

Welcome to the first edition of the G-A-P Newsletter - produced specifically for people who have been treated for Head and Neck disease. This Newsletter has resulted from a meeting of a group of people who are grateful for the treatment and support they have received, and who wish to offer encouragement to people in similar situations, making them aware of the work done by the Get A-Head Charity and by passing on information based on their own experience. All feedback would be welcome and contact information regarding feedback can be found at the end of this Newsletter.

A group of volunteers met with Louise John and Anne-Marie Patrick of Get A-Head (GAH) and decided that a Newsletter for patients should be trialled as a way of contacting H&N (Head & Neck) patients - and that two meetings a year should be arranged, to which all H&N patients would be invited, at which, for example, a speaker would talk about one kind of Head and Neck condition. It was also thought that it would be useful to offer to arrange some events where patients could meet and enjoy time together.

In this first G-A-P-Newsletter some of that group of volunteers introduce themselves, some events will be suggested and some questions answered.

You are invited to read the Newsletter, make use of what is offered **and please offer feedback.**

Janet Wiggins - A Patients story

Nearly sixteen years ago, after a series of throat problems, I was diagnosed with having a tumour on the base of my tongue. I had never smoked, or drank heavily, at any time of my life. So to discover I had this illness was quite a shock. Plus it was a worrying time for all my family and friends. I had two young sons and a husband.

After a series of tests, scans & biopsies to confirm the extent of my illness, I was referred to Mr John Watkinson at the Queen Elizabeth Hospital (QEHB). A major operation was necessary, which was undertaken by Mr Watkinson and his team, where they removed the tumour, followed by a stay in hospital for some 2 weeks. This was a pretty quick recovery period, due to the most part of the great care and attention that I received, and a good positive mental attitude.

Some weeks later, after recovery at home, I then underwent radiotherapy, which was harsh, but necessary. The radiotherapy treatment and recovery was very hard, and time consuming, as family assisted me by taking me back & forth every day for treatment, until finished.

Weeks and months later, I recovered sufficiently to return to work, and try to get some normality back in my life. However, because of the radiotherapy, the side effect was that as I had very little spittle, and an incredibly dry mouth all the time, my teeth were being damaged. Plus eating was a major problem because of the radiotherapy. Things I could eat with ease before, I couldn't eat now.

Anything with citrus, sauces, salads, spicy foods etc., I could not now eat. So the on-going issue was, to be able to find something to eat, and enjoy it. A problem I still have today, but with time I have discovered what I can enjoy, although with limitations.

The discovery of the illness I had was a shock in itself, and the recovery of the operation that followed was long and hard. However, there was a host of other things I had to deal with, which I never accounted for family impact, eating and diet, stress and worry, dependency on family and friends, side effects of radiotherapy etc.

However, having put up with all that was thrown at me I recovered and was able to lead an active life, go back to work, be a Mother to my children, and a wife to my husband. With the support of my friends and family, they got me through the dark times – of which there were many.

To show our appreciation of what Mr Watkinson and his team did for me, before, during, and many times after treatment and recovery, my husband and I decided to undertake a charity walk weekend every year for the Get-A-Head charity. That was 11 years ago – and we've done walks for charity every year since, with work and ex work colleagues participating, raising over £11,000 to date for a great cause.

If anyone has just been diagnosed with a similar illness, or is currently being treated, or recently treated, then if you would like to contact me for advice, or ask about experiences, then you can contact initially at ken.wiggins@hotmail.co.uk, and I will be happy to respond.



CHRISTMAS PARTY for
*patients and their family and
friends*

FRIDAY 6TH DECEMBER
19.00 - 23.00

This year's party will be at the Edgbaston Priory Club, Join us for a free, fun-filled festive celebration. There is no charge for this event and we hope that many of you will attend.

Please book via the Get A-Head office.

Families coping with illness.

When a member of your family become ill with a serious life threatening illness, such as head & neck cancers, the impact on the family members can be devastating, leading to problems and issues that you cannot imagine, at a time when you are coming to terms with news that your loved one is seriously ill, and a time of great worry and change beckons.

As in our family case, Janet, my wife became seriously ill with cancer. She was diagnosed approximately 16 years ago with a tumour on the base of her tongue.

When you have children still at school, in our case two boys, one has to look out for them, take the worries and concerns away from them best as one can, whilst looking after the house, the shopping, the bills, and the myriad of all the other things that you cope adequately with, when with your partners. Then of course one has to make out you are coping OK to your partner, so not to burden them with additional worries they don't need!

Families played a big part in coping with the whole experience, and getting through those weeks of uncertainty – Mothers, Fathers, Brothers, Sisters, friends, neighbours yes, they all played a part, for which we would be forever grateful.

When things settle down weeks or months later, there are still tasks ahead, as life in some cases will never be quite the same as it was before – learning to cope with the illness the loved one has had, the after effects of the illness, and of course dealing with the future.

One of the best ways to try to overcome all those fears before, during and after illness, such as head and neck cancers, is to share those fears and apprehensions with hospital trained staff, or indeed people like Janet the patient, or myself the husband, who have experienced those fears, and know first-hand the experiences patients and family members are going through.

If you wish to share those fears, or ask about anything related to coping with a serious illness such as head and neck cancers, feel free to email me at ken.wiggins@hotmail.co.uk

Life after a Laryngectomy

It began with a groggy throat on a Baltic cruise to celebrate our Ruby Wedding in August 2009. The voice at times seemed to improve but eventually I went to see my GP in January 2010, and was immediately referred to our local General Hospital for investigations. Discovery of what was thought to be a benign polyp led to two attempts to sort it out by laser treatment – which did not work. 35 treatments of radiotherapy followed after that – again, unfortunately that did not work and I was referred to Mr Pracy, ENT consultant at QEHB.

