



Anniversary Special Edition

NEWSLETTER No.77 - April 2024

Celebrating two decades of raising awareness, giving support and providing information

The view from the Chair



*“Onwards and upwards!”
by Chairman
John Ladd*

I am a relatively new member of the group having been diagnosed with prostate cancer at the end of 2015. My father died of prostate cancer and my GP closely monitored my PSA level from 2009, when I retired from teaching. The PSA level steadily rose in 2015 and I was referred to the hospital. After several biopsies I was diagnosed with prostate cancer. I was offered two treatment paths, radiotherapy, or a radical prostatectomy. I had a high Gleason score and my wife and I were anxious for treatment to start as soon as possible.

We decided that the best approach was to get rid of it and opted for surgery and a radical prostatectomy, which was successfully carried out in February of 2016. It was after my surgery that I was made aware of the Support Group. I was very warmly welcomed at the first ‘Meet and Chat’ session at the Big C centre. Meeting other men in the same situation as me was very reassuring: I wasn’t alone. I felt supported by the group. Partners are very welcome to attend and are part of the support network.

The group is very effective because of a very dedicated committee and trustees who work tirelessly in the background. We also have the support of the specialist nurses who give up their time to regularly attend our meetings. We are also very thankful for the guest speakers who lead our open meetings. Support was also maintained during the covid pandemic by using Zoom.

Thanks must also go to all the organisations and individuals who have supported us financially. This has enabled us to have our own website, provide information and to provide the three hospitals with examination couches for taking biopsies.

Finally, the group is going onwards and upwards! Attendance is starting to exceed pre-pandemic levels and we are getting positive feedback from members.

Here’s to the next 20 years and beyond.

“Our Support Group”

by the Patron, Martin Bell OBE

It seems a long time ago that I was asked to be Patron of our Support Group. That was because it *was* a long time ago. I accepted immediately and instantly discovered, at the early meetings in Norwich, the value of the togetherness and solidarity of the people involved, not only the men who might have developed that condition, but their partners, wives and families. At the same time the medical science was advancing and we were kept up to date, mainly through the Norfolk and Norwich Hospital, with the latest developments. My special thanks to David Haines, who as I remember did more than anyone to make it happen and provide the necessary encouragement.



A timely tribute is also due to King Charles, for going public about his need for the treatment of an enlarged prostate. I write here in my capacity as a former royal correspondent, or a ‘reptile’ as we were known in the Palace. The Royal Family needs to be seen in its ceremonial comings and goings, which is why our late Queen, by her own account, always wore the brightest clothes with matching hats and gloves. But, the Royals were secretive to an extreme degree about their medical conditions. An enlarged prostate is no longer an ‘unmentionable’, if it ever was, and prostate cancer is always a risk in men of a certain age. Royalty provides no exemptions. So, it was greatly to King Charles’s credit that he made sure we knew why he was in hospital and for how long (three days as it turned out) before release.

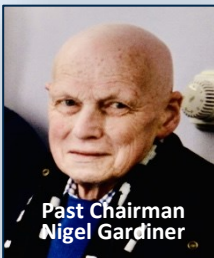
I remember my friend former BBC colleague, the late Bill Turnbull, doing the same; using his relative celebrity, (as a contestant on *Strictly Come Dancing*), to alert men, of about his age, to the symptoms to watch out for. I was never on *Strictly* myself, for I wisely turned it down, twice. But, like the King, I did reach that ‘certain age’ status and underwent the necessary tests to discover that I too might need treatment. Even now I am awaiting the consultant’s opinion on my latest blood test. My knowledge of the condition, derived from the early meetings of the Support Group, has stood me in good stead in dealing with it calmly and without undue alarm. I am not only the Group’s Patron, but one of its beneficiaries. **Long may it prosper!**

A Team Effort

When my husband, Nigel, was diagnosed with Prostate cancer, back in the beginning of 2012, it came as a complete shock to him, me and our family. Like many men he had insisted he had no symptoms; thus, no concerns. However, as it turned out, it was the beginning of a journey, for both of us. Nigel was told he was not suitable for surgery, so it was to be hormone treatment then, luckily, the opportunity of joining in a drugs trial and chemotherapy.

But, one thing was certain; it was a journey we were to follow **together**. Having been told about the Support Group and the chance to go along to Meet and Chat sessions, I joined Nigel to attend our first meeting at the Big C Centre only to find that there were very few other women there.

