



Torbay Prostate Support Association

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

Newsletter Autumn2023

Welcome to the Autumn edition of our newsletter. We hope you have been able to enjoy your summer holidays and continue to enjoy the Autumn weather which is often surprisingly good. We trust you will enjoy the content of this edition and do 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

Our July meeting

We were fortunate to have Ellyse Webb and her colleague Cyrus to speak at our July meeting. They ran through a very interesting slide show to illustrate how the prostate biopsies were evolving at Torbay Hospital under her guidance. Ellyse explained how she had moved from Southampton Hospital to take up



a one-year post as a grade 7 Nurse Practitioner. Thankfully due to the huge success of this setup, the Hospital has managed to convert her one-year contract to a permanent position for both her and Cyrus. Ellyse undertakes the biopsies, having reviewed previous investigations, including MRI scans. Ellyse explained that this process means that, where appropriate, a biopsy can be done more speedily after referral, leaving the Urology Consultants to deal with more complex operations and decisions regarding future treatment options.

Ellyse was happy to take questions which were many and, in several instances, she was able to make a note of the questioner's name and promised to speak to them once she was able to review their records back at work. This new treatment approach is very refreshing and greatly appreciated by all concerned.



Following the talk, the group took a coffee break and the partners formed a discussion group at the rear of the room while the men had the opportunity to ask more personal questions of Ellyse.



Ian then went on to update the group on various matters of interest. One aspect was that of travel insurance and below we list companies that may be able to assist those who are in the treatment process or waiting to receive treatment. As always there is no guarantee that any of these companies will provide cover. It is a list of companies that people have found to have been helpful in the past.

Please note TPSA are not recommending or endorsing use of any of these companies.

List of Holiday Travel Insurance Companies

Avanti Travel Insurance - Phone **0330 175 8283** Monday to Friday 9am-5pm
Closed Saturday, Sunday, and Bank Holidays

Puffin Travel Insurance - Phone 0333 772 0346

Allianz via Lloyds Bank - Phone 0371 200 0428 Monday to Friday 9am-5pm

Staysure Travel – Phone 0808 281 3025 Monday to Friday 8.30am-8pm Saturday 9am to 5.30pm & Sunday 10am to 4pm

Insure & Go – Phone 0808 281 1904 Monday to Friday 8.30am-8pm Saturday 9am to 5.30pm & Sunday 10am to 5pm

SAGA Travel Insurance-Phone 0800 015 8055. **Weekdays:** 8:30am to 6pm **Saturdays** 8:30am to 5pm



September Meeting and AGM

We held our AGM on Wednesday 27th September which was well attended by 40 members. The meeting started with a very interesting presentation by Gill Dell, who is the Lead Urology Cancer Nurse at Torbay Hospital.

Gill explained, with the use of slides, the location and function of the prostate. She talked about how prostate cancer feeds from male testosterone and explained how current hormone drugs worked by acting on the pituitary gland to stop it sending the chemical message to the testes to produce

testosterone. With early diagnosis this treatment, can effect a long-term cure and, when the cancer has already spread (metastasized), hormone drugs can be given on a long-term basis to halt the growth of cancer cells.



Gill discussed the various side effects of these hormone drugs and assured those present that, whilst the side effects could not be eradicated, there are a number of ways to help manage these symptoms to make them less distressing.

Her talk lasted for about one hour after which Gill answered many questions and we were all impressed by her knowledge and expert explanations.

After a short break for coffee, we commenced our AGM led by Ian Nightingale. Ian explained what the TPSA had achieved during the past year and Robin Causley, standing in for Trevor Wykes, read out our Treasurer's financial statement. This was followed by Clive Richoux's Secretary's report.

Our Trustee, Gill Clay, told the audience about her endeavour in setting up a Partners' group and how she wanted that group to share their own experiences and provide mutual support to each other.

Our Trustee, Mike Clay, informed the group that he had taken over the production of the newsletter from Mark Smith and its circulation to help Clive. Mike mentioned that he wanted it to be of interest to the group. Mike also explained why the offer of Lasting Power of Attorneys, in exchange for a donation to TPSA, was included in a previous newsletter, together with information relating to deceased estates which led to several requests for information, which is included later in this newsletter.

Finally, our current officers were re-elected, and we are pleased to welcome Debbie Hosking the daughter of our founder, the late Peter Hosking, to our group as a new Trustee.

2023 Prostate Health Awareness & PSA Testing Event

Following on from the overwhelming success of the events last year, we put 2 events in the diary for this year.

