Most people reading “Prostate Matters” probably already know how helpful support groups can be, but maybe some of the people reading this are new readers who have just been diagnosed.

I’m a firm advocate of support groups, but I wasn’t always. Before being diagnosed I had preconceived ideas about them up to when I sceptically tried one 5 years ago. I then tried a few more for good measure and I’ve now ended up as a regular attender at two very different groups. I like both for different reasons and I’ve got so much out of going to them, not least making new friends and finding out stuff I’d never have got to hear about otherwise.

I have found them to be a bit like pubs because one big thing they have in common is that they’re all different from each other. I mention that because I still meet people with cancer who’ve tried loads of different pubs but they’ve either never been to a support group at all, or they’ve tried one, didn’t like it, so never went back despite all the studies that show that people who do go are the ones who have better outcomes. I wonder how many of us would never go to a pub again based on just one that we didn’t like?

Doctors and all the other health professionals are a massive part of the information equation with their years of training behind them but, usually, they haven’t had any type of cancer nor any of the treatments. That leaves them without the insight that can only come from personal experience. So, along with everything else that support groups provide, I’ve found them to be an invaluable forum of people with personal understanding of what I’m going through, because they’ve been through similar themselves, and that complements what I get from my medical team.

Some groups are open to any man with prostate cancer, even if they’re attached to a hospital. Others are just for that hospital’s patients, but there are quite a few that aren’t connected to any hospital. Whichever sort they are, many groups encourage partners to come too. If you don’t like the first one you try, try another. because there’s at least one out there that will be your right up your street and, if you’re not sure where to start, try this link: https://www.tackleprostate.org/find-a-support-group-near-you.php or google ‘tackle prostate find support”

Jim Peters
Screening for prostate cancer in the UK has remained static for some time, that is until the “Turnbull and Fry effect” resulted in a reported 40% annual increase in treatment. NHS England chief executive Simon Stevens has authorised £10m of additional investment to “help ensure the NHS can manage this jump in demand, so that all people with suspected cancer are tested and treated quickly.”

This increased awareness of prostate cancer coincides with advances in post-diagnosis treatment that greatly reduces the problem of early stage overtreatment, which has been a factor in so many men not being given, or not asking for PSA tests.

These advances are backed by solid and highly influential UK trial and audit evidence. The following is a summary of these trials.

**The PROMIS and PRECISION trials**

These UK trials demonstrated that if a multiparametric MRI (mpMRI) was performed prior to biopsy for men with a raised PSA, no biopsy was necessary for 25% of men in whom no MRI abnormality was detected. If prostate cancer was present in such men, it was non aggressive and not clinically significant. Thus, the risk of “over-diagnosis” and risk of unnecessary biopsy have been greatly reduced. Visible abnormalities, however, are likely to be significant and can be targeted with certainty.

**The ProtecT Trial**

This UK trial reported the 10-year outcome of 1643 UK men with apparent non-aggressive PSA screen detected prostate cancer, randomised to receive radical treatment or active surveillance. After 10 years the death rate was only 1%, whether treated radically, or followed merely by active monitoring. It thus confirmed the safety of active surveillance alone for non-aggressive prostate cancer.

**The 4th National Prostate Cancer Audit**

This demonstrated that between April 2015 and March 2016, nearly 42,000 men were diagnosed with prostate cancer in England and Wales. 54% were over age 70 and 51% had advanced prostate cancer at presentation, 15% having metastatic disease. Whilst these statistics confirm the paucity of early diagnosis in the UK, the latest statistics on biopsy and treatment are much more encouraging. mpMRI is increasingly being used prior to prostate biopsy and only 8% of men with low-risk, localised prostate cancer underwent radical treatment. Thus, potential "over-diagnosis" is being minimised and "over-treatment“ continues to reduce, having fallen from 12% in 2014/15.

Finally, concerns about the utility of PSA as a screening tool have been fully addressed by Prostate Cancer UK's “13 Consensus Statements”.

Although most of our members will have passed through this stage of treatment, this is information which we need to publicise, not least amongst our own friends, until it becomes the norm for men to be given a baseline PSA test when reaching the age of 50, or earlier for men in “at risk” categories.