Prostate cancer, like all cancers, affects everyone in the household, but by forming a Ladies Group it provided a time to not only supporting partners and husbands, but an opportunity for us girls to just have a chat, to laugh, to ask advice and yes... be handed the tissues! Most importantly, to help us to realise that you were not alone.



Joining the Committee was the obvious next option for both of us and, over the years, Nigel and myself were privileged to meet some lovely people; not only within the group, but also the nurses and specialists we met on the way. Nigel lost his fight at the end of 2019. At the time he was chairman of the Group and his determination and dedication to

the work of the NWPCSG was paramount in our lives. Thus, it seemed very natural for me to continue supporting the group. Last year I was invited to become a trustee of the Group; one which that I was honoured to accept

Every day, new prostate cancer diagnoses will be made, more men will hear the news they didn't want to hear, but new treatments are being developed all the time. By staying closely attached to the group and to continuing to serve on the Committee, and as a trustee, provides me with a chance to offer positive support. Don't forget I have been there, done that and got the T-shirt....I speak from experience and can appreciate how you may be feeling and I am happy to help you on your journey.

JUDITH GARDINER - Trustee

The Group's Chairmen

2004 - 2008 DAVID HAINES

2008 - 2012 RAY COSSEY

2012 - 2017 NOEL WARNER

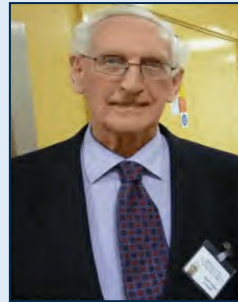
2017 - 2019 NIGEL GARDINER

2019 - Present JOHN LADD

Success Story

I have been asked to offer my memories over the 20 years since our Support Group was founded, in which I and others took leading parts. We were encouraged by our dedicated specialist nurses initiative; thank you Sally, Claire, Wendy and Lizzie.

It is now 23 years since I began what was, and still is, a long cancer journey. My late wife, Yvonne, urged me to consult with my GP after I developed urinary problems, at 70 years old. I knew nothing about prostate cancer and was reluctant to admit to, or discuss, having such problems. I felt well, was active and still working, after many years, as an active volunteer with charities.



It was 2001 when there was then no specific, local prostate cancer charity, where we could ask questions. So, I took my wife's advice and my GP's advice was, "Don't worry about it, all men get these problems as they age." By 2002 my symptoms had grown worse and I next consulted an older locum GP, who told me about the PSA test. He referred me to the hospital for assess-

ment and tests, which diagnosed me as having prostate cancer. I immediately began a course of treatments, ending with radiotherapy, which proved to be successful and now, at the age of 93, I continue to live in remission and help others when asked.

In early 2004 the specialist nurses at the N&NUH invited affected patients and their partners to an open meeting to identify what else was needed, by both patients and the public, to improve the approach to prostate cancer. From this meeting three priorities emerged; firstly a major effort to increase public awareness of the biggest male-only cancer killer. Secondly, to make available safer and more reliable information and guidance to encourage men to seek medical advice. Thirdly, to enable patients themselves to support each other. A steering committee was formed, from experienced volunteer patients, which adopted these three priorities as its founding principles.

Over these past 20 years my involvement with the Group brought me into contact with many fellow patients and some leading clinicians, such as Dr. Tom Stuttaford, Mr. David Baxter-Smith. From them I gained knowledge, motivation and both physical and mental strength, to help form and develop the Group and to deal with my own cancer battles.

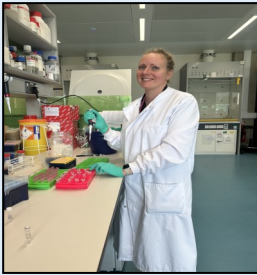
Our Group has helped so many men and their families to meet these challenges and has played an effective local and national part in all these areas. A succession of hardworking chairmen, officers, committee members and public support has achieved notable success in fundraising, providing information and active help to patients. It has also donated urgently needed urology equipment to all three major hospitals in the region and has helped fund local research.

May I extend my thanks to all those who have helped and worked with the Group and wish it continued success in its endeavours.

DAVID HAINES—President

The Research

Dr. Kate Manley
Specialist Registrar in Urology
Norfolk & Norwich University Hospital



I am a urology doctor with an interest in research. I have been fortunate enough to be given the opportunity to take time out of my clinical training to undertake a PhD project in Prof. Colin Cooper's laboratory in the Bob Champion Research and Education building (UEA). Prof. Cooper and his team have utilised the combination of

complex maths and artificial intelligence to further our understanding of prostate cancer genetics and to develop two new prostate cancer tests with the potential to revolutionise prostate cancer diagnosis and management.