As reported in our last newsletter, our first test on 3rd May was a huge success and we are looking forward to hosting our second event at the Livermead House Hotel on 8th November, at 6pm to 9pm. If anyone is willing to help us man our awareness display, your support would be much appreciated, please contact Ian Nightingale on 07801775683 or e-mail chairman@tpsa.org.uk

Inheritance Tax (IHT) Information

For those who wish to know more about IHT, I have included below the link to the HMRC Government IHT Calculator. Just click on the link (or copy and paste it into your internet browser) and it will take you to the calculator.

<https://www.tax.service.gov.uk/guidance/check-inheritance-tax-due/start/date-of-death>

Click on the green start button and answer the questions. The results are not recorded or retained by HMRC, so it is possible for you to use it as an interesting tool to see if IHT would be due on your estate should you die. Below are some definitions...

Property is the value of your real estate like land and houses. Cash assets include cash ISAs. Household goods include jewellery, cars, boats, furniture etc. Trusts where you benefit, like receiving income, need the total trust value inserted. Debts and funeral expenses are separate questions. Gifts with reservation of benefit are where you make a gift but retain the use of the gift. Finally enter the value of gifts to married partners and charities, both these are exempt.

Remember the deceased should have a nil rate band of £325,000 plus if their married partner died leaving all their estate to them, they will have their £325,000 on top making £650,000. In addition, if the value of their last home passes to their children under their will, there could be 2 amounts of £175,000 available make a total exemption to IHT of £1,000,000.

This is a very simplified explanation so please contact me if you would like a more accurate assessment of your potential IHT liability on death.

There was a further question regarding "if, like myself, one has no living relatives, is there any alternative to having a solicitor as my executor". The short answer is yes as the government is encouraging us to deal with a loved one's estate and the Probate Court and HMRC are very helpful in this respect. However, you do need to choose someone who knows you and who you can confide in and trust.

Fund Raising

Trevor Wykes, our Treasurer, has been proactively pursuing our gift aid refund from HMRC amounting to £1,453.29. At our AGM, total donations and expenditure for the year were reported as follows.

Total Donations received (including £1,453.29 Gift Aid refund from HMRC)	£ 8,499.66
Total Expenditure (including £14,216.30 for 2 PSA testing events)	£17,883.98
Current Bank balance	£19,965.96

Preston Rotary Club Charity Golf Day back in June raised £1000 for TPSA and a cheque was presented in September to our Treasurer, Trevor Wykes by John Turner at Churston Golf Club.

This donation is gratefully received, as is the continued support by our local Rotary Club.



Information about a new development

Prostate Cancer study raises hope of scans for all men over 50

A study suggests that a National screening programme would save lives.

Article below - Taken from the Times newspaper by Eleanor Hayward, Health Correspondent - August 21st 2023

An MRI scan is a quick non-invasive procedure that can provide more accurate results than available testing (GETTY Images)

All middle-aged men could one day be offered MRI scans to check for prostate cancer, after new research paved the way for a national screening programme that could save thousands of lives each year.

The study led by University College London found that the scans are effective at spotting tumours and could form the basis of a “desperately needed” first NHS strategy for routine prostate screening.

Experts hope that within five to ten years all men over 50 will be invited for the 15-minute scans, in the same way women are offered mammograms for breast cancer, saying this would “significantly” reduce deaths.



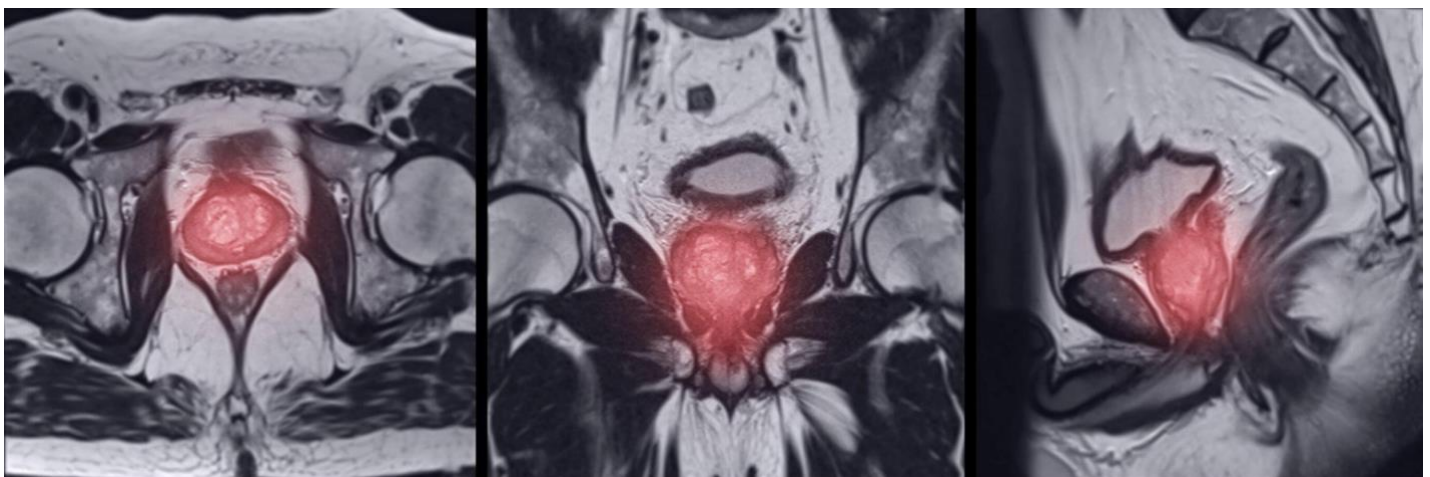
Only one third of men know Prostate Cancer can have no symptoms

