



A note from the Chairman

As Autumn starts to take hold, I hope that this newsletter find you and your families in good health. It was great to meet so many of you at our first face to face meeting for many months at the meeting on 3rd September. We had an excellent presentation by Linda Welsh & Gill Dell from Torbay Hospital, who explained the developments and changes to working patterns & pathways within Urology and Oncology. A copy of the presentation can be found on our website.

BEM Presentation to Peter Hosking

As many of you will have read in an earlier newsletter in the 2021 New Years Honours List our President Peter Hosking was awarded the BEM for services for his commitment to supporting people with Prostate Cancer. Under his leadership TPSA has raised over £500,000 and supported hundreds of men and their families. Due to COVID the award presentation was delayed but was finally presented at the end of October by the Lord Lieutenant of Devon David Fursdon. Well done Peter.



Members Reflections

Keith Wilby – My Experience with the PACE Trial.

Firstly : What is the PACE “C” trial

It is the third PACE Trial overseen by The Royal Marsden and designed to assess the benefits and disadvantages of using Stereotactic Radiotherapy (SBRT). PACE “A” compared prostatectomy with SBRT. PACE “B” compared conventional radiotherapy with SBRT on patients with low grade tumours. PACE “C” is comparing conventional radiotherapy with SBRT on patients with medium/high grade tumours. A total of 1182 men are being chosen across several countries. Torbay NHS Trust has been chosen as one of the participants. Patients have to meet certain criteria and benefit from closer monitoring for 10 years. Once chosen, 50% of the participants are randomly selected to undergo SBRT treatment whilst the other 50% have conventional

treatment.

Stereotactic radiotherapy (SRT) gives radiotherapy from many different angles around the body. The beams meet at the tumour. This means the tumour receives a high dose of radiation and the tissues around it receive a much lower dose. Patients receive 5 treatments spread over 1-2 weeks. The prostate receives a radiation dose of 36.25 Grays over the 5 fractions. This compares to conventional radiotherapy of 20 fractions and 60 Grays. Follow up is at 2,4,8 and 12 weeks then 3 monthly to start with, lengthening to 6 months for the first 5 years.. The benefits include the reduction in treatment time (5 vs 20 fractions/visits to hospital which allows more patients to be treated using SBRT. SBRT targets the tumour with high dosage whilst the rest of the prostate receives lower dosage. Lower side effects are expected.

Secondly : My experience of Prostate Cancer and the trial – to date.

After 8 years of rising PSA readings, 2 MRI scans, one rectal and one transperineal biopsy and being on active surveillance I finally succumbed to a very unexpected Gleason grade 8 (4+4)- found by a random core sample in March 2021. Lucky or what! I was put on the Active Treatment track. Given my age (65) and excellent health etc I was given the option of either a prostatectomy or radiotherapy plus hormone treatment for 9 months and a bone scan. After much research and great help from people who had experienced these treatments, including a number of TPSA members, I opted for radiotherapy. I already knew of the PACE trials and that recruitment was just underway for the PACE “C” trial and Torbay was one of the hospitals selected to take part. I asked to be considered, met all the requirements and was put forward and accepted. I wanted to take this opportunity to help advance the treatment of men who will find themselves in the same situation as me – having PC. I started hormone therapy in May 2021 with the first of 3 quarterly Decapeptil injections- it didn't take long for the hot flushes to start!

I was fortunate to be chosen, purely at random, to have the SBRT treatment. Then followed 