



Awareness Support Information

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a Founder Member of the Federation of Prostate Patient Support Groups, known as 'TACKLE'

Newsletter No. 76 - December 2020

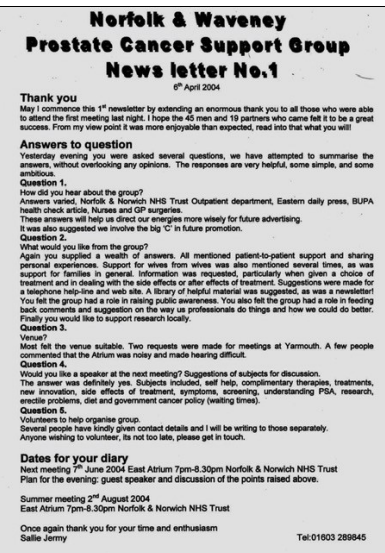
Final edition... It's time to sign off

Regrettably, this is the 76th, and final, edition of our quarterly Newsletters.

When this support group was formed, almost seventeen years ago, the internet was in its infancy in this country and there were very few sources of information about prostate cancer. So, hopefully, our Newsletter served a useful purpose for our members. (See facsimile of first edition below)

So much information, on any subject you care to mention, is now at the finger-tips of most of us on the internet. We readily accept, of course, that not everyone embraces the internet, but these are becoming less with each passing year.

The great majority of our members choose to be communicated with via the internet, mainly using the device of emailing. They also have online access to our website and Facetime page. These members also save the Group the cost of printing, packaging and postage, by reading the Newsletter and other information online.



In the September edition of this Newsletter we carried an appeal for articles from members, telling us of their own experience of prostate cancer and, very surprisingly, we did receive a couple of contributions, both of which appear in this edition. We say 'surprisingly', because such appeals in the past have not been successful.

Unless you have ever had to edit a newsletter, such as this, you will not, perhaps understand just how difficult it often is to fill four full pages. In the

past we have had to use a lot of copy from other publishing sources, mainly national newspapers. Such recycling of material is far from satisfactory and is something we have often been loathe to do.

From time to time we have been able to highlight the fundraising of supporters of our support group and this has given us much pleasure to do so. Now, the Covid-19 pandemic has pretty much put paid to our fundraising, as you will see when our annual accounts are published next April. So, with no fundraising activities there is very little to tell you about.....sad but true.

Over the past almost sixteen years we have benefitted by the talented services of a number of editorial volunteers; the longest-serving and innovative of these being **Chuck Lyons** and the late **David Paul**.

They, like us, must have often found it difficult to fill the pages with interesting-to-read editorial. In truth, they had it more difficult by having to produce six editions a year. When we took over it was reduced down to only four, quarterly editions each year, so we had it somewhat easier.

We would like to use this opportunity to say a big 'thank you' to Chuck and to wish him well in his current fight against ill-health. We appreciate that the cessation of the Newsletter will be a disappointment to you, Chuck, but we hope that you will, more than anyone, understand why this decision has been made.

You will still be able to keep abreast with all that is happening in the sphere of prostate cancer. Any copies of the magazine 'Prostate Matters' will still be mailed out to those members not using the internet. All others will be notified when this publication, from Prostate Cancer UK, is available to read online.

As regards notifications of our meetings we will, during December, send out a **2021 Calendar of Meetings**, to our internet-user members, which can be printed-off and retained for future reference. All other members will be mailed a copy of the meetings' calendar for next year.

In conclusion we would like to say that it has been a privilege to serve you, producing the Newsletter over the past just over four years; especially to the many who have provided us with the material to tell you about their fundraising efforts. Stay safe during these difficult times

Geoff Walker - Editor **Ray Cossey** - Production design



Then there were three



Norfolk & Waveney Prostate Cancer Support Group have donated transperineal medical couches to both the James Paget Hospital, Gorleston and the Queen Elizabeth Hospital, Kings Lynn.

Last year the support group donated this type of couch to the Norfolk & Norwich University Hospital.

To aid the detection of prostate cancer, transperineal biopsies are performed through the perineum, (the skin between the scrotum and the back passage), under a general anaesthetic in theatre, where around 30 passes of a biopsy needle are made.

This is the current 'Gold Standard' approach, which has a lower infection rate and better access to the prostate, whilst taking more biopsies.

Until recently the procedure was to undertake transrectal prostate biopsies, involving 12 cores of tissue being taken through the back passage, under local anaesthetic in outpatients. With this procedure, there is a slightly higher risk of infection, (due to passing through stool) and, in larger prostate glands, some parts may be inadequately sampled.

As well as having to make a number of punctures in the perineum, there are also the risks associated with any general anaesthetic.

Furthermore, the demand for theatre space currently may leave the waiting list at several weeks.