A leading example of members spreading the word is Phil Ormesher, he is a volunteer speaker on behalf of Tackle and PCUK. He was diagnosed with Prostate Cancer in 2012 and successfully treated with brachytherapy. Phil’s early diagnosis was due to some sound advice from a friend of his, Mike Lockett, to have an annual PSA test and look for a change in profile. When diagnosed Phil had no symptoms and his PSA was only slightly above the norm, but further tests revealed cancer that had to be treated. Phil firmly believes that Mike's advice saved his life. Recognising that most men knew little about prostate cancer, and even less about testing, Phil embarked on a series of awareness talks (over 300 to date) with the objective of giving men sufficient
information to make an informed choice about getting themselves tested.’
He tends to source his own awareness talks rather than wait for them to come via the charities and it was through this activity that he contacted Warburton’s Bakery at Bolton, a business where the majority of the workforce is male.
After several attempts to engage them, Phil finally spoke to a young HR manager, Daniel Watts, who said ‘this is exactly what we want to do.’
A subsequent meeting devised a plan to tackle the 24/7 workforce at Bolton. Phil recruited 3 other volunteers to help out: John Taylor, Chris Bergman and John Heyworth and between the four of them they spent a total of 4 days at Warburton’s talking to staff.
A month later, Phil received a call from one of the managers, Darren Rowan.
Darren had listened to Phil’s 5 minute ‘elevator speech’ and decided that as a 52 year old man he would go for a PSA test. The result was PSA score of 28ng/ml with his GP fast tracking him for biopsies. He was diagnosed with early, but aggressive prostate cancer and subsequently had a successful radical prostatectomy.
Over the ensuing months, before and after treatment, Phil and Darren spoke several times on the phone and discovered that they not only both played golf, but shared the same handicap. A game was arranged at Phil’s home course and a very enjoyable 18 holes was played with the result being, of course, an honourable draw!
Phil and Darren talked a lot during the round of golf but one of Darren’s comments really hit home: ‘you made a massive difference to my life, I dread to think where I would be if I hadn’t had met you at Warburton’s and subsequently decided to have a PSA test.’
So, if at times your motivation flags, think of Darren’s story. If we can impact and perhaps save one life, what we do is all so worthwhile.
Respected institutions are still promulgating advice based on outdated treatment protocols, follow https://www.independent.co.uk/voices/stephen-fry-bill-turnbull-prostate-cancer-symptoms-screening-a8583246.html to see such advice published by The Independent on-line in October.
Roger Wotton and John Coleman

This is the second edition of Prostate Matters that I have edited since we lost Hugh Gunn and I’m still climbing the slippery learning curve. Thank you to everyone who sent in contributions for this issue and my apologies to those whose contributions I have not been able to fit in this edition. Please keep them coming.
If there is interest, there is the possibility of a letters page where our members could exchange advice, news and even moans. If you are interested, please send letters to editor@tackleprostate.org and we can assess the level of interest. Please write ‘letter’ as the first word in the subject box.
Another thread worth exploring is member to member advice on coping with the minor frustrations which always occur during the journey through treatment and which are so annoying. I have in mind contributing an article myself on living with a Foley Catheter after being fitted with one with zero warning and minimal advice.
David Marsh, Editor.
KAYLEIGH DAVIES HAS RAISED OVER £3600 FOR TACKLE PROSTATE CANCER

29 year-old Kayleigh Davies from Skipton is a lady determined to raise awareness of prostate cancer and raise funds for our federation. In June she attempted to swim the English Channel as part of a four person relay team, but on this occasion didn't complete the swim due to bad weather conditions.

Kayleigh has also taken part in open water swims throughout the summer including a 5K swim in London and the Dee swim. She has achieved this despite the fact that up until two years ago she could hardly swim. When she was eight years old Kayleigh was diagnosed with sarcoidosis, which is an autoimmune condition which can affect any part of the body and leaves her in constant pain as well as being prone to chest infections.

