



**Registered Charity No. 1108384**

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**Patron: Martin Bell O.B.E., President: David Haines**

**Newsletter No. 63 - Summer 2017**

## Immediate Past Chairman, Noel Warner, reflects on the last five years

Just over six years ago, when I attended an open day at 'Volunteer Norfolk' in Norwich, I wasn't looking for a role as a chairman, or anything that carried a great deal of responsibility. I considered a couple of options, but didn't feel attracted to them. Then it was suggested that I might look at a cancer charity who were seeking a Chairman. Instead of "doing a runner", which was my first inclination, I agreed to meet with the then chairman, Ray Cossey and the president, David Haines at the Dunston Hall Hotel & Golf Club. What a very persuasive pair they were!

So, it was suggested that I join the group, as Vice Chairman to Ray, with a view to taking over the chair after a year.

Coming, as I do, from a sales background and being naturally enthusiastic about any new project, I admit that some of my early ideas were so over the top that the group members were questioning the decision to bring me on board. I well recall trying to interfere with the content of the Newsletter and the then editor, David Paull, saying words to the effect, 'Look here, laddie, I am the editor and I will decide what goes in and what is spiked'!

If we fast forward three years I felt I was beginning to settle into the role and understand the key aspects of our support group. Raising awareness of course, and having a voice about PCa policy via Prostate Cancer UK and Tackle. But, above all is the comfort and companionship gained by newly diagnosed men and their partners following a "Meet & Chat" event. The feedback after those meetings is always positive.

During my time as Chairman we have lost three Davids - first David Wiseman, a lovely man who with his wife Ros were our first Welfare Team; then the above mentioned David Paull, who produced very fine newsletters, and finally David Capp, who with

Adrienne were our most recent Welfare Team. You could tell that David Capp spent a long time teaching by the way he assembled the newcomers at Meet & Chat events and made sure they all spoke to one another, so that nobody was left out.

I am not certain that I will leave "a legacy" behind me, but if I was to be asked, "what gave me the most satisfaction it would be the Targeted Radiotherapy Appeal (TRA). The N&NUH wanted to purchase equipment in order to provide a form of treatment only available in London, or Cambridge. Patients wanting this would have the added burden of travelling long distances.

Initially the fund raising was slow, not helped by the fact that the then editor of the EDP refused to give the Appeal any news coverage because "this should be funded by the NHS not by the general public". I felt I had to try and change this so devised a plan to get a group of Norfolk dignitaries together to promote the TRA.

Happily most of those asked agreed, including the Chief Constable, the Grand Master of Norfolk, the WI and not least the Bishop of Norwich. When the EDP learned that there was a powerful group supporting the TRA the editor changed his mind about publicising it. In the end we donated £50,000 to the appeal which was a combined effort between us and Brundall Cancer Community Chest.

Last April saw the beginning of our 14th. year and I have to say that years 12 and 13 began to cast doubt over the future of the group. We almost decided to wind the charity up, but then, without any rhyme or reason, the sun came out and new volunteers came forward.

Our current chairman, Nigel Gardiner and vice-chairman, Roger Bassham have taken over leadership, assisted by the ever-supporting committee members and new members George & Jill Siely, Steve Costin, Mark Threadgold, John Ladd & Graham Manning. I feel that our Support Group is as strong as it's ever been and



*Left to right, Anna Dugdale, (former Chief Executive N&NUH), Simon Bailey (Chief Constable of Norfolk), John Rushmer, Bishop Graham James, Martin Bell, Noel Warner, Philip Blanchflower, (former Chairman of Big C), Daniel Williams, (former CEO of Big C), Wendy Adams, Dr Tom Roques, Dr Jenny Nobes.*

## A Big Thank You And Hello.

The sad passing of David Paul, the previous Editor of this Newsletter, left a big hole to fill. To preserve publication and thus keep our readership up to date on current issues and developments, one of our elected committee members, Chuck Lyons, stepped forward in the time of need and took on the mantle of both Editor and compositor.

This was a great commitment on his part, particularly as he is still in business and not in the best of health himself. The time has now come when Chuck needs to hand on this mantle to others and, in accepting the role of your next Editor, on behalf of all the Committee Members and our readership, I would like to thank him publicly for what he has done and achieved during his term of office.

His dedication and loyalty to the cause of keeping prostate cancer issues to the forefront of our minds will continue and we are grateful for that. I'm sure he will have many valuable contributions to make in the future. Well done, Chuck, and THANK YOU. In the meantime, we all wish him well in his journey through chemotherapy treatment.

Now to the 'Hellos'. You all know Ray Cossey, who will be taking over as the new compositor, and I am looking forward to working alongside him. I'm sure I will be asking many questions as I get familiar with my new role. But this will be a team effort.