The '**Prostate Urine Risk**' (PUR) test uses biomarkers secreted in the urine by the cancer. Patients are sent an 'at home' testing kit, where they provide a sample of urine first thing in the morning and one an hour later. The samples can then be posted back to the lab for analysis. The PUR test is able to predict the presence of cancer without the need for MRI or biopsy. In addition, the information from the PUR test can be used to help predict whether prostate cancer is aggressive and needs treatment, or if it can be monitored under active surveillance? This test is currently undergoing a large validation study, to demonstrate its effectiveness. To date we have collected over 2000 samples from men in Norfolk and also from around the world.

The **Tiger Test** is a revolutionary, new clinical test that can reliably distinguish aggressive prostate cancers from harmless ones. The test uses samples of tissue taken at prostate biopsy. Genetic signatures are analysed to determine the presence, or absence, of the signature associated with a poor prognosis (also known as the 'DESNT' signature). This would enable a more individualised approach to prostate cancer treatment, ensuring that men with more aggressive disease get appropriate treatment, whilst sparing others from unnecessary treatment and unpleasant side effects.

I am incredibly fortunate to have received funding towards my PhD project from the **Norfolk and Waveney Prostate Cancer Support Group**. As part of my project I have been working on both the PUR and Tiger Tests to help try to bring them one step closer to being able to be used for real patients. Both tests have now entered their final stages of development. The Tiger Test and Prostate Urine Risk (PUR) Test will be presented to the UK Accreditation Service (UKAS), the national body responsible for managing the treatments to be licensed by the NHS and other health providers. We are hoping that the PUR test will be accredited by the end of 2024 and the Tiger test by mid-2025.

I am so grateful for the funding I have received from the **Norfolk and Waveney Prostate Cancer Support Group** It has enabled me to be involved in an incredibly exciting area of research with the potential to transform early detection and treatment outcomes for patients. Thank you to all my donors who have made this possible. My studies are due to finish in October this year, and I look forward to coming to report the findings from my work at one of the Norfolk and Waveney Prostate Cancer Support Group's meetings.

Prostate Cancer 20 years on

Professor Krishna Sethia MA, DM, FRCS
Consultant Urologist



The incidence of prostate cancer in the UK continues to rise with the last 20 years seeing an approximately 40% increase in the number of men diagnosed. However, the mortality rate, per 100,000 men, has fallen by nearly 10% over the same period. Sadly that still leaves over 12,000 men per year dying of the disease. On the brighter side,

there have been significant advances in the methods used to diagnose and stage prostate cancer and in its treatment especially that of advanced disease.

For diagnosis, MRI scanning has now become part of the standard investigation of any man suitable for radical treatment. It has the ability to detect over 85% of clinically significant cancers and, when normal, saves many men the need for prostate biopsies. Should biopsies be indicated most units have now abandoned the transrectal biopsy method in favour of performing biopsies through the perineum. This technique has massively reduced the risk of infection and does allow much more thorough sampling of the gland. In addition small tumours can be accurately biopsied by using software, which allows MRI images to be 'fused' with the ultrasound images relied on in the procedure. Finally CT-PET scanning, using a tracer which binds to Prostate Specific Membrane Antigen, is capable of identifying areas of spread on cancers which could not be detected by conventional imaging.

In men who have disease localized to the prostate it is now well-recognised that many low and some intermediate risk cancers do not need immediate intervention and that active monitoring, or surveillance, is both safe and often preferable to radical treatment. There is also more information available to help men decide as to whether to have treatment or not, for example the Cambridge Prostate predict website:-

<https://prostate.predict.cam/tool>

Twenty years ago men with metastatic disease relied upon hormone manipulation to control the disease and when that failed there was little more that could be done. Fortunately there are now both drugs (chemotherapy) and more advanced hormonal agents all of which can add months, if not years, to average survival. We are therefore moving to a situation in which prostate cancer becomes more of a chronic disease, not necessarily curable but controllable, in a way that allows men good quality life.

And still it goes on...

Having been invited to submit a contribution to our 20th Anniversary Edition, I thought it would be a good idea to review those editions which were produced before I became a member of the Group. So, I have just spent a day reading through the first 28 editions and must congratulate everyone involved who contributed to making them such an informative read; I know a lot of time and hard work, to get them to such a high standard, must have been expended.