Kayleigh's fundraising has been inspired by two of her father's friends who have prostate cancer. Her desire to raise awareness of the condition and of the work of Tackle, as well as raising money, has led her to go on to organise a charity ball. The ball took place on October 13th with over 100 people attending. Guests arrived to a drinks reception followed by a three course meal. £350 was raised on the night, raffle prizes were generously donated by local companies including Teddy Boutique, Boyes, Alexanders, Cake That Bradford and Holdsworth House. The total rised by Kayleigh now stands at more than £3600, including contributions she has raised from from local businesses.

Kayleigh said: "I organised the ball at Herriot's Hotel, Skipton and do swims for Tackle Prostate Cancer because I have seen the effects of this disease. Men are dying daily because they are not routinely checked by GPs for prostate cancer." She added that without the help and support from all the staff of Herriot's Hotel and the meetings with Chris she wouldn't have been able to do the ball.

The chairman of Tackle Prostate Cancer Roger Wotton attended the ball and said: "Kayleigh should be congratulated on organising a fantastic event. The charity ball took some organising and Kayleigh pulled it off superbly. Well done Kayleigh and thank you for continuing to raise awareness of prostate cancer as well as raising funds for Tackle."

Kayleigh added: "I have personally seen the effects of this devastating disease as it has affected friends and family and believe that it is important that we do everything that we can to fight and 'tackle' the illness."

Prostate cancer is now a bigger killer than breast cancer, making it the third biggest cancer killer in the UK. Every penny Kayleigh raises will make a difference, lives will be saved and more people will be aware of the need to be tested. The money will help the charity continue to meet its objectives of campaigning on behalf of patients and raising awareness in the community.

Roger Wotton chairman of Tackle Prostate Cancer says: "We know how devastating the diagnosis of prostate cancer can be. Raising awareness will hopefully see more men being tested earlier, and help accelerate a reduction in mortality figures. Prostate cancer doesn't just affect the man diagnosed – it affects his whole family. Kayleigh is a true inspiration to others she and she deserves all our support. Go girl!"

Kayleigh added: "I would swim all around the world to make a difference and help raise awareness."

Kayleigh has set up a Just Giving page and Facebook page for her swims. To sponsor Kayleigh's...
Kayleigh puts me to shame. Some time ago, my friend Hugh Gunn, the late editor of this newsletter, persuaded me to sign up to easyfundraising to generate money for Tackle from donations from online retailers at no cost and very little effort from myself. I signed up, but mostly failed to put in the small amount of effort needed to go to a retailer’s site through easyfundraising when shopping online. I have just looked, and at the moment the amount raised in my name is a grand total of £0.15. In contrast, our top fundraiser has generated over £215! However, I’m not alone in this, it turns out I’m the 28th biggest generator of funds from online shopping. To date, we have only 66 members signed up and we have raised a total of £546.40. Clearly with so many members we could do better.

Here follows some easyfundraising pro-forma blurb:

Hi (INSERT NAME HERE),
We need your help! If you shop online, please could you sign up to easyfundraising to support Tackle Prostate Cancer? It’s a really easy way to raise money for us – you just use the easyfundraising site to shop online with more than 3,300 well known online stores like Amazon, Argos, John Lewis, ASOS, Booking.com, eBay, Boden, and M&S and when you make a purchase, the retailer sends us a free donation, at no extra cost to you.
We want to raise as much as possible, so please visit our new easyfundraising page at https://www.easyfundraising.org.uk/causes/tackleprostatecancer/ and click ‘Support this cause.’

Thank you!

It turns out that when it’s set up all I have to do when shopping online is go to the easyfundraising app and from there click through to the retailer’s site (and there are hundreds of them including all the well known names. From there I just carry on with my shopping as normal, and the donation is automatic. The easiest way to get to our easyfundraising site on a PC or a Mac is to Google “easyfundraising tackle” and it is near the top. On a phone or tablet there is an App which will probably be easier to use. Tackle has also signed up to Amazon Smile which enables 0.5% of the cost of Amazon purchases to go to a charity of your choice at no extra cost, all that is required is to go to your account through the web and select Amazon Smile and enter ‘prostate’ in the search box. Tackle is listed as ‘The National Federation Of Prostate Cancer Support Groups’, (some of our local support groups are listed there as well)
Job done. Except that shopping using the Amazon App on my iPhone is much less user-friendly than using the App. My workaround for this is to put my purchases in the basket using the App, and then go to the Smile version on the web, where my purchases are waiting in the basket ready to complete the purchase with the donation. (This technique also works with easyfundraising).

