



Torbay Prostate Support Association

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

Newsletter Summer 2023

Welcome to the Summer edition of our newsletter. As we continue to enjoy the warm weather and have either been on, or are looking forward to, our summer holidays, we hope you will enjoy the content of this edition. We would be interested to get your feedback and would welcome articles for future editions. These can be sent to Mike Clay, the Newsletter Editor.

New initiatives

Prehabilitation for Cancer service in Torbay is a pilot scheme designed to help you and your body prepare for future cancer treatment.



We held an interesting meeting on the 24th May 2023 at the Livermead House Hotel when Alison Poyner and Julie Eason, both from The Lodge (an NHS support facility for cancer sufferers), gave us a clear insight into how they can support prostate cancer sufferers from first diagnosis right through their treatment plan and beyond. Not only can the patient be supported but they both made it very clear that they wanted to include partners in their support package.

increases a patient's chances of their treatment producing a better outcome.

Research has shown that being fit from a physical and mental viewpoint greatly



The Lodge Cancer Support and Information Centre, based in Torbay Hospital Annexe, is available for anyone affected by cancer. They offer telephone or face-to-face support. You do not need a professional referral and you may be having treatment at hospitals other than Torbay.

They offer information, emotional support, financial and benefits advice, applications for Macmillan grants, complimentary therapies, relaxation classes, pamper sessions for both women

and men, genetics counselling clinics and signposting to a wide range of local support and services.

The Lodge is a warm, welcoming house; an oasis of calm away from the hustle and bustle of the hospital, with a pleasant garden to relax in when the weather is fine.

Alison and Julie would like volunteers to come forward to share their stories with others to relay what they have experienced, while being careful not to give advice, as each person must make their own choice regarding their form of treatment, but having the knowledge of different treatments is considered important. Contact details for Julie are julie.eason1@nhs.net

The Lodge website link is <https://www.torbayandsouthdevon.nhs.uk/services/cancer-support-services/the-lodge/> (Just click on this link or copy and paste this link into your browser)

Our speakers also mentioned an award winning “Cancer Companion App” designed by NHS Cancer teams for NHS Cancer patients called “**MySunrise**”. The app supports patients every step of the way through treatment at their local NHS Cancer Centre. It provides complete up-to-date information and a support tool for patients and their families, before, during and after cancer treatment at their Cancer Centre. This app is available for both Apple and Android devices.

Our speaker, Allison Poyner, has sent us the following text which we hope will be of interest.

The Look Good Feel Better workshops are a great way to engage and learn techniques to support men through treatment and beyond (an interest list for men is available)

Complementary therapies are also open to patients and carers on an appointment basis, but patients must be free of treatments (chemo/radio surgery) for up to 8 weeks.

We have a wide range of community support from yoga to sea swimming, arts & crafts etc

Appointments for Financial support with a Citizens Advice advisor are available Monday – Friday

Holistic Needs Assessment to support patients in identifying their concerns and for health care professionals and support workers understand their needs.

Hope Programme for patients who have finished treatment and are looking for strategies to help support them day to day

All the above are available to book through the Lodge, we are open Monday – Friday 9-4pm



After our formal presentation, we had coffee but invited partners to have their coffee away from the men who were able to raise any personal questions with our two speakers. One of our Trustees, Gill Clay spoke to the partners/wives and explained that it was felt the partner needed as much support as their loved one undergoing the prostate cancer treatment. Several of the ladies were glad of the chance to talk about their feelings and fears and all agreed it was a very worthwhile exercise which we will be repeating at some of our future meetings. Debbie Hosking, the daughter of the late Peter Hosking who founded the TPSA, was present and was able to explain the reason why her father set up the charity and what he would want it to achieve.

We must never underestimate the pressure and emotional strain put on partners once their other half has received a diagnosis and that they too need a forum to discuss their feelings. At our recent supporters' meeting we change the format somewhat to have a breakout session for partners. This gave the men and their partners a "safe space" to open up about personal issues they might find hard to discuss with "strangers".

