



## OMFS About Face - Newsletter No. 7. Winter 2005 - 2006



Welcome to this, our 7th Newsletter. In this issue we concentrate on "Eating" and "Speaking" after invasive surgery. We also have an article from Mr. Leo Cheng on his experience working aboard a "Mercy Ship". We always welcome feedback from our readers on our newsletters and web site content. If you have any comments, ideas etc. please email us at [info@omfsaboutface.org.uk](mailto:info@omfsaboutface.org.uk) or ring Peter on 01760 724120.

### EATING AND SPEAKING!

After complicated and invasive surgery, facial cancer patients still have two huge problems to overcome. Both are important life skills and need to be mastered before patients can properly return to society. EATING in a socially acceptable way and SPEAKING intelligibly are enormously difficult to achieve and cause a great deal of stress and anxiety to those involved. In an earlier issue we touched upon the difficulties of returning to eating solids and now we should like to share our experiences with you regarding the problems of regaining speech. Mastering it can cause a lot of distress, but we hope to dispel some of your concern and worry.

#### JOYCE BLAKE tongue cancer

When I regained consciousness in the Intensive Care Unit my first and worst thought was how could I let anyone know how I felt when I couldn't talk? The tracheotomy in my throat which enabled me to breathe also prevented me from speaking. I found too that I was not getting enough air through and had trouble letting the nurse know. I had to spell it out from words on a clipboard. The next morning the nurses placed a nebuliser in my throat which made my breathing easier. Later, when the tracheotomy was removed. I found I was frightened to speak, but I was helped to overcome this by the speech therapist who worked wonders! Trying to move my tongue to form words was very awkward so I was asked to move my tongue from side to side and backwards and forwards. I found it difficult because the flap of skin on my tongue was coming off and after being home only a few days I had to return to hospital to allow Mr. Cheng, the surgeon, to remove it. (Then I could drink soup a lot better!) I went to the speech therapist for a while and began to speak a lot more clearly but with a lisp which only I seemed to notice. It's wonderful how the human body repairs itself after an operation and I also think positive thinking helps. I hope my words help others to overcome such a worrying time. It can be done.

#### MARLENE GAUNT tongue cancer

I worried more about learning to speak again than regaining my eating skills...after all, I could do that in private and 'dribble and slobber' my way behind closed doors! More than anything, I was desperate to return to singing with my ladies' choir and re-experience the joys of shared conversation with friends and family. The hospital therapist coaxed and encouraged me although at first I thought she was asking me to do the impossible! I repeated her words and exercises endlessly and other patients in the ward even devised a little poem for me. I continued at home and read aloud passages from my favourite books and poetry. I found the words had to be formed far slower or everything emerged as "gobbledy- gook"! Out shopping I quickly became embarrassed when shop assistants asked me to repeat myself. Words including "S" or "SH" sounded watery and splashy..

My tongue felt too big for my mouth and constantly sluggish and reluctant to move. Five years on there is still a partial paralysis on the left-hand side of my face and it helps to practice facial exercises...usually when I'm out driving my car. Thinking about it, I must present a frightening spectacle to other motorists when they see my hideously contorted face! I realise, however, that it is only time and constant repetition of exercises that help you to regain the gift of speech. And I think of it as "a gift" as, without it, we are woefully impoverished. I still find it difficult to eat and speak at the same time, so I try to avoid this. I must have reached a certain degree of intelligibility as I've spoken twice at conferences on the subject of facial cancer and also broadcast on Radio Scotland. Friends taped this for me and, although it was clear, I must have enunciated my vowels too carefully as it sounded a bit too "top drawer" to my liking! To others still on that long, uphill struggle I would say don't give up; don't despair and if you are still having problems ask your surgeon or G.P. to send you to another speech therapist. Good luck....



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### **JEAN HASLOP tongue cancer**

I found the speech therapy in hospital very helpful and I enjoyed doing the exercises. Later on, various sounds were given to me to try out. When the small amount of saliva I managed to find became as thick as glue, the speech therapist came up with a good solution....she got me to breathe through my mouth over hot steam. Much care was taken over this and, at home I used my Pyrex jug so I had a handle to hang onto! The therapist was also very good when I had a job swallowing and arranged for me to have a videoscope to watch me swallowing. Nothing abnormal was found but they advised me to drink more water. I still do my facial exercises as I find it loosens my face muscles.