I was admitted to Ward 408 for a procedure 23rd August 2011. That had been preceded by very useful and informative meetings with Mr Pracy, his specialist nurse and one of his speech therapists who I had had the fortune of already having met at my local hospital. A successful procedure led to a rather less successful time of healing. After ten weeks I went home, where it was good to be – but for all this time and for a further period of time I was unable to speak or to eat. I actually had two Christmases when I could not eat.

I returned to QEHB 24th February 2012 for a graft to be done – another four weeks on 408 - and eventually a successful swallow test on Maundy Thursday that year – so at last I was able to eat and life since then has been getting back to normal. Speaking is now relatively straightforward – singing, which I used to do a lot, is not possible – eating has over time become much easier, though it is a little slow and occasionally things stick!! I now lead a very normal life and very happily play 18 holes of golf twice a week if time allows. We also go on holiday in the U.K. and abroad – and visit grandchildren regularly.

What helps? An amazing team at QEHB that filled both my wife and I with confidence before the procedure... and that has continued. My wife, who is a nurse who trained at QE some years ago, has been wonderful. Friends and members of our church have given support and patience that has helped both of us. Additionally I am very pleased to say that all people we have met have helped a great deal -

we have on purpose wanted to lead a normal life and people in shops, restaurants, on the phone, have been very patient and considerate.

My advice? Nobody wants this problem – but being on 408 was a privilege, support from all at QEHB has been tremendous – going out and doing things has been crucial and very rewarding. I would urge people in a similar situation to do the same – do not worry about feeling a bit different from everybody else – start doing things again and hopefully you will be surprised by what you can achieve.

David – dms27@btinternet.com

QUESTIONS & ANSWERS

It was felt that it would be very useful to invite patients and carers to submit general questions about their condition or treatment – and Get A-Head would seek an answer from medical staff at QEHB.

Q. During the annual check-up for Differentiated Thyroid Cancer, what is the purpose of the Thyroglobulin blood test? What is the normal reference range? What does it mean in respect of further possible investigations or treatment if your result is outside of the reference range?

A. Thyroglobulin is a normal protein product of Thyroid function and is present in everyone who has a thyroid. It acts as part of the storage mechanism for thyroid hormones which are released on demand. It does have a normal range in blood but we do not use that clinically. Its role comes in the management of patients with Differentiate Thyroid Cancer following treatment with total thyroidectomy and radioactive iodine ablation. In this setting, all thyroid (normal as well as cancer) should have been removed and therefore no serum thyroglobulin should be measured, therefore what we are looking for at the annual check-up is an undetectable serum thyroglobulin. If it is raised the possible causes are interference with the assay from thyroid antibodies, an erroneous lab result, functioning residual normal thyroid tissue, non suppressive doses of thyroxine or residual or current thyroid cancer.

Professor John Watkinson



A GOLF EXPERIENCE

For players of any level!
Good fun, good exercise,
chance to meet people.

Where? Gaudet Luce Golf Club, Droitwich, Worcs.

What? 9 or 18 holes on a parkland course - OR a taster session on the driving range and Par Three course that has been offered by the golf professional at the club - all equipment for this taster will be provided free of charge.

Who with? We can play as a group – or I can contact people who have supported me and will happily play with us on this occasion.

Food? We are very welcome to make full use of the clubhouse facilities.

When? I will need to arrange a date/time when I know how many people would like to take part.

Cost? I would guess around £20 for 18 holes

Please contact David on dms27@btinternet.com

FEEDBACK to the Patient Group will help a great deal. You may have ideas for the Newsletter or for meetings.

You may want to be put in touch with volunteers, if so, please contact the Get A-Head office either by email, telephone or by post:

getaheadcharity@uhb.nhs.uk

Tel: 0121 371 5046

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Room 23F, 4th Floor, Nuffield House,
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B15 2TH

Thyroid Cancer Patient and Volunteer

My name is Janet; I was diagnosed with Papillary Thyroid Cancer with local nodal spread at the age of 30 in February 1994. I became a volunteer for the GAH in 2009 and my main role at that time was to be a face to face patient contact for other thyroid cancer patients in the ENT out-patients clinics. I was often asked if the cancer and treatment had any effect on my fertility. I was lucky, at the time of diagnosis I had two young children aged 4 and 2 and after the safe period of having my treatment I went onto have a healthy third child in August 1996 without any complications. I am more than happy to talk to patients or their family and friends if this will help.

Get A-Head is a charity based in Nuffield House, QE Hospital, Birmingham. The charity seeks to raise money to assist the work in the field of Head and Neck cancer in as many ways as possible. Over the last 12 months Get A-Head have been able to:-

- ▲ assist CyberKnife funding by donating £100,000 to the QEHB Charity Cancer Appeal
- ▲ help purchase 3D Cone Scanner for the Maxillofacial unit at QE, for use in ENT and Maxillofacial Departments
- ▲ help funding for a 2nd Year of research into MTC (Medullary Thyroid Cancer)
- ▲ provide funding for 5 Electro Larynxes, for both City Hospital and Heartlands Hospital
- ▲ assist purchases of a OAE/Tympanometer for use of specialist hearing tests in the young
- ▲ Grants to pay for attendees to annual BAETS annual Scientific Meeting in Rome

Donations to Get A-Head can be made by contacting their office.