To get back to my original point, I couldn’t admire Kayleigh’s commitment to our cause without rectifying my own lack of effort. Please do the same.

David Marsh

Swimming Challenge visit:
http://www.justgiving.com/kayleigh-davies6?utm
or google: ‘Kayleigh Davies Just Giving Tackle’
Siobhan Connor
A NEW SPACE FOR PROSTATE RADIATION TREATMENT.

Over the years there have been many advancements in the planning and delivery of radiation therapy for prostate cancer. Radiotherapy is proven to be an effective, non-invasive method of treating prostate cancer but many men fear the potential side-effects which can result from radiation exposure (toxicity) to the surrounding organs and tissues, such as the rectum.

Professor Bahl says, “A number of recent improvements, such as intensity-modulated radiotherapy (IMRT) and the more recent addition of image guidance, allow us to be more accurate in the delivery of the radiation to the prostate. Aside from the radiation delivery systems (known as a Linear Accelerator) there have also been advances in the software used to plan and execute the radiation therapy and the devices used to stabilise the patient to reduce organ movement.

The rectum mucosa is very sensitive to radiation injury. Its immediate proximity to the prostate makes the rectum the primary organ at risk (OAR) during prostate radiation therapy. Too much radiation exposure to the rectum can result in long-term side-effects such as abdominal pain, diarrhoea, incontinence, bleeding, and mucus discharge.

Oncologists and Urologists are always working together to provide patients with better treatment plans and reduced long-term complications. One new technology we’re implementing to combat these potential complications is an innovative, soft hydrogel spacer called SpaceOAR, which is clinically proven to lower radiation exposure to the surrounding organs and tissues.

When we started to implement SpaceOAR in our practice we were confident of the safety profile and positive impact to the patient, as the hydrogel is supported by over 72 clinical publications and a 222 patient randomised control trial. In the UK it has received positive guidance from NICE and so far, it has been implanted in around 30,000 men worldwide.”

Professor Persad says, “The hydrogel is a relatively simple concept. We use a very fine needle (under anaesthetic) to inject the gel between the prostate and rectum. The procedure only takes a few minutes, the gel positions the rectum on average 1cm away from the prostate. This space moves the rectum out of the zone of high dose radiation and minimises the risk of bowel damage.

The clinical studies have shown that not only does the gel spare the bowel, it also has positive benefits in reducing urinary incontinence and erectile dysfunction (for men who were sexually potent prior to treatment), giving men their life back following treatment.”

Professor Bahl continued, “In the near future, hydrogel spacing will enable us to push our radiotherapy planning and delivery systems harder, eventually reducing the number of radiotherapy sessions from 20 to 5.

Today, the potential side-effects from radiation exposure are a major concern for men who are given the option of radiotherapy and can often negatively impact the decision to accept this treatment option. New technology such as radiotherapy delivery systems and SpaceOAR hydrogel are important, they give men the confidence that not only are we doing our best to treat the cancer, but also that we are protecting their long-term quality of life from bowel, urinary and erectile dysfunction.”

Professor Amit Bahl is Consultant Clinical Oncologist and Clinical Director, Bristol Spire Oncology Centre & Bristol Urology Associates.

Professor Raj Persad is Consultant Urological Surgeon, Bristol Spire Oncology Centre & Bristol Urology Associates

This article was compiled by Augmenix, the suppliers of SpaceOAR hydrogel. The product is currently only available in the private sector, negotiations are underway for availability on the NHS.
As reported briefly in the last edition of Prostate Matters, our patron, Dr Thomas Stuttaford OBE, sadly died on 8th June. “Dr Tom”, as he was invariably known, was himself a prostate cancer patient, and was, both in Parliament and in his journalism, a champion of men with the disease.