This new development now allows clinicians to take prostate biopsies via the transperineal approach, but under a local anaesthetic and, more importantly, in the outpatient setting. This procedure allows patients the use of a Couch where, at the most, only four punctures are made through the skin.

The biopsies can be undertaken within days of a clinician seeing a man with suspected prostate cancer. Not only will this help relieve anxiety, as there will be no wait to biopsy, having seen a specialist clinician, but hours of theatre time will be freed-up, so other, perhaps, more urgent procedures can be performed.

This innovative technique now available at the region's three hospitals, will benefit many thousands of men in years to come

The Couches were purchased, on behalf of the JP and QE hospital's Urology Departments, by our Support Group at a cost of £27,440, but the annual saving in theatre costs, for the two hospitals is several hundreds of thousands of pounds. The couch at the N&NUH is estimated to have already saved over £300,000 annually on theatre costs.

John Ladd, chairman of Norfolk & Waveney Prostate Cancer Support Group, said: -

"We are indebted to all the individuals, firms and organisations throughout Norfolk and Waveney who have donated the monies, which has made possible our Support Group's provision of couches, to each of our region's three main hospitals.

We have already seen the tremendous benefits to patients, by their use of the couch at the N&NUH, and now we are especially pleased to be able to help both the JPH and the QEH, so that all men, in the whole of Norfolk and North Suffolk, will have the 'Gold Standard' for prostate biopsies.

They deserve no less. This substantial donation has somewhat depleted our coffers and during the Covid-19 pandemic we have seen donations reduced to virtually nothing, so more fundraising, to aid our patient work, will be called for during next year."



The Biopsy couch, now in use at the N&NUH

Paul Dennis - Delays To Prostate Radiotherapy during Covid

December 2019, Gleason score 10, T3/4 staging denoting disease outside the prostate. At age three months short of 70, not a good early Christmas present, but my bone-scan showed no bony metastases or nodal disease; bad enough, but not as bad as it could have been. Prescribed a minimum of three months hormone treatment (ADT) followed by radiotherapy (EBRT) with a brachytherapy boost (HDR).

I'd had regular PSA checks and at least two digital rectal examinations (DRE) by my GP and was aware I could be at an increased risk of prostate cancer (PCa) because of my familial link; my father and his brother had both suffered from PCa. I was eventually referred to the One Stop Urology Clinic in September 2018.

Following a further DRE, although my prostate was shown to be enlarged, the consultant said he was not worried about anything being medically untoward. I was offered a transurethral resection of the Prostate (TURP) or a Urolift operation. I opted for the latter, being less invasive, which was performed in March 2019 after which my ability to urinate improved, but not as much as I had hoped. I was still having difficulty at my post-op review. Further surgery in the form of TURP, or Holmium laser enucleation of the prostate (HoLEP) was suggested. Being wary of more surgery because of the recovery time, I was referred to the Continence team instead.

Mid 2019, my PSA was raised but it was thought to be the result of my earlier surgery. It was re-checked three months later and in October it was still raised. My GP recommended a further PSA test in November, following which I was referred to the two-week prostate cancer clinic. The diagnosis I related earlier was a shock. I felt annoyed, angry, partially surprised but partially not surprised, in view of my family history. Prostate cancer is supposed to be slow growing, so how could I have gone from no cancer detected by a consultant's DRE and a low PSA to an aggressive G10 in just over a year?

By this time, I was suffering from retention, but was self-catheterising. I was on Zoladex and my treatment of radiotherapy was scheduled to start at the end of March, or early April 2020. I began to feel positive about my situation and started planning holidays abroad for July/August.

And then Covid-19 reared its ugly head, and everything was turned upside down. My radiotherapy was postponed. My cancer that had evaded PSA and DRE checks was inside me. What could I do? I had done my best to find any cancer as soon as possible being aware of the familial link. It felt an exceptionally low, anxious and frustrating time. It was also very annoying as there was nothing I could do. I felt lower at this point than at diagnosis. At the time, '*The NHS is open for business*' mantra politicians told us, didn't ring true with me.

But I must emphasise that both my consultant and the uro-oncology nurse team were exemplary in their support, re-

assuring me that the Zoladex would control the cancer. And it did, bringing my PSA down to 0.1. I will also add that two members of our support group reassured me that the EBRT + HDR Boost were well tolerated by them; their support helped me to wait patiently (or perhaps impatiently!) **The Zoom meetings organised by NWPCSG have been supportive and made me realise I am not the only one out there with this disease.**

The summer weather was fantastic, but it seemed a long time to wait for my HDR appointment to arrive. Fortunately, I have a super supportive wife who does her absolute best to keep my mind off the situation we are both facing. She's kept me busy with jobs around the house!

