



Torbay Prostate Support Association

Serving men of all ages, and their partners, through a programme of support before, during and after diagnosis.

Newsletter Spring 2024

Welcome to the Spring edition of our newsletter. Winter is hopefully behind us, and we can look forward to longer sunnier days. March in the UK is Prostate Cancer Awareness Month. In TPSA its EVERY month.

Please pass on any feedback or interesting articles for future editions. These can be sent by e-mail to Mike Clay, the Newsletter Editor, mj.clay27@gmail.com

Article taken from the Winchester Magazine

Following on from King Charles's recent diagnosis of prostate issues, below is an interesting article from The Winchester Magazine which details Tim Dudderidge, an expert in the field, who conducted a very interesting zoom meeting with our group during November last year.

When ITV News Royal correspondent Chris Ship wanted to talk to an expert on Prostate, following the Kings discharge from hospital, he called Winchester Prostate Clinic Consultant, Tim Dudderidge. Tim, who featured in a zoom meeting last year, offers cutting edge and often completely non-invasive technology to treat men with prostate cancer and other urology issues. Chris Ship says we are so lucky to have such a high level of expertise across the board in our city of Winchester.

MAN TALK

It's the most common cancer in men, but most men with early prostate cancer don't have symptoms says consultant urologist Tim Dudderidge of TD Urology

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WHAT IS THE PROSTATE?

The prostate is a gland the size and shape of a walnut and grows bigger as you get older. It sits underneath the bladder and surrounds the urethra, which is the tube that carries urine out of the body. The prostate's main job is to help make semen – the fluid that carries sperm.

WHAT IS PROSTATE CANCER?

Prostate cancer can develop when cells in the prostate start to grow in an uncontrolled way. Some prostate cancers grow too slowly to cause any problems. But others grow quickly and are more likely to spread. Prostate cancer is not always life-threatening but, when it is, the earlier you catch it the more likely it is to be cured.

SIGNS AND SYMPTOMS

Prostate cancer that's contained inside the prostate doesn't usually cause symptoms. But if you have urinary problems it's important to visit your GP. These include difficulty starting to urinate or emptying your bladder, a weak flow or needing to urinate more often than usual, especially at night.

WHAT TESTS ARE DONE?

A GP will usually examine the prostate and request a PSA test – a blood test that can help diagnose prostate problems, including cancer. They may need to make a referral to a urologist. At TD Urology we can take self-referrals and offer an MRI scan, which can detect the presence of cancer at a very early stage with high accuracy.

WHAT TREATMENT IS AVAILABLE?

Treatment will depend on whether cancer is contained within the prostate gland, or has spread just outside of the prostate or to other parts of the body. I offer precision diagnosis with MRI-guided biopsy and treatment with focal therapy and robotic surgery. Patients benefit from access to the very latest technology and treatment options under one roof. Many localised prostate cancers grow too slowly to cause any problems or affect how long men live. In fact many with localised prostate cancer will never need treatment.

WHY GO PRIVATE?

TD Urology specialises in urology and offers individualised care. Waiting times are minimal and tests and treatment are carried out in the comfort of a private hospital. Often tests and consultant diagnosis are available on the same day.

023 8076 4391 | www.tdurology.co.uk



News of an award for Torbay Hospital (article provided by Nigel Bright)

Certificate of Achievement South West Integrated Personalised Care Awards 2023

Exercise Classes (Supported by TPSA) Wins Award

Cancer Services, (Torbay Hospital) were awarded the Choice & Control award at the South West Integrated personalised Care Awards 2023



At a TPSA speaker meeting I attended in 2023, mention was made of an exercise class. This was intended initially for people (men & women) starting radiotherapy; however it was widened to include men who were scheduled to have prostatectomies.



The class is known as a PreHab exercise class, run with help from Macmillan Cancer Support and some financial support from TPSA.

The objective is to get participants fitter in preparation for their treatment or surgery.

On the first visit you are assessed by doing four simple exercises each timed over one minute.

1. Chair stand up and sit downs
2. Wall push ups
3. Step up and step downs
4. Hand Grip strength test using a Dynamometer

The number of repetitions is recorded and the exercises are repeated again a number of weeks later to measure the improvement.

I thought I was fairly fit but the improvement before my operation was amazing.

The class is very friendly, and we all have a good laugh while doing the exercises. David, the instructor, is excellent and encourages everyone to do their best but not putting anyone under pressure to do more than they are comfortable with.