Born in 1931, he was brought up in rural Norfolk, becoming the fourth generation of doctors in his family. He was educated at Gresham's School, Holt, then read medicine at Brasenose College, Oxford, where he began writing for student publications and became the editor of the British Medical Students’ Journal.

He relished his National Service with the 10th Royal Hussars so much that he stayed on for Territorial Army service with the Scottish Horse regiment. He then returned to Norfolk to join his Uncle Tom's sleepy medical practice, where it was said that no one had opened a medical textbook for more than 40 years. But Tom was not destined to spend all his life as a rural GP. By 1966 he was appearing on Anglia Television and in 1970 was elected as a Conservative MP for Norwich South. He was not really a “party” man, and he frequently rebelled against Ted Heath's government – memorably forcing the Chancellor of the Exchequer to drop plans for charging VAT on children's shoes – a move from which Ronnie Corbett is said to have benefitted, although history doesn’t record whether he ever expressed his thanks.

After losing his seat in Parliament in 1974, he concentrated his non-medical extra-curricular activities on journalism, becoming a favourite column writer in The Times where he was well liked for a down-to-earth and entertaining writing style.

He came to the Federation's Inaugural Conference in 2008 and immediately expressed a desire to help us develop. He joined the Trustees Committee as a co-opted member, as Media and Political Advisor, and his experience and advice were a great help in framing the Federation's policies. He spoke memorably at our 2009 Annual Conference and at the Great PSA Debate later that same year, where he revealed some interesting facts, long suspected by many, about the Department of Health's on-going campaign to conceal the true magnitude of the prostate cancer problem. In particular he noted that the death rate from prostate cancer is much higher than that actually recorded, as it is rarely the primary cause of death, but a significant contributory cause to the condition that finally kills the patient. He also spoke of nasty methods used on him by the Government' Whips when he attempted to campaign for prostate cancer screening.

Tom accepted our invitation to become a Patron of the Federation in 2011, but at the same time had to cut back his activities in order to devote himself to looking after his wife who was suffering from a long term illness, from which she died in 2013. We are grateful to the moral and practical support he gave to the Federation, and offer our condolences to his three surviving sons.

Sandy Tyndale-Biscoe
tackle prostate cancer
www.tackleprostate.org

The National Federation Of Prostate Cancer Support Groups
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The editor would like to thank everybody who has contributed to Prostate Matters. Without you, we would not exist. Please keep the contributions coming to: editor@tackleprostate.org Please send any photos separately at high resolution.

PROSTATE CANCER AND A HEALTHY MIND

I challenge anyone diagnosed with prostate cancer at some stage not to have had some degree of psychological or emotional concern. If they haven’t then maybe their family has.

We men are supposed to be strong, sensible, well balanced and impervious to such emotional turmoil during our prostate journey, aren’t we? But it’s not a perfect world and we are not all perfect. At some stage or other most men will have struggled with issues such as “What is the likely outcome for my current course of treatment?” or “Am I the only one feeling this way?” or “I wonder what my next PSA or scan result will show?” or even “Why me?” Some men discuss these issues with their families, some men successfully deal with them privately but others struggle from time to time, building up emotional and/or psychological concerns and end up not talking about how they feel.

At the moment mental health seems to be a popular topic in the media and on everyone’s agenda, but we could do with understanding more about the level of support across the country for men and their families struggling with prostate cancer. To this end we have embarked upon a Freedom of Information request to every NHS Trust in England and Wales trying to find out the level of awareness, support, signposting and follow-up from a psychological perspective. The results from this study will help inform us as we open the debate about improving the level of support men and their families deserve. If anyone has good or bad experience of using local psychological support services and would be willing to share with others please write to editor@tackleprostate.org

The study has just started and is expected to report by year-end. It is in conjunction with the Red Sock campaign in Wales www.theredsock.co.uk and facilitated by Wicked Minds www.wickedminds.co.uk I will keep you posted on developments.

Roger Wotton, Chairman Tackle Prostate Cancer

Free Help Line - 0800 035 5302