Eventually the HDR appointment letter and EBRT schedule arrived – it should all be completed by 19th November, some 11 months since diagnosis. It is most unfortunate that this has happened during Covid but it is now going forward and with slight trepidation about it all and potential unwanted effects of radiotherapy, I am in the 'Positive' zone. The uninvited 'guest', 'squatter', 'beast', or however we refer to our cancer, is going to be dealt a hammer blow.

Bring It On!

Footnote: - since this piece was submitted, I have received an e-mail from Paul. He has already started his treatment and is full of praise for Dr. Nobes and all the radiography team who have put him at ease. We wish him well in his continued treatment. **Geoff Walker - Editor**

Garth Willson - My Prostate Cancer Story

At the end of the last century, I was made redundant. I decided to have a career change and trained to become an English teacher. I taught for a year in Poland and then moved to Thailand.

Thailand was exciting and interesting; it was also a great centre to travel from. I visited most countries in SE Asia as well as making longer trips to New Zealand and later to Australia. But, in 2008/9 I experienced a big change in my health. Several teachers had decided to have a health check and were worried about good and bad cholesterol levels, blood sugar and other criteria, so I thought I might have a check-up myself.

I had all the tests one day and the following lunchtime I went back for the results. Everything was great except for one reading for a test called PSA, which I had never heard of. I had a reading of 20 and here was a note saying I should see a urologist. I had no idea what it was about, so I asked a nurse, but she said I should see a urologist; I tried asking a doctor as well, but got the same reply. I had to go back to the school, because I had a lesson to teach, but I had a few minutes to spare before the class so I did what we all do now: I googled PSA and that's how I found out I had prostate cancer.

(continued overleaf)

No Macmillan nurse to hold my hand, I just went and taught my lesson. In the following months I did a lot more research online. I discovered a PSA test was not fool proof: false positives and false negatives. Also, there was a lot written about, what I thought would be, horrendous side effects of incontinence and impotence from both a prostatectomy and even having a biopsy. I'd had no symptoms, so I decided to watch and wait. I did see a urologist, but he thought it would probably have metastasised and wanted to do a biopsy. I was still concerned about possible side effects and I reasoned that if it had metastasised, there was nothing that could be done. Also, I didn't know if I could afford to pay for an operation, so I watched and waited. One of the urologists said he would do a biopsy and take 12 samples and if there was no sign of cancer, he would take another 12 and if they were clear, I would be declared free of cancer.

You need to understand that in Thailand doctors make their money by doing such things. Having had a biopsy here in the UK, where only 4 samples were taken, I'm very pleased that I declined his offer. In 2011 I was eligible to return to the UK and came back to Norwich. I registered with a doctor and when I told him my PSA was about 57, he asked me if I'd like to have a biopsy. Eventually I did and was diagnosed with a Gleason score of 7 (4+3 with 5) and stage 3b.

It was considered too late for a prostatectomy, so I had radiation therapy with hormone treatment, which I stuck with for nearly 2 years. The oncologist wanted me to have 3 years, but my own research indicated that the first 6 months were most important.

The hormone was generating strong hot flushes, which is why I wanted to come off it. I was also starting to get osteoarthritis in one hand, which I was told had nothing to do with the hormone, but when I stopped, the arthritis went away. Has anyone else ever noticed this?

Over a couple of years my PSA eventually rose to 16 from being undetectable and I was advised to go back onto a different hormone treatment. (During this time Sallie, who is a member of the uro-oncology nursing team, had always been really helpful despite my possibly unusual views). Now, I've been on bicalutamide for 4 years and my PSA has reached its lowest point. However, I've started to get arthritis in my hip and I plan to come off the treatment for a while just to see what happens.

Since I've been back in England, I've still travelled, visiting India, Sri Lanka, China, Russia and Chile without too many problems: the two main issues are access to toilets and getting travel insurance with cancer.

For the first, I try to follow a strict eating and drinking regime and I also carry my N&WPC SUPPORT GROUP "**Get into a toilet free card**" (mine still has a 2012 calendar on the back) although I've never had to use it. For the second, I declare the cancer but exclude it on the basis that it's not likely to change that quickly. I don't say that my way is the best way; you need to talk to your oncologist and make up your own mind. I just offer my story to show you can carry on for some time and have fun.

Last Meeting for this year is on Monday 7th. December

Online ZOOM Meeting with Speaker (7pm - 9pm)

Please visit our website for all up-to-dates and information - www.prostatesupport.org.uk

Members who have registered their email addresses with us will receive an email giving the ZOOM LINK to enable you to join in this online meeting. If you have not yet registered your email address with us email your details to Steve Costin at nwpcsg@hotmail.co.uk

OUR WELFARE TEAM ARE GEORGE & JILL SIELY

who live in Happisburgh and are always available to give help and support to any member, and/or their family, who requests it. They have a contact list of fellow members of our support group and are able to put you in contact with someone who has been on the same prostate cancer treatment journey as you.

Call 01692 650617 if you would like to have a chat with either of them.

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