### **ANN JOHNSTON jaw cancer and a recurrence.**

Except for the odd bout of laryngitis I'd never thought much about the miracle of speech and for sixty years words came out of my mouth effortlessly – even after my first operation for jaw cancer. Things haven't been so easy since my second operation two years ago. I've had difficulties because I've lost the full mobility of my tongue (tissue grafts had to be attached to the floor of my mouth) and there is still some weakness in my lips after the facial nerve had yet another battering though this is getting better. Initially I had problems because I had no front teeth to put my tongue against, but now I have a bridge with a couple of teeth attached and it's amazing what a difference that has made. When I started speaking I often had trouble controlling excess saliva (I know I'm lucky not to have a dry mouth) and I'm constantly aware of being too slushy – a word I can't say without sounding too slushy! It still comes as a surprise that it's so hard to speak clearly. Since leaving the hospital I've had very little help with my speech – just three sessions (with three different SALTs over the course of a year). By my first appointment I was managing quite well, especially compared with the hard-pressed SALTs' other patients, so I felt I couldn't ask for much support. I could, for example, cope with the telephone. I was given exercises for my tongue and lips which I continue to do in a rather haphazard way. There are no SALTs at the clinic I attend now and, with hindsight, I wish I'd had someone regularly to push me as I did for my shoulder from my physiotherapist and surgeons. Despite having a piece of my shoulderblade

removed and grafted in place of my lower jaw, I've now regained the full use of my arm. Could I have done the same for my speech? I'm now wondering about seeking help from someone who works on diction with actors rather than in a medical setting. In fact my problems are far more apparent to me than to other people. I do have to repeat myself more often than in the past, but I soon learned not to become tense and just to try again. Luckily I don't have to speak for a living, but I have managed to speak in public about my experiences as a mouth cancer patient, albeit to sympathetic audiences. The real test was when I was asked to take part in a listeners' panel on Radio 4's 'Feedback' programme – nothing to do with cancer. I felt I had to warn the producer, but she said, "Well, you sound perfectly fine to me." I DID sound normal and doing the broadcast gave a huge boost to my confidence.

NOTE If you want to learn more about Ann's courageous story please visit the "Saving Faces" website ([www.savingfaces.co.uk](http://www.savingfaces.co.uk)) It's a lesson in stamina and endurance and wonderfully inspiring.

### **FRANK OSBORN. Tongue cancer**

It is now just over four years since I had surgery for tongue cancer. At the outset, Mr. Cheng, my surgeon, advised that there was a probability that my speech would be affected. This was quite worrying as like most people the thought of any impediment is quite daunting. In the first six months after the operation I found my speech was slightly slurred and I tended to speak more slowly than I used to. Pronunciation of certain words was difficult and, even today, I find that I occasionally have to repeat a word. But, overall I am quite normal. In retrospect, I think it is better to try and speak AS MUCH AS POSSIBLE in the early days as this helps to build confidence and also allows the tongue and face muscles to adapt to their new conditions.

(Please see "A Sadder Note" on Page 3 Column 2 of newsletter)

### **AN ACKNOWLEDGEMENT**

We owe a debt of gratitude to Joyce Blake, a Support Group member, for her third donation to our Charity, as a result of a car boot sale and a separate Yard sale. Thank you Joyce.



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### DAVID WILLIAMS .Tongue cancer

I'm a University professor. What does a professor do these days? Does he or she sit in their study thinking and writing great thoughts? Not any more! Professors raise research funding – they call this selling or business development in the outside world. They lead and project manage, they work with collaborators, they mentor and advise. They occasionally lecture, teach and interact with students. They address large and small groups of people in both very formal and informal situations. They seem to have to talk all the time!

You might think that all this talk is a pretty strange job for someone who had oral cancer and the surgery that went with it nearly five years ago now. How does one manage without a chunk of tongue, a few less salivary glands and the scar that was left behind when the offending piece of tongue went to a better place?

Obviously one does manage. You get on with the job! We all know about getting on with it. Speech and language therapy was very important to start things rolling again (thanks Lee). Regaining confidence in public speaking was important, setting goals to do the things you used to do routinely and achieving them progressively was critical.

