



Torbay Prostate Support Association

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

Newsletter Spring 2023

After a fairly cold winter the spring bulbs are starting to flourish, and the birds are out in full song and we in TPSA look forward to an exciting year ahead. Giving us renewed energy to ensure we take every opportunity to raise awareness of Prostate Cancer in the wider community and offer effective support to our members.

New Year Lunch

It was great to see so many people at this event in January held at the Livermead House Hotel. 18 people attended and there were some new faces present which was exceptionally pleasing. It did feel a bit strange to be listening to Christmas Carols and pulling crackers in January. The food was lovely and there was lots of interesting conversations and a strong feeling that we should repeat it again maybe with an additional mid-year event.



Members' meetings

In February we were very fortunate again to have Dr Helen Saxby, Consultant Clinical Oncologist join us at our meeting. During the morning she explained that this is an exciting time for prostate radiotherapy with new national clinical trials opening at Torbay Hospital Oncology Centre. Torbay Hospital is currently recruiting to the Pivotal Boost Trial which aims to improve the effectiveness of treatment by giving a higher dose of radiotherapy to the area within the prostate where the tumour is located. Torbay Hospital is also working to open the PACE-NODES trial investigating the use of stereotactic ablative body radiotherapy in the treatment of prostate cancer and pelvic



lymph nodes; thus, reducing from 37 to 5 treatments. Helen spent nearly 2 hours with us answering numerous questions, helping put members' minds at rest.

New initiatives

Prehabilitation Initiative in Torbay

We have been approached by Debby Hill from Torbay NHS, to see if and how TPSA can help support a new project she is proposing to run. The programme is a Prehabilitation Project for men with Prostate cancer to support them to enhance their functional capacity prior to cancer treatments. The aim is to provide Prehab for these patients as part of a group setting, providing peer support as well as education. The funding for this project has come from Macmillan and it is being run via staff recruited by Torbay Hospital. We have agreed that we will support this project by funding the costs of venues for the trial period and attending the group sessions, when possible. As noted later, we are delighted that Debby will be joining us for our meeting on the 24th May.

Project to Develop a 'Late Effects of Radiotherapy' service in Torbay



Suzanne Hill, a Therapeutic Radiographer, working at Torbay Oncology Unit has been selected to take part in a Southwest Regional pilot project to develop a Late Effects of Radiotherapy service, to benefit people who may be experiencing ongoing effects from the radiotherapy they received to treat their cancer.

Radiotherapy can be a life-saving, effective treatment for certain cancers, but one of the less well recognised side effects of the treatment is that some people who have received treatment may be affected by long-term side effects as a result. These might be physical or psychological effects months or even years after treatment has finished, such as bladder or bowel changes, skin changes or pain or swelling in the treated area.

Macmillan are providing funding to establish a regional Radiotherapy Late Effects Service for centres in Taunton, Bristol, Bath and Cheltenham. At the moment Torbay, Exeter and Truro are not funded by Macmillan but staff in these centres have been allocated some time out of their clinical roles to begin to build services locally with the long term aim after the two-year project is complete to

be able to provide a full-time service. The project is the first of its kind in the UK, whereby NHS trusts across the region have worked with Macmillan to give all patients the same level of support.

As part of the Radiotherapy Late Effects Service, Suzanne will be able to provide specialist advice and support to people living with ongoing effects from their treatment. This ranges from lifestyle changes and self-management through to prescribing, counselling and specialist referrals. The service hopes to reduce the impact the late effects are having and improve people's quality of life.

Anyone who's finished radiotherapy treatment for cancer and who feels they might be suffering from treatment side effects should ask their GP or health care professional about getting a

referral to the Late Effects Service - please contact Torbay Oncology Unit, Suzanne Hill, email address suzanne.hill@nhs.net for further information.

Further information: Macmillan – [Late effects of treatment | Macmillan Cancer Support](#)



Use your smart phone to click on the QR code above for more information.

Meetings

We recognise that it might help attendance at meetings if we were able to publish at least an outline schedule of proposed meetings for 2023. To this end we are working on putting together a programme, which will be emailed to everyone on our mailing list, published on the website www.tpsa.org.uk and also on our Facebook Group. However, our planned dates are detailed at the end of this newsletter for those who do not have an internet connection.