There's one major topic, which kept being highlighted; **the reluctance of GPs to allow men of 50 and over a PSA test**, despite it being their right to have a free test annually. My then GP declined my request in December 2001, when I was 58, and if he hadn't been so condescending to my plea, I might have accepted his assurance that at my age there wasn't a chance of anything being wrong. His attitude annoyed me, and I persisted. The rest is history; I had to have a radical prostatectomy in March 2002 and 22 years later I am still around, without medication. Thank you to Professor Sethia, my surgeon. I raise this issue because stories of GPs' resistance to the PSA test still abound. Even today, when prostate cancer has a much higher profile than it did 15 years ago, my daughter Helen, who is currently the Prostate Biopsy Advanced Clinical Practitioner, comes across this problem regularly.

In 2009, the Prostate Cancer Support Federation produced a leaflet for every GP in the country, the text of which follows, but the full story can be read in Newsletter 27 on our website.

Seven Things a Man Should Be Told When He Requests a PSA Test

1. *The PSA test is a simple blood test, which is used to help detect prostate cancer. In its early stages, prostate cancer generally produces no symptoms, so it is important to diagnose the disease before any symptoms arise and while it is still potentially curable. Recent results of a major European trial suggest that treating prostate cancer may significantly prolong a man's life.*

2. *A high level of PSA (usually 10 ng/ml and above) is likely to be an indication of prostate cancer and should therefore prompt further investigation.*

3. *A moderately raised PSA level (usually 4 ng/ml and above, but this depends on age), means that other factors, including digital rectal examination, ethnicity, family history, prostate volume, PSA history, and free to-total PSA ratio, should be considered in determining whether to send a man for further tests such as biopsy.*

4. *However, in three-quarters of such cases, further tests do not detect cancer. There can be other reasons for a moderately elevated PSA (e.g. urinary infection, enlarged prostate) and these may need treatment.*

5. *Prostate cancer is not always aggressive or life-threatening. Even if further tests do detect early-stage prostate cancer, a specialist may not be able to tell whether the condition is life-threatening or harmless. This may make treatment choices difficult for both patient and clinician.*

(continued...)

6. *A low level of PSA (usually below 4 ng/ml, but this depends on age) does not guarantee the absence of prostate cancer. This is because localised prostate cancer does not always produce a raised level of PSA.*

7. *All these factors have led to the controversy over the value of the PSA test. However the uncertainties may be reduced by men having a regular test, ideally on an annual basis. Regular monitoring of PSA levels can highlight any significant or gradual increase, so even when the PSA is within the 'normal' range, one may be alerted to the need for further investigation.*

In March 2009, the Group arranged a mass, free PSA testing session for over 200 men from Norwich and later in Great Yarmouth, Fakenham and Thetford.

Although I realise this Newsletter will be issued in the main to Group members, I urge you to encourage your qualifying male friends and relations to seek a PSA test; you could be saving lives. I have done that three times so far. The trick is to catch these things early. Talk freely about this disease; follow the example of our Monarch, King Charles III. Thank you, your Majesty, for speaking so openly. And thank you too to the Princess of Wales who has stressed that no one is alone who is stricken by the cancer disease. There are so many support groups now who are waiting to help and support anyone; the NWPSCG is one of them – **PLEASE USE US.**

The Group's Commitment to Support Medical Procedures



Mention has already been made, in some of the preceding articles, of the change in how biopsies are taken today, as compared with 20 years ago. Transrectal prostate biopsies have now been superseded by the very much safer transperineal method.

To allow clinicians to perform this new technique, a 'Procedure Couch' was donated by this Group to the main hospitals in our region (i.e. the Norfolk & Norwich University Hospital, the Queen Elizabeth in King's Lynn and the James Paget in Gorleston.)

Each couch cost in excess of £14,000 so you will realise just how big a commitment (£42,000+) it has been for such a relatively small Group.

Biopsies are taken on the ward rather than in an operating theatre and the annual savings in theatre costs is estimated to be in excess of £300,000. This has been a huge success all round and one of which the Group is justly proud. Whilst we are not specifically a fundraising charity, any monies raised will be donated (after very careful consideration) to whichever cause it is felt will promote better understanding of prostate cancer and/or medical procedures.

GEOFF WALKER - Trustee