My name is Geoff Walker and I am your new Editor. I had a radical prostatectomy in March 2002 at the age of 58, since when (and so far) my PSA has been 0.1; thank you Prof. Sethia. Perhaps, on a future occasion, I will relate my story in the 'Our Journeys' section.

I joined the support group just after it was first formed and fully intended to get more involved then, but another commitment came my way from which I have only just stepped down. My first thoughts about picking up the reins here are that there is a much higher profile for prostate cancer now than ever there was at the time of my op. and it is quite a task picking out that information which will be most relevant and beneficial to our readers.

This is my aim and I will do my best to achieve it. Contributions for consideration for inclusion in future editions are sought and would be most welcome and gratefully received. My e-mail address is:-

**geoffreyowalker@gmail.com**

If you are not a computer-buff then please give me a call on 01603 712778 and we can chat about your story

I am also the father of Helen Walker who, until she emigrated to Australia last December, was part of our wonderful team of Specialist Uro-Oncology Nurses. I believe many of you will know her and she sends her best wishes to you all. And mentioning our nursing team leads me nicely into the next piece.

## We Are So Lucky in Norfolk & Waveney

At the time of writing this piece, I've only had five days since meeting Chuck and Ray to get things together to meet our next printing-deadline. However, one of the many pieces I've sieved through confirms just how lucky we are in Norfolk & Waveney to have such an experienced and dedicated team of Uro-Oncology Nurses to give pre/post-operative support and advice.

NHS England has recently published the results from its sixth National Cancer Patient Experience Survey.

They show a worrying decline in the number of men with prostate cancer who say they've been given the name of a Clinical Nurse Specialist for support.

The results are important as they are used to drive improvements in care for people with cancer across England, by promoting best practice and reducing regional variations in patients' experiences.

Men with prostate cancer continue to face variations in their quality of patient support, depending on where in the country they live. The figure ranges from 52% to 100% across Trusts.

It is believed that every man with prostate cancer should have access to the expertise of nurse specialists throughout their treatment and care journey, and in relation to their specific needs.

There is strong evidence that demonstrates the allocation of a dedicated nurse specialist has a positive impact on patient experience and outcomes, so it's worrying to see an increasing variation in men getting access to a named specialist nurse across the country.

Prostate Cancer UK's Change Delivery Team is working to address issues of variation and inequity of access.

Hence the reason I chose the heading of this article. So, to all of our specialist nurses at Norwich, Gorleston and King's Lynn hospitals.....

***"I know from Helen just how committed and dedicated you are. Well done; you are much appreciated and I know you will keep up the good work. "***

## Exercise & Diet After A Radical Prostatectomy

We all like our food and as we get older perhaps do not move around as easily as we once did. The internet link below could be of benefit to us all as we seek to keep mobile and have a healthy diet.

[https://prostatecanceruk.org/media/11576det\\_and\\_physical\\_activity\\_for\\_men\\_with\\_prostate\\_cancer-ifm.pdf](https://prostatecanceruk.org/media/11576det_and_physical_activity_for_men_with_prostate_cancer-ifm.pdf)

## Lavatory Cards?

According to one report, men who have suffered from prostate cancer will soon be able to carry discreet plastic cards to avoid the embarrassment of asking to skip the queue at public lavatories. The cards, issued free by Macmillan Cancer Support, explain that the holder has had cancer and needs to use the lavatory urgently.

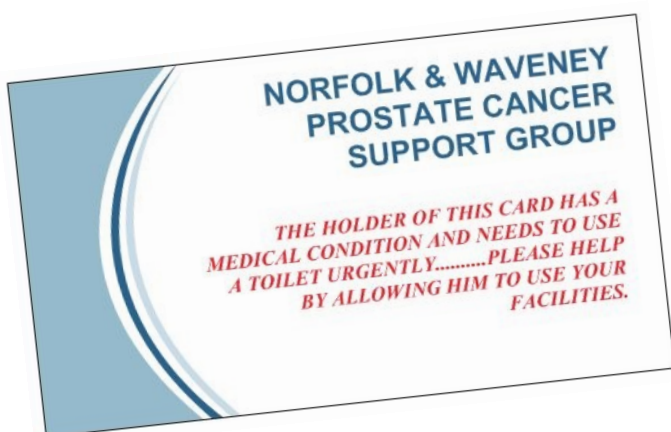
More than 100 men are diagnosed with prostate cancer every day and rates of diagnosis have increased by 10% in the past five years. Although procedures are improving, surgery still often damages the nerves and muscles of the bladder.

The card states: 'Urgent: Due to my cancer treatment I need urgent access to a toilet. Please can you help?'

Macmillan hopes the cards will soon be widely recognised. They are also considering whether they could be used to gain access to lavatories in railway stations without charge.

