved granddaughters...



● Phyllis & granddaughters Donna (left) & Leanne

Ever since Leanne, 13, and Donna, 11, were born in 1994 and 1996, Phyllis has never been able to hold a conversation with them. She would play games with them as toddlers and give them cuddles, but has never been able to say 'I love you'. Phyllis said: "It was wonderful to be a grandmother and I loved my granddaughters but I've had to watch my granddaughters being born and growing up without being able to talk to them. It has been so frustrating. All I wanted to do was talk to them; ask how they were doing at school, and just to tell them that I loved them. We had a great relationship and my son John explained to them why I couldn't speak, so they were used to me being silent. But I really wished that I could speak to them and ask them about their friends and school. And most of all I just wanted to tell them that I loved them."

Phyllis, who is 73, lives in Lowestoft with husband George, a former crane driver. She had been able to speak perfectly normally until she went to a party at her sister's house in 1993 and woke up the following morning unable to speak.

She said: "I opened my mouth the following morning and no words came out. I couldn't understand it. I had been able to speak perfectly the night before, yet now I couldn't make a single word come out.

It was terrifying. I couldn't tell George what had happened, but he could see that I couldn't speak."

Phyllis and George went to see her GP and were referred to an ear, nose and throat specialist at her local hospital, but neither could provide any answers.

"No one could understand what had happened to my voice. I was treated by a psychiatrist as it was thought my problem was psychological but that didn't work either. I was even given a bottle of indigestion remedy, but nothing worked. My voice never came back," she added.

She spent the next decade unable to answer the phone, answer the door to anyone or even go shopping. "It was just impossible. George had to do everything and I felt completely helpless. I couldn't go shopping because I couldn't ask for anything, or communicate with any of the shop assistants", she said. "I got very depressed as I'd gone from living a normal life, to living in a shadow, without any independence. George got very good at lip reading. He could understand what I was trying to say just by reading my lips. So I didn't have to resort to writing things down for him. He would always understand me. He was a rock of support – I couldn't have done it on my own."



My story *continued*



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● *George & Phyllis*

In October last year, she saw a specialist in Harley Street, London for a private consultation and, after years of not knowing what was wrong, Phyllis was finally diagnosed with laryngeal dystonia, a neurological voice disorder that involves involuntary spasms of the vocal cords, causing speech interruptions, or in the rare case of Phyllis, the complete disappearance of her voice. She said: "I was so shocked when I was diagnosed, but it was a relief too, after years of doctors just believing that it was all in my head. Finally I had some answers."

Phyllis underwent her first treatment in May this year where she was injected with botulinum toxin A into the voice box, which has released the muscle spasms. Her second injection resulted in some voice improvement. Then after her third injection two months ago, she finally got her voice back properly. She said: "It seemed so strange hearing my own voice again. I'd almost forgotten what I sounded like. I was so thrilled and so was George. My voice was wobbly at first as I'd been so out of practice, and I was only able to talk for a few minutes at a time. Also it came out very loud at first – I was almost shouting – as I didn't have much control over my vocal cords.

But the first thing I wanted to say was 'hello darlings,' to my granddaughters. They were so shocked when they heard me speak as they had never heard me before. Now I ask them all the things that

I've always wanted to ask them and they tell me how they are getting on at school, which is wonderful."

Phyllis has now got her voice completely back, although she is still having the injections every four months. "The specialist didn't know whether the treatment would work," she added, "but it has been marvellous and I am very grateful. It has given me not only my voice back – but my life back too. The only thing is that I can nag George as much as I like now. He's had a quiet life for 13 years – and I've got a lot of catching up to do!"

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- Phyllis's treatment has taken place in the **Harley Street Voice Centre at the Harley Street ENT Clinic** in London by Mr Gerald Brookes, Consultant ENT Surgeon. The clinic's ethos is that its state of the art diagnostic and treatment facilities should be available to all patients. Despite being a specialised unit in a private clinic, the Voice Centre also treats NHS patients for NHS tariff rates funded by their Primary Care Trust (PCT). Phyllis's treatment has therefore been paid for completely by her local PCT. Mr. Brookes commented:

"This lady's voice result is as close to a modern day miracle as you can get. She has a severe form of a very uncommon type of laryngeal dystonia. Over the last 20 years I have only previously treated 2 or 3 similar dystonia patients with complete loss of voice in a personal series of nearly 700 cases. I am delighted with the outcome of Phyllis's treatment and for the new lease of life it has given her."