2023 Prostate Health Awareness & PSA Testing Event

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

Again, they will be held at the Livermead House Hotel, Torquay on 3rd May and 8th November, both 6pm to 9pm. If you can help us man our awareness display on either evening, your support would be much appreciated, please contact Ian Nightingale on 07801775683 or e-mail chairman@tpsa.org.uk



On the 30th March 2023 we provided an awareness presence at an event run jointly by the Rotary Club of Dartmoor Vale and the Rotary Club of Newton Abbot at Dainton Golf Club where 198 men were tested for

their PSA level. We were able to hand out our information booklets entitled “Know Your Prostate” which were well received as many men did not know where the prostate was in the body or its function. Our presence was very well received with grateful feedback from those who took part and those who organised the event.

We managed to raise the TPSA profile and explain the role of the TPSA to those taking part, and gave them information about our meetings, and lectures at which we told them they and their partners would be welcome. This intervention has resulted in us collecting 95 e-mail requests for our TPSA newsletter. We would like to thank the Rotary Clubs of Dartmoor Vale and Newton Abbot for inviting us to support them, for making us feel so welcome and for their offer of help at any future event that we might hold.



Message from a past satisfied participant

Dear all

I would first like to thank the TPSA (Torbay Prostate Support Association) and the Rotary Club of Preston, for setting up the two PSA (prostate-specific antigen) sessions at the Livermead House Hotel in 2022, of which I attended the first one they held in June.

It all started in May 22, after my wife saw on Facebook that a session was being held at one of our local hotels. She thought it would be a good idea for me to go for a test. I did some research and quickly jumped at the opportunity to have a PSA test, especially as I was over the age of 50. Until then I had no idea on what PSA meant and what was involved. During the session I was given so much information, which explained everything and was then given a simple blood test. Also throughout the session the volunteer's and nurses were extremely helpful, supportive and very welcoming.

After having the test, a few days passed and I received an email informing me the results had shown abnormal levels. From that point you fear the worse, but checked online and the levels seemed low enough to be at an early stage. I waited a few weeks before I discussed it with my GP, who then arranged a follow up PSA test that came back slightly higher. My GP recommended further tests and referred me to the Urology Department at Torbay Hospital. Within two weeks I was flat on my back having an MRI scan, the results did highlight an enlarged prostate. The consultant recommended a prostate biopsy which came back clear two weeks later, however they did recommend that I continue with PSA tests every 6 months.

I did read a recent post on the Rotary Club of Preston Facebook page, which confirmed that over 230 men had attended the same session from which 14 received red letters, me being one. I will admit the red letter does cause some concern, but for all the right reasons. I understand that further sessions are planned in 2023. So please do get yourself checked, especially if you are over 40 or speak to your GP if you have any questions.

Thank you again TPSA, Rotary Club of Preston and Torbay Hospital Urology Department.

Marcus
Torquay

Fund Raising

CORRECTION - In our last newsletter we made reference to a very generous donation made by Margaret Tomlinson. This should have said it was made from the Martin Tomlinson Family Fund **and not** the Tomlinson Family Trust. We apologise for this inaccuracy.

During the period from December 2022 to mid-March 2023, TPSA received donations in the region of £2,000. This was made up of £750 associated with Mike Clay's tremendous efforts with Wills & LPA's, £500 from Torbay Council Community Fund (in support of our new website), the balance being from individual donations, collecting tins, etc. We recognise people are struggling financially, so we are even more grateful for these donations that allow us to continue our Awareness and Support activities.

Have you considered a Lasting Power of Attorney?

A Quote from Martin Lewis's Money Saving internet page in March 2023

“One person in the UK develops dementia every three minutes. Yet relatives can't just walk into a bank and access your money, even if it is to pay for your care. Unless you've a Power of Attorney, loved ones would need to apply through court, which can be long and costly. I think in many ways, a Power of Attorney is more important than a Will, because if you die, you die, and the money is going to go on to other people and you won't use it anymore.”