I'm not sure how long the class will go on being supported as it is, but I think the hope is that the NHS will provide future funds when they see the benefits.



Without being at the T.P.S.A. meeting I may not have known about the PreHab class.

To join the class, speak to your Urology Cancer Support/Specialist Nurse who can refer you to David.

Regards
Nigel Bright

Urology Department Paignton opening ceremony

On the 2nd of February 2024 Trustees Ian Nightingale and Trevor Wykes attended an official opening of the new Urology Investigations Unit at Paignton hospital.

The following pictures show the cutting of the tape ceremony, the cake that all enjoyed who attended the opening and more importantly the Biopsy chair and scanning equipment that the TPSA purchased on behalf of the hospital. Also shown is the area in the Recovery and Restroom where we cover the cost of refreshments to those undergoing investigation.



Urology Staff



Refreshment area



Biopsy chair & Scanner

Extract taken from Kevin Foster MP's recent newsletter published 7 February 2024

New urology investigations unit opens in Paignton

A new Urology Investigations Unit has officially opened at Paignton health and wellbeing centre. The urology investigations unit was opened by Torbay and South Devon NHS Foundation Trust chair Sir Richard Ibbotson on Friday 02 February 2024. The new unit serves the whole population of Torbay and South Devon.

Joanne Harrop, urology nurses outpatient manager and team lead, said: "The new urology investigations unit has given us the opportunity to expand and start new services, such as our trans perineal prostate biopsy service which is fantastic news for patients. We are now able to provide a one stop service for patients which gives them a much better experience.

"Our team has also grown since we have moved to our new unit and again, that will help us reduce waiting times for people. By seeing people more quickly we can give early diagnosis or reassurance, giving, where needed, earlier treatment, better outcomes and improved survival rates and quality of life for people."

Sir Richard Ibbotson, chair, added: "This new unit is a big step forward for us. We have never had a dedicated urology investigations unit in Torbay and South Devon before and thanks to everyone's hard

work in making this happen we now have everyone in the urology team all working together on the same site.

"We are delighted that representatives from Torbay Prostate Support Association who work closely with our urology service and who, over the years, have made significant donations of equipment, were able to join us for the official opening and to see the latest equipment they have funded in situ.

Bowel and Bladder talk

What an amazing start on 28th February to our 25th Anniversary year, with a bumper turnout of around 45 supporters (including 5 new ones). Hollie Campbell (Specialist Assistant Practitioner) and her colleague Steph from the NHS Bladder & Bowel care based out of Newton Abbot, gave an amazing presentation on symptoms and potential solutions to problems people may face. She dealt with this very sensitive topic in a way that generated so many questions and great interaction. She commented after how open people attending had been to talk about their personal experiences. A big thank you from all at TPSA.

To learn more about Hollie's presentation, open the following link to see her slides.

<https://1drv.ms/b/s!AuiP7xklsriNEEd3cUaW0KoOJa5g>



Hollie explained that pelvic floor exercises were a very important part of bladder control and she described many of the exercises that she thought would be beneficial to our group. To read more about these exercises please click on the link to view Hollie's slides about bowel and bladder and at the end of her slides you will find two further links. One on how to better evacuate your bowels and one on the pelvic floor exercises.



Following our Bowel and Bladder talk, Nigel Kelland gave us a very interesting and frank account of his experiences following his Prostatectomy

Performance Summary after Prostate Cancer Diagnosis

Prostate Cancer

Following irritative voiding symptoms and a gradual increase in my PSA to 8.4 in June 2009 and an internal check by my Doctor, I had a prostatic biopsy at Torbay hospital on 12 January 2010. The results gave Gleason values of 6 & 7

and I was advised to take early remedial action. Following detailed discussions with the joint oncology medical team at Torbay, I elected to have my prostate removed by a minimally invasive radical prostatectomy.