Each year more than 52,000 men have prostate cancer diagnosed, and it kills 12,000. The UK’s death rate is twice as high as in the United States, Spain or Italy, which experts blame on low take-up of testing — meaning fewer cancers are caught early when they are treatable.

Unlike breast and bowel cancer, there is no routine NHS screening for prostate cancer because, until now, tests have been judged as unreliable. Older men can request a blood test from their GP to measure levels of prostate-specific antigen (PSA), which may indicate cancer if high. But PSA testing is unreliable, sometimes leading to unnecessary, invasive biopsies and over-treatment, while also missing too many cases of aggressive cancer.

The new study, published in the medical journal BMJ Oncology, found that MRI scans can “mitigate” these downsides and are more effective than the PSA test at diagnosing cancer. The trial, called Reimagine, involved 303 men aged between 50 and 75, who had both a screening MRI and a PSA test.

The scans picked up prostate cancer in 48 men, and 29 of these were found to need cancer treatment after further investigations. More than half of the men with cancer had a “low” PSA score, meaning that if screening had relied on the blood test alone they would have been wrongly reassured they did not have cancer.



Prostate Cancer is the most common cancer in men in the UK, but the prognosis for patient is vastly improved by early detection. (ALAMY image)

Using the scans also meant that less than 1 per cent of the men were “overdiagnosed” with low-risk cancer that did not require treatment, a significant improvement on [PSA testing](#), sparing them potentially harmful biopsies.

The team have now launched a larger trial as the “next step” towards a national screening programme, and will use a “scan in a van” initiative to visit communities and offer drop-in tests.

Professor Mark Emberton, author of the study, said: “Given how treatable prostate cancer is when caught early, I’m confident that a national screening programme will reduce the UK’s prostate cancer mortality rate significantly. There is a lot of work to be done to get us to that point, but I believe this will be possible within the next five to ten years.”

The UK’s National Screening Committee, which advises ministers on whether to roll out national prostate cancer screening, said it “notes with interest the findings of the study”. Professor Sir Mike Richards, who leads the committee, said screening is presently not recommended but that six proposals for [prostate screening](#) were being considered.

Simon Grieveson, assistant director of research at Prostate Cancer UK, said: “When a man’s prostate cancer is caught early, it’s very treatable. Sadly, more than 10,000 men each year are diagnosed too late, when their cancer has already spread.

“MRI scans have revolutionised the way we diagnose prostate cancer, and it’s great to see research into how we might use these scans even more effectively. These results are extremely exciting, and we now want to see much larger, UK-wide studies.”

Professor Nick James, from The Institute of Cancer Research, said: “The well-known limitations of the old PSA-based screening studies of over diagnosis and linked over treatment are increasingly mitigated by the use of MRI. Similarly, MRI can also spot cases of prostate cancer in patients with normal PSA levels, who would have been missed using PSA only screening programmes.

“This study adds further important data on the potential use of MRI as an upfront test independent of PSA and will allow planning of further studies aimed at optimising screening strategies.”

Why is there no national prostate screening yet?

1 in 8 white men and 1 in 4 non white men will develop prostate cancer at some point in their lives and the disease accounts for 14 per cent of all cancer deaths in males according to Cancer Research UK.

Despite being the most common cancer in men, proposals to roll out prostate screening have consistently been rejected because tests are simply too unreliable. The NHS has three national screening programmes: for breast, cervical and bowel cancers.

Previous hopes of adding prostate screening have been based around blood tests measuring levels of a protein called PSA, which can pick up cancer before symptoms emerge.