***Well done, Macmillan, but our Support Group have had this type of card available to members for the past five years and here it is:-***

***We suggest that you cut this card out, pop it in your wallet and use it when, and where, necessary.***



## 3-in-1 Test?

It is reported that a revolutionary blood-test could pave the way to precision treatment for patients with advanced prostate cancer. The 'three-in-one' test has the potential to transform the way the disease is tackled by targeting specific gene mutations.

By looking for cancer DNA in blood samples, researchers were able to identify men with defective genes who were likely to benefit from drugs called PARP inhibitors. The test was also used after treatment had started so patients who were not responding could be switched quickly to an alternative therapy.

Professor Johann de Bono, who led the team at the Institute of Cancer Research in London, said "We were able to develop a powerful three-in-one test that could in future be used to help doctors select treatment, check whether it is working and monitor the cancer in the longer term.

It could be used to make clinical decisions about whether a PARP inhibitor is working within as little as four to eight weeks of starting therapy. Not only could the test have a major impact on treatment of prostate cancer, but it could also be adapted to open up the possibility of precision medicine to patients of other types of cancer as well."

In future, the test could allow PARP inhibitor olaparib to become a standard treatment for advanced prostate cancer by targeting those most likely to benefit, picking up early signs that the drug might not be working and monitoring for emerging resistance. The new test, described in the journal 'Cancer Discovery', was developed with the help of 49 patients enrolled in a clinical trial of olaparib.

Men responding to the drug were found to experience an average drop in circulating cancer DNA of 49.6%. In contrast, cancer DNA levels rose by 2.1% in patients who did not respond. Patients whose cancer DNA blood levels were lowered by olaparib survived an average of 17 months, compared with ten months for those whose levels stayed high.

Professor Paul Workman of the Institute of Cancer Research said: "Blood tests for cancer promise to be truly revolutionary. They are cheap and simple to use but, most importantly, because they aren't invasive, they can be employed or applied to routinely monitor patients to spot early if treatment is failing. This test is particularly exciting because it is multi-purpose, designed for use both before and after treatment. We believe it can usher in a new era of precision medicine."

*This is an extract from a Daily Mail article dated 19.06.2017*

The Church Hall,  
St. Andrew's Church  
Cromer Road, Sheringham

**Saturday 23rd. September**

Curtain up at 7.30 pm  
**FREE PARKING** - Interval refreshments

**TERRY CHAPPELLE and Friends**  
*proudly present*



**Old Time  
Music Hall**

*Light-hearted, family show of music and laughter  
and Terry Chappelle's farewell concert show.*

*Feel free to dress-up, if you wish, with an audience **best hat' prize** !*

Supporting

**NORFOLK & WAVENEY PROSTATE CANCER SUPPORT GROUP**

***Tickets can be purchased from  
BIG C SHOP, 50 Station Road, Sheringham***

*or by post from -*

***N&WPCSG, 73 Blofield Corner Road, Little Plumstead,, Norwich, NR13 5HU,***

***( Please enclose an SAE and make cheques payable to "N&WPCSG" )***

## Diary Dates

**Open Meetings**  
with Speaker

**Monday 4th September**

(7.00pm)

Benjamin Gooch Theatre  
Norfolk & Norwich Hospital

**Monday 4th December**

(7.00pm)

Benjamin Gooch Theatre  
Norfolk & Norwich Hospital

**'Meet & Chat' Evenings**

**Saturday 14th October**

(11.45am)

at Louis Hamilton Centre  
James Paget Hospital, Gorleston

**Monday 6th November**

(7pm)

at the Big C Centre  
Norfolk & Norwich Hospital

**Committee Meeting**

**Monday 2nd October**

(7pm)

at the Big C Centre -  
Norfolk & Norwich Hospital

Whilst we are more than happy to provide members with a printed copy of our Newsletters, our Support Group does incur the costs for printing, stationery and postage

If you presently receive a mailed copy, but have the facility of the internet, we can email you a PDF file of our Newsletters, which you can print -off, should you wish to do so.

If you are willing to have your copy of our quarterly Newsletter emailed to you please send an email to:-

[nwpcsg@hotmail.co.uk](mailto:nwpcsg@hotmail.co.uk)

Please type 'email newsletter' on subject line

## How to Contact Us

### Specialist Nurses:

Sallie, Wendy, Rachel & Elaine

**Norfolk & Norwich University Hospital - 01603 289845**

Angie, Wendy & Simon

**James Paget Hospital, Gorleston - 01493 453510**

Sally, Clare & Anne-Marie

**Queen Elizabeth Hospital, King's Lynn - 01553 613075**

## Help or Advice

We have a number of members who are available to help and there is probably one near you.

For more information please call George or Jill Siely on 01692 650617 or e-mail us at [nwpcsg@hotmail.co.uk](mailto:nwpcsg@hotmail.co.uk)

**Letters to the Editor:**

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