Incontinence

Following a prostatectomy at Musgrove Park Hospital Taunton, on 1st April 2010, I recovered quickly from the keyhole surgery and was able to return to near normal physical activities after a month. The major problem was after attending

consultations with the urological surgeon at Torbay and an outstanding continence physiotherapist at my local hospital in Totnes, and carrying out regular pelvic floor exercises with a registered Pilates teacher in Totnes, progress being able to control voiding was very limited. I was eventually comparatively dry at nights and was able to exercise reasonable control over voiding when sitting down at my desk or watching television. However, when standing up, walking, doing DIY, singing, sneezing etc., I had no control at all and had to change my wet day pad at regular intervals, typically 1 – 1.5 hours. I therefore regularly used a sheath when circumstances required, which significantly improved matters. Although incontinence did tend to dominate my life, I was in control and was able to minimise its impact by sensible preparations. Consideration had been made by my Torbay Consultants for fitting an artificial urinary sphincter and preliminary contact made with the consultants at Southmead hospital in Bristol. Unfortunately, investigating this permanent solution had to be put on hold due to an increasing PSA count and I had hormone treatment prior to radiation treatment scheduled that commenced at the end of June 2010.

Radiation Treatment

The radiation treatment continued for six weeks at the Oncology Department at Torbay Hospital in a professional manner with a very caring and friendly attitude. This went a long way to making what could have been a difficult experience considerably less arduous. The team answered any question, which helped my situation. Perhaps the most useful response was allowing me to see one of my scans and explaining what it meant. As a direct result I increased my morning in-take from five to six cups of water before treatment, which I believe contributed to the minimal side effects, apart from increasing tiredness over the last two weeks. Undoubtedly the worst experience was the nearly twice an hour hot flushes following the hormone treatment which, reduced to two a day following the prescription of cyproterone acetate tablets.

Following a good report some six weeks after the radiation treatment with my PSA count being < 0.01, my Torbay consultant arranged a meeting with the experts at Southmead Hospital Bristol for fitting an artificial urinary sphincter.

Artificial Urinary Sphincter (AUS)

I undertook urodynamics flow tests at Southmead Hospital on 15 Nov 2011 to assess my suitability for being fitted with an AUS. Perhaps the best Christmas present I have ever received was a letter telling me I was suitable for having an AUS fitted. The urodynamic studies found I had a low bladder compliance and detrusor overactivity incontinence, which could have the risk of my persisting with some leaking with an artificial urinary sphincter fitted.

The operation was carried out on 07 March 2012 and the device was activated after seven weeks on 10 May 2012. I am completely delighted with the outcome and although the warning of some leaking has proved correct, I use a single pad at night with very little leakage and generally manage with one pad during the day unless I am spending time being active, as when gardening or carrying out DIY, when I occasionally need to fit a second pad.

Remedial Issues

I began having problems with my AUS towards the end of 2022 with decreasing flow, the need to frequently having to activate it to void and increasing leakage. Following an appointment with the truly wonderful Urology Nurse Practitioner at Southmead Hospital in Feb 2023, I attended the urology department on 20th June for urodynamic tests. These were unsuccessful due to a stricture below my AUS and I was informed I would need a general anaesthesia cystoscopy for dilatation/laser of the stricture and I attended a pre-operative assessment on 11 July. The procedure was delayed due to the ongoing NHS pressures until 29th Nov 2023 when I was fitted with a catheter removed after seven days by two Totnes based nurses. The senior urologist consultant at Southmead Hospital had stipulated I had to wait up to eight weeks to make sure I didn't get another stricture. I therefore had to revert to using pads (up to six a day) and a sheath system for special occasions. It was particularly rewarding I was still able to control my pelvic floor muscles at night before voiding when I sufficed with a single pad!

Following a camera check on 1st Feb this year to check my stricture was sorted, my AUS was reactivated to my considerable relief, and I am now back in control of my waterworks again.

NHS Support

I emphasise I have been very pleased overall with the advice and support I have received from everyone I have been involved with and continue to be so in the NHS. The only possible criticism I have is not having had explained to me at the onset what total incontinence involves in practice, although perhaps it is only fully understood by those who suffer from it. It had crossed my mind on more than one occasion during the two years following my prostatectomy in 2010 before the fitting of my AUS, that the cure was far worse than the ailment as I changed yet another incontinence pad as I have had no physical manifestation of having cancer. But....I have had to remind myself that the cure hasn't killed me and I am still alive and active fourteen years later.

Nigel C Kelland (1st March 2024)

Disabled Sailing Association

In 2022 we enjoyed a talk from this organisation and below is further information about them and the voluntary services that they provide. We hope they will be able to attend our March coffee morning at the Paignton Club to update us on their activities.

Disabled Sailing Association receives the Kings Award for Voluntary Services (14 November 2023)



The Disabled Sailing Association is pleased and proud to announce that we have been awarded the Kings Award for Voluntary Services (KAVS) in recognition of the outstanding contributions made by our volunteer team. We are privileged to be one of the first organisations to receive this prestigious award given by our new King, which will both encourage and inspire our volunteers to continue to strive to support the wellbeing of our disabled communities, both locally and nationally.