What about doing these things routinely? Yes, you can do it. Yes, your tongue and mouth will get sore and go “wooden” on you. When you are selling the adrenaline will kick in and you won't notice your tongue, but other times you will. That scar is still there. Make sure you drink, make sure you eat. Eating still gets things moving again. It relaxes and lubricates things. Have a green apple before you give a talk. Eat lots of grapes – especially at the end of the day. We always have a fridge full of grapes, I think we keep a couple of stalls on Loughborough Market in business. Grapes are just the right size for getting the tongue moving again and that juice really makes a difference. Take a bit of quiet time and just sit to let your mouth have a break. Brushing your teeth with toothpaste you find comforting helps. I still use calendula toothpaste as soon as I get home at the end of the day. Remember to take your toothpaste while you are traveling, do this for a long trip and for a long day out. Brush your teeth before you have that business dinner in the evening after a long day's talking. Be careful with the wine with dinner, especially if it's white, take water with it, the alcohol will make your scar sore.

Katy, my wife, says that I have two sorts of speaking voice. The first is my lecturing (or “trying” voice)- according to Katy, I even have a special face that I pull. The second is my family or “not trying” voice. I also used to mumble and I guess I still do. I know that I need to try as hard at home as I do at work, but when it's the end of the day and I'm tired.....

### A SADDER NOTE.

It was with shock and great sorrow that we learned of the death of one of our most loyal and committed “Aboutface” members, Frank Osborn who died at the age of 71. Although he was impaired by failing health, one of the last things he did was to forward his thoughts on regaining his ability to speak. Frank had the reserve of many an English gentleman and was reluctant to talk about his illness so other Support Group members were unaware of the severity of his secondary cancer...cancer of the pancreas which spread to his stomach. Several years earlier, Frank accompanied his surgeon and two other face cancer patients to share his experiences with an assembly of Sixth Form pupils at a private school in Cambridge. We are told that, even today, the students still talk about Frank's speech, made all the more moving by his cool and detached delivery. He was a warm and affectionate man with a huge zest for life, taking part in his home town's activities, particularly art, music and drama and was also a talented painter in his own right, often exhibiting pastels, water colours and oil paintings in local galleries. Other hobbies included golf and also a dedicated love of jazz and swing. It was his close association with Cy Payne's Swing Band of Downham Market which led the band to make a donation to “Saving Faces” last year. We shall miss our dear friend and extend our heartfelt and most sincere sympathy to his widow, Jean and family.

### ANOTHER ACKNOWLEDGEMENT

A big “Thank You” to Watlington Players and their producer, Kate Carpenter, for their generous donation to “Saving Faces” following a successful production of “Beauty and the Beast.” Surgeon, Leo Cheng, together with his wife and family and several “Aboutface” members were present one evening and afterwards met the cast and congratulated them on their performances.



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### THE MERCY SHIPS

Bringing hope and healing to those without hope of paying for treatment

Mercy Ships is an international charity providing floating hospitals to serve the poorest of the poor in the developing world. Anastasis is one of 3 MercyShips and is the largest non-government hospital ship which is not tied to one location and it can visit many needy countries. Leo Cheng, our Consultant Oral and Maxillofacial Surgeon, spent 2 weeks on the Anastasis performing specialist surgery to face, mouth, head and neck, and he is going again next year.

Leo flew to Cotonou, Benin in West Africa to board Anastasis and offered his skills and time with other surgeons and nurses to provide corrective and reconstructive surgery to the mouth, face, head and neck. Other surgery was also undertaken on board to change lives and included orthopaedic surgery, ophthalmic surgery especially for cataracts and squints, gynaecological surgery for a serious consequence of obstructed labour, goitre, hernia... etc. Every crew member including the captain, surgeons, nurses, chef, engineers, electricians...etc have to pay for their own accommodation on board, and transport to and from the ship. Hence all the donations to the Mercy Ships go directly to the maintenance of the hospital ship and patient care.



Anastasis – harbour of Cotonou, Benin

Leo Cheng  
Consultant Oral and Maxillofacial Surgeon



Pulleys ropes, stretcher, manpower, etc are required to carry a patient between floors.

Anastasis' next destination is the war-torn Liberia in West Africa. In addition to thousands of operations offered on board the ships, community development projects take place in the surrounding villages. Following the example of Jesus, Mercy Ships seeks to become the face of love in action: bringing hope and healing to the poor, mobilising people and resources worldwide.

Caribbean Mercy, one of the ships, is currently providing relief to victims along the Gulf coast of America following Hurricane Katrina.



Two Maxillofacial Surgeons working together to repair facial defect of a child

Word of wisdom from the chief executive of Anastasis, 'If you have a problem, think, how does it fit into eternity.' 'If it is possible, then why not say yes.'