A Lasting Power of Attorney (LPA) enables you (the donor) to appoint one or more people (the attorney/s) you trust to make decisions on your behalf when you can no longer do so or just when you need a little

extra help. As well as your Will, an LPA is another important document you should have in place, but as costs range from £250 to £450 per LPA, (plus the Court registration fee of £82 per LPA), many people do not bother. An LPA can only be made whilst you have all your mental faculties so don't delay as we are offering you the services of one of our Trustee members who is a qualified retired professional with qualifications relevant to Investments and various tax implications, plus Wills and the Administration of Trusts and Deceased Estates, (*having retained his membership of the Society of Trust and Estate Practitioners as a retiree*). All we ask in exchange for this assistance is a meaningful donation to the TPSA. Please be aware that the £82 Court registration fee still needs to be paid per LPA.

There are two types of LPA, one deals with your **Property and Finance** and the other deals with matters of your **Health and Welfare**. Once these documents have been signed and registered at the Court, you can rest assured that, if you become unable or unwilling to look after your own affairs, your wishes can be actioned by those you have chosen and trust. Without an LPA, those near to you have no legal right to make decisions or speak on your behalf, unless they go through the Court of Protection which is a very expensive and protracted process. If you would like to contact Michael Clay regarding help with your LPA, his e-mail address is mj.clay27@gmail.com or you can phone him in an evening on **01803 – 812052 or Mobile 0751 303 5557**

Facebook Group

If you have not already joined the group, please search T.P.S.A and ask to join. This is where hot topics and areas of interest can first be viewed, and you have the opportunity to tap into the wealth of knowledge in the group.



Request for information regarding treatment of Metastatic Castrate Resistant Prostate Cancer (mCRPC)

We have received the following request from a group who are working with Evolve Fieldwork on a study about Metastatic Prostate Cancer and they would like to collaborate with the TPSA.

They are conducting opinion research to gain insights into patients' experiences and behaviour while coping with Prostate Cancer Disease in a way to improve their quality of life when going through the disease. This research is NOT related to clinical trials for Prostate Cancer patients and would like participants who would be willing to complete an online survey. Below is an extract from their request, so please feel free to complete their survey.

“Evolve Fieldwork is working with Evidera, a scientific research company, working on behalf of a global pharmaceutical company, to learn about patients' preferences for treatments of Metastatic Castrate Resistant Prostate Cancer (mCRPC). If you are interested and eligible to take part, you will be asked to complete a 30-minute online survey. The study does not involve taking any treatments; we are only interested in your opinions. As compensation for your time, you would receive an incentive of £40.00 for taking part in the interview.”

Thank you - Gretel Urdambidelus Rodriguez

Click the link to complete the form <https://forms.office.com/e/pBs0LRPN53>

How can you help TPSA

Our current Secretary, Clive Richoux moved some time ago to live in Exmouth, but continues to support the TPSA. We are looking for a successor. If you think you might consider taking over this role, please speak to Clive (Phone number 01395 269334 or Mob 07932 997 983) or Ian Nightingale, our Chairman, to find out more.

Forthcoming meetings – Details to follow

We have confirmed the following meeting dates with the Livermead House Hotel, Torquay in the Kingsley Suite.

24th May. 10am for a 10.30am start concluding around 12.30pm. As noted previously, Debby Hill will be giving us more information about the new Prehabilitation Project. This Project aims to maximise the benefits of treatment by providing information and support at the beginning of their treatments.

We are also pleased to welcome a representative from The Lodge, Cancer Support and Information Centre, who will be able to update us on their services for both patients & their partners.

We hope to have a coffee break mid meeting, when the partners attending can retire to a different area to enjoy their coffee giving the men the opportunity to ask personal questions.

26th July. 6.00pm for 6.30pm start. Ellyse Webb, who spoke at our Zoom meeting last November, will be giving a presentation about progress of the Nurse led Diagnostic Clinic. We intend to offer a voucher towards the cost of purchasing refreshments at the hotel. Once again, partners are invited and will be made very welcome.

27th September. 10am for a 10.30am start concluding around 12.30pm.

22nd November. 6.00pm for 6.30pm start. THIS WILL BE A ZOOM MEETING

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