Today, the DSA is supported by more than 70 active volunteers who fulfil critical roles including boat crews, boat maintenance, IT and administrative support, fundraising, finance, safeguarding, health and safety and market communications. We celebrate this award on behalf of all our volunteers.

The DSA was established as a charity in 2005, its purpose to provide safe and affordable sailing opportunities to adults and children, their families and carers. Since then, the organisation has grown to over 400 members, including the widest range of disabilities, ages and backgrounds, from the local area and beyond. Whilst some members suffer from physical disabilities, the majority of our members have other conditions, including all forms of mental health issues, prostate cancers, strokes, COPD, visual impairment, and other, less obvious, disabilities. Over the last few years people have been much more open about their various situations, which has helped them to come to terms with their conditions and also helped others to provide relevant support.

The DSA offers all our members the thrills of yacht sailing along our beautiful coastlines and the associated health benefits that this can bring. Our yachts,



which sail most days of the year, (weather permitting), are named DSA Freedom and DSA Free Spirit by our members because of that feeling of elation they experience when sailing, which brings so much relief and healing into their lives. It also promotes a healthy and active lifestyle

The DSA is an RYA Recognised Training Centre (RTC), which offers all our members the opportunity to gain valuable skills and knowledge to enhance their personal sailing experiences. The RTC is also run entirely by volunteers, headed by a Principal, and has a team of qualified cruising instructors who deliver both shored based and practical courses.



If you would like to know more about us, to understand how you, a member of your family or friends can join us, please contact us using the details below. We look forward to welcoming new members aboard.



www.disabledsailingassociation.org.uk



enquiries@dsadevon.org.uk



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Forthcoming meetings

TPSA meetings programme for the remainder of 2024

Please note Paignton Club is at the end of Paignton Sea Front at 1 The Esplanade, Esplanade Road. TQ4 6ED. This is a turning off the roundabout parallel to the sea front exit road which has a No Entry Sign. You will drive along the narrow road to the right of this No Entry Sign.

There is limited parking in front of the Paignton Club, there are a couple of Blue Badge spaces at the back of the building on Roundham Road. There is a multi storey car park on Cliff Road, first left after the harbour on Roundham Road, with a lift down to harbour level. There is also free parking in Cliff Park Road. Those with Blue badges can park for free on the seafront, others need to pay at the meters provided.

March 27th Coffee & Sharing Experiences (Paignton Club)
April 24th Speaker Helen Saxby (Torbay Hospital Consultant) (Livermead House Hotel)
May 22nd Coffee & Sharing Experiences (Paignton Club)
June 26th Speaker Sayeuri Buddu (Torbay Hospital Consultant) (Livermead House Hotel)
July 24th Coffee & Sharing Experiences (Paignton Club)
September 25th Speaker Amanda Lynn (Palliative care) & AGM (Livermead House Hotel)
October 23rd Coffee & Sharing Experiences (Paignton Club)
November 27th Speaker Rohan Davidson Carer Support (Livermead House Hotel)

Please note all meetings will be 10.00 am for 10.30 am start, for which there will be NO charge. Refreshments will be available. If you would like to contribute to the cost of these it would be much appreciated.

We look forward to meeting you at one of our future events.

Kind regards, ***Your Trustees***
(Please see our Website www.TPSA.org.uk for full details of your Trustees)

Disclaimer:

From time to time in our newsletters we provide information about developments in the diagnosis and treatment of Prostate Cancer, research articles, documents, presentations and other interesting materials. However, the TPSA Trustees and the Editor of this newsletter do not have the medical expertise required to make an informed evaluation of the conclusions and recommendations presented in such materials, and we have not verified such conclusions and recommendations through appropriately qualified medical professionals. The information presented in this newsletter must not be interpreted as being endorsed or recommended by the trustees or the editor. Any recommendations made in such materials may not be applicable in your particular case. Before implementing any recommendations made in the materials that are reported, it is essential that you obtain advice from appropriately qualified medical professionals. The view of the TPSA trustees is that no two Prostate Cancer cases are alike and that no single treatment option is better than any other in all cases. While the information in this newsletter should be of interest, there is no substitute for getting informed medical advice from your own GP, specialists and other medical professionals.

TPSA is registered with the Charity Commissioners as Number 1095734