Seven partners attended the session and were able to talk about a wide variety of topics and needs. It was recognised that partners look for a different level of support to their men and maybe at a different time, therefore establishing a group longer term, would provide that much-needed resource. If your partner would like to attend the next session this will be held as part of our next meeting on the 26th July, 6pm for 6:30pm start at the Livermead House Hotel.



Following coffee, the partners re-joined the main group and discussions were finalised. At the end of our meeting we discussed a possible Christmas/New Year celebration lunch and, on the evidence received, we booked our meal for the 17th January at the Livermead House Hotel 12pm for 12.30pm at a cost of £26.50. Full details of the menu will follow a little later in the year when you can book and make your choice of food from the menu. We merely mention this now so you can hopefully keep this date free in your diaries.

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 advised in our last newsletter, the Livermead House Hotel, Torquay hosted the first test on 3rd May (see below) and will host our second test on 8th November, both 6pm to 9pm. If you can

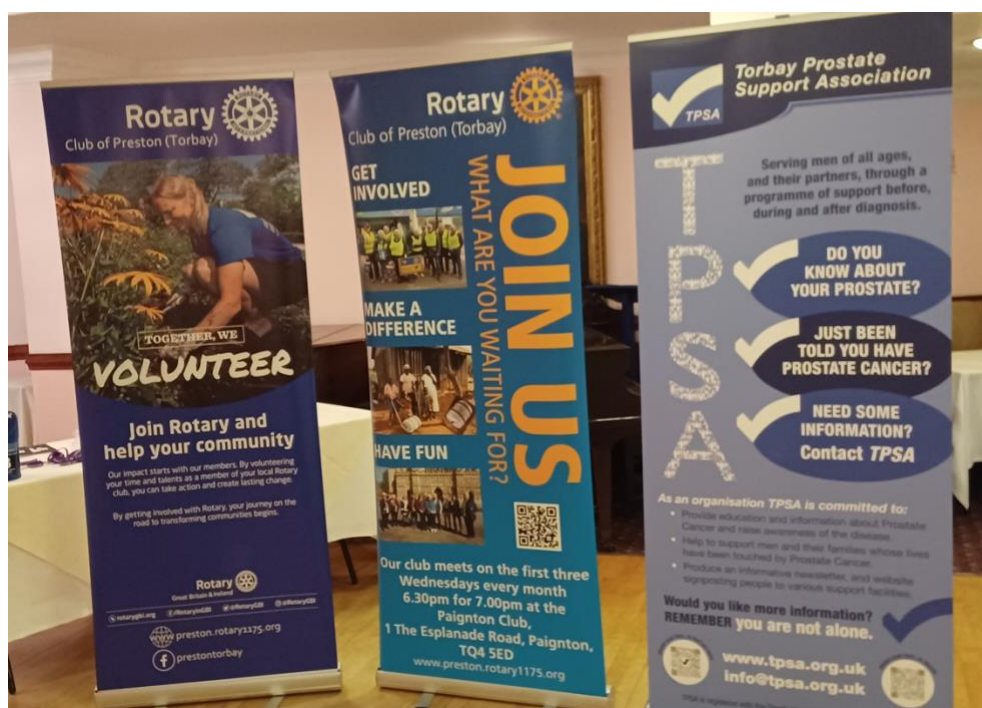
help us man our awareness display, your support would be much appreciated, please contact Ian Nightingale on 07801775683 or e-mail chairman@tpsa.org.uk

On the 3rd May 2023 we conducted a PSA testing event at the Livermead House Hotel and tested 341 men. The results were very much in line with previous events, with 19 men receiving red warning letters and there were 8 amber warnings. All were advised to follow up this with their GP. Four of these warnings were to men in their 40s and five were in their 50s which highlights the importance of these events.