Instead of a national programme, the NHS offers an “informed choice” scheme that means men over 50 can request a PSA test from their GP. But three quarters of men with raised PSA levels will not have cancer and about one in seven of those with normal PSA levels may have cancer. However, thanks to scientific and technological breakthroughs, an effective prostate cancer programme is likely to be launched in the next decade. Research shows that new, more accurate, [MRI scans](#) are an effective way of determining if men could have cancer and need further investigations.

This reduces the number of unnecessary biopsies, and means the risks of screening may finally be outweighed by the benefits of picking up early-stage disease. Any screening programme may initially focus on those who are at the highest risk, including black men.

Early diagnosis is crucial to reducing the UK’s mortality rates, which lag behind many of our European neighbours. Survival rates are close to 100 per cent if it is caught early, falling to just 50 per cent if it is caught at stage 4, when it has spread to other parts of the body.

This Times article has been included for information only. The TPSA has no link to the article and cannot accept any responsibility for its accuracy.

Whilst the research reported above is on-going, both the national charities, Prostate Cancer UK (PCUK) and TACKLE prostate cancer support PSA testing based on an individual risk assessment. PCUK & Tackle are both lobbying the government for a risk-based screening programme, however until a better screening method is widely available PSA is the best option so don't wait to get tested. (The risk checker is available from PCUK)

Trial Information update

The use of trials is a key factor in developing new drugs and treatments. However, a reluctance to participate has been identified by PC UK and Mike Clay recently attended a Zoom meeting, run by Sara Nelson, relating to this matter. The main prohibitor for people taking part seems to be the language used in the 20 to 30 page document that has to be signed by the participant. During the meeting we considered the various medical terms and agreed a simple definition of some of these terms in the hope that it will enable more people to feel comfortable with taking part.

As an example, we agreed the following definitions.

Random - A selection made without consideration of the consultant or person selected.

Placebo - A substance having no known medical properties.

Blinding - A selection where only the consultant knows who is given the new drug or placebo.

Double Blinding - A selection where only big Pharma knows who is given the new drug or placebo.

Trial phases were also explained, these being Phase 1, safety and side effects, through to Phase 4, evaluation of long-term use and NICE authorisation.

Forthcoming meetings – Details to follow

22nd November. 6.00pm for 6.30pm start. THIS MAY BE A ZOOM MEETING. (To be advised)

17th January 2024 - Our Christmas/New Year lunch at the Livermead House Hotel.Meeting at 12pm for our meal at 12.30pm. The cost will be £26.50 per head.

See booking form at the end of this newsletter. Please indicate your menu choices and make payment by cheque payable to TPSA or by a BACS payment, details below,,,

TPSA at NatWest Bank

Sort Code: 52-10-18

Account: 10270108

Please send booking form to Mike Clay, Well House, Blackstone Road, Ipplepen, Nr Newton Abbot, Devon, TQ125QN, together with your cheque if not paying by BACS.

Kind regards,

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



TPSA Christmas Menu at The Livermead House, Hotel
On 17th JANUARY 2024 at 12 noon for our 12.30pm meal



STARTER

- Smooth Chicken Liver and Brandy Parfait,
Winter Fruit Chutney and Melba Toast
- Chef's Homemade Tomato & Basil Soup (V)
- Classic Prawn Cocktail with Brown Bread & Butter

MAIN

- Traditional Roasted Crown of Torbay Turkey, Bacon Roll,
Chestnut Stuffing, Madeira Jus
 - Baked Fillet of Salmon "Bonne Femme"
(White Wine, Mushroom & Shallot Cream Sauce)
 - Ragout of Wild Mushrooms (V)
Chestnuts & Cranberries in a Filo Basket
- Selection of Fresh Seasonal Vegetables and Potatoes**

DESSERT

- Cream Filled Profiteroles coated with Hot Belgian Chocolate Sauce
- Livermead Home Made Christmas Pudding with Rum Sauce
- Fresh Fruit Salad with Devon Clotted Cream

FOLLOWED BY

Fresh Filter Coffee and a Warm Mince Pie



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Please complete and send the lower part of the booking form to Mike Clay, together with your cheque payable to "TPSA", for £26.50 per person, as soon as convenient, or advise Mike that you have paid by BACS **. **The last date for booking, with full payment, IS REQUIRED by the end of November 2023. Send all booking forms and your cheque/s to :-**
M Clay, Well House, Blackstone Road, Ipplepen, Devon. TQ12 5QN - by the end of November 2023.

** Please circle your chosen payment option I have paid by BACS OR Cheque (attached)

MEMBER NAME Guest/Partner

STARTER

MAIN

DESSERT

Your menu choice will be noted on your place name which will be displayed on the table to assist the serving staff in providing you with the correct meal choice.