That evening we managed to raise the TPSA profile and explain the role of the TPSA to those taking part. We gave them information about our Association and its meetings. We also collected over 156 e-mail addresses from those interested in receiving our periodic newsletter. We would like to thank the Livermead House Hotel for their support and for making us feel so welcome.

Once again, a big thank you to the Rotary Club of Preston (Torbay) for their continued financial and practical support in marshalling the event. We could not do it without them.



Fund Raising

During the period from May to June, the TPSA received donations of £3,969. This was made up of £2,216 in May through general donations, £300 in June, associated with Mike Clay's fund raising efforts with providing guidance with LPAs and obtaining Probate and Estate Administrations plus Wills, and £1,453 from HMRC regarding Gift Aid. As previously mentioned in an earlier newsletter 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 and is your Will up to date?

Unlike a Will, that only takes effect on death, a Lasting Power of Attorney (LPA) can be utilised during life and 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. The TPSA is offering you the services of Mike Clay, one of our Trustee members who is a qualified retired professional with relevant legal qualifications, to assist you with your LPA. All we ask in exchange is for you to make a meaningful donation to the TPSA. Please be aware that the £82 Court registration fee still needs to be paid per LPA.

Michael will explain the two types of LPA and complete the 20 page document, ensuring it is completed properly and ready for registration with the Court in Birmingham. 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**

Regarding Wills

Many people believe that following their demise, their estate will pass to their spouse so there is no need for a Will. Sadly, this is not the case for those who die intestate (*with no Will*). According to recent data 60% of adults do not have a Will and therefore, their estates will be distributed under the rules of intestacy.

For low value estates under £270,000, a surviving spouse or civil partner will inherit the whole estate, but for those estates exceeding £270,000, or where there is no partner, you will need to follow the table at the end of this newsletter to determine who will inherit your money. If there is nobody able to take, then the estate will pass to the Duchy of Cornwall or Lancaster, depending on where the deceased lived. **From 26th July 2023 this £270,000 is set to increase to £322,000.**

Unfortunately, the intestacy rules do not necessarily reflect the modern world. Unmarried couples are not included in the order of inheritance, nor are unadopted stepchildren. Where blended families are concerned, not leaving a Will could result in loved ones (and those financially dependent on you) not being provided for and a possible increase in inheritance tax charge. If all beneficiaries are of age and agree, it is possible to include outsiders by completing a Deed of Variation within 2 years of the death.

Those outside the order of intestacy can make a claim under the Inheritance (Provision for Family and Dependants) Act 1975. This must be made in most cases within 6 months of the issue of the Grant of Letters of Administration but there is no guarantee of success.

Finally, you should be aware that your last marriage will revoke any prior Will made, unless that last Will has been made in “contemplation of marriage”.

At the end of this newsletter is a flow diagram that indicates who will inherit your money on your intestacy.

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

We would like to re-run our Spring newsletter article about Metastatic Castrate Resist Prostate Cancer from the Evolve Group who would like those affected to contact them so they can work with them 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>

Information from our member, Richard Rogers, for those who have had Radiotherapy in the past.

*In the last TPSA newsletter, I noticed mention of a new Radiotherapy Prostate Initiative at Torbay Hospital. It goes by a very catchy title **Macmillan Radiotherapy Late Effects Service**. It is part of a wider South-West Region project to develop a network of support for patients and radiotherapy centres. It is a follow-up service for those who may have received Radiotherapy treatment. Late effects can occur anytime, from 6 months to many years after treatment. I fall into the second category having undergone this treatment about 14 years ago following a laparoscopic prostatectomy.*

My GP recently prescribed Solifenacin a drug to help control my bladder. It has, as many drugs, an unpleasant side effect. My mouth has been horribly dry at night making my tongue and palate sticking together. It restricts the pee, I want to gag, but I slept for almost two hours - not up every hour.

The article caught my eye and set me on this new path. I was due to see my GP Doctor the following day, so I went armed with the information for him to read. A GP's referral letter is required, and he immediately emailed my details to the Late Effects team. Within days a letter arrived with a lot of information to absorb and an appointment to meet Suzanne Hill who is part of the Torbay Oncology Team. In the letter were diary pages; bladder, bowel and stomach questionnaires; pages of detailed questions covering physical, family or relationship concerns, physical and practical concerns among many more. I have never experienced such detailed questioning of my overall health, physical and mental wellbeing. The Team is looking at and considering the whole body, not just the immediate ache or pain. I found this to be an excellent approach to care. I was tasked to keep the diary pages of my liquid input and output. This was monitoring for three days, on a 24 hour basis, accurately measuring all liquid, both in and out. Also noted was the type of liquid - tea, coffee, water, squash, coke and alcohol. It is a 24 hour task and I took a couple of 'dry' runs at it until I got used to measuring pee at 3 or 4am and noting it accurately. There were also searching bladder health questions. All this information is returned to the hospital in advance of your appointment.



Suzanne has access to this record and to your prescription drugs, so she is able to discuss your health as a whole, not just your cancer details. She is incredibly easy to talk to and during the

hour or so that we sat together we covered a wide area of my health and family concerns. I also learned a lot about myself and MY approach to health. It was a very constructive and reassuring meeting. For example, this new clinic offers information about clinical services, bladder retraining, side effects, nutrition & diet and alternative approaches to conventional medicine. This is a broad, thoughtful approach to one's health and nutrition that may include pro and pre-biotics, mineral supplements and vitamins such as D3. (I have my daily D3, K2 and Zinc!). An alternative may be a course of acupuncture! There is some evidence that Acupuncture may assist with bladder problems and control.

I have been following daily bladder and pelvic floor exercises that will be reviewed in a telephone call with Suzanne later this month. This will be followed by a clinic appointment to look at my overall improvement in a couple of months.

Article from Richard Rogers

The Infopool - is a patient resource of information.

We attended a recent Tackle meeting where Harriet Lee, their guest speaker, explained the Infopool. This is a search facility which is primarily designed for newly diagnosed Prostate Cancer sufferers. It is written in straightforward plain English. It is an interactive menu driven facility where the user can first pick their ethnicity, their age, and specific information about their Prostate Cancer diagnosis which includes, where possible, the Gleason score, etc. Based on this information, by following menus on the programme they can: -

- Learn about testing and diagnosis
- Understand treatment choices
- Get information on clinical trials
- Find information on living with side effects

The information is displayed in several formats, one being videos of different people talking about their experiences and outcomes of many types of clinical treatments.

One can log into The Infopool website by typing or clicking on this link

<https://www.theinfopool.co.uk>

Forthcoming meetings – Details to follow

The following meeting dates are at the Livermead House Hotel, Torquay in the Kingsley Suite.

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. Topic to be advised.

22nd November. 6.00pm for 6.30pm start. THIS WILL BE A ZOOM MEETING. (Topic to be advised).

17th January 2024 **A date for your diary** - 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, we will ask you for your menu choices a little nearer the date.

Kind regards,

Your Trustees

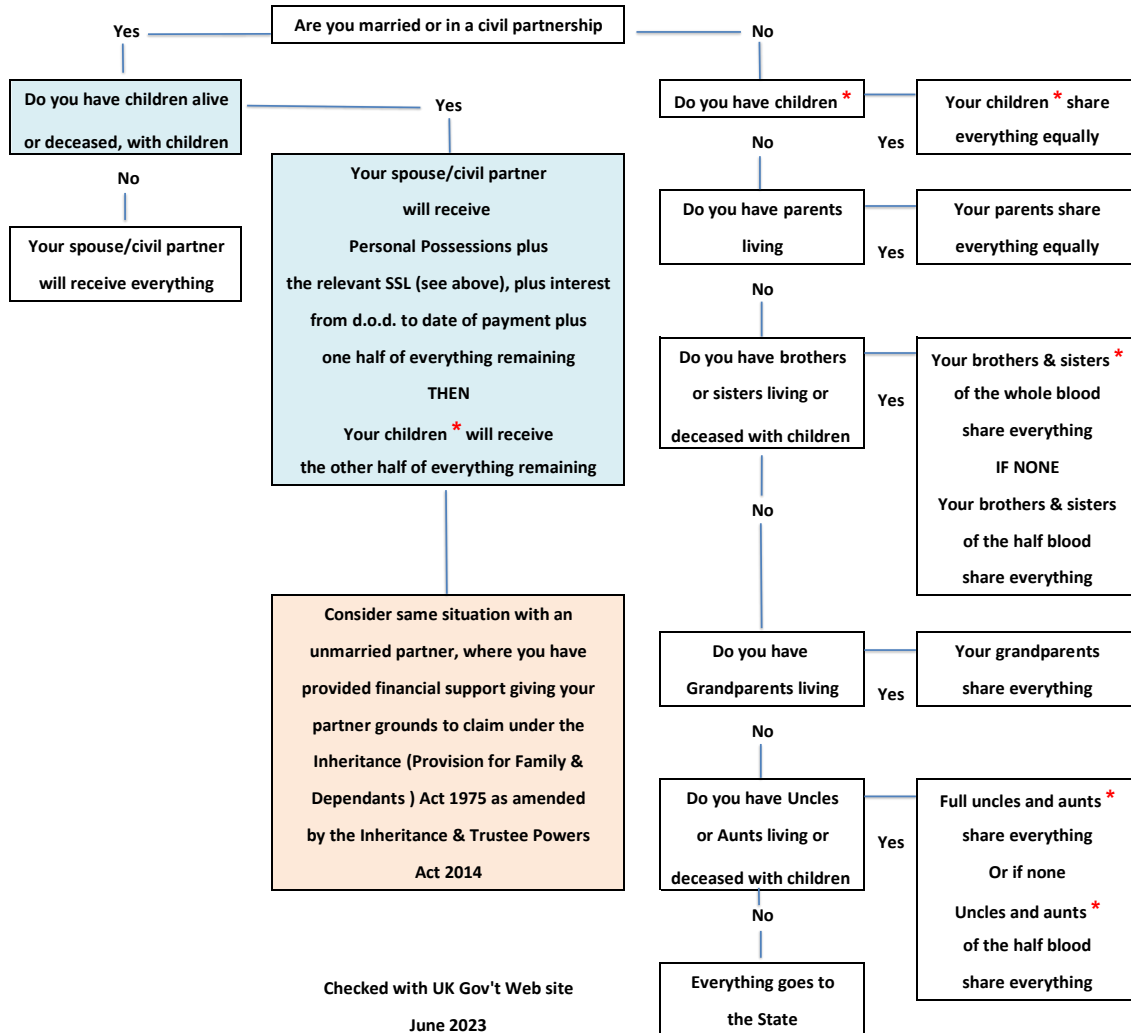
Disclaimer:

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

Inheritance & Trustee Powers Act 2014 - Intestacy Flow Chart

ALL Questions relate to deaths after 1/10/2014 when the Spouse Statutory Legacy (SSL) was £250,000 up to 5th February 2020 but from 6th February 2020 to 25 July 2023 SSL increased to £270,000 and from 26th July moving forward, the SSL will be increased to £322,000



Where two people die in circumstances where it is impossible to determine who died first, the Commorientes rule states the elder predeceases the younger (s184 Law of Property Act 1925) HOWEVER, where intestacy is involved there is a presumed 28 day survivorship clause under (s46 {2a} Law of Prperty Act 1925) so another good reason to make a Will.

*** NOTE ***

Where a class of person has predeceased leaving children surviving, those children will take per stirpes their deceased parents share

Children includes adopted and illegitimate but not step children

Chart created by Michael Clay (E&O Accepted)

FAAI, ACIB, Cert Ed (FE); IAC, TEP Retired, Trust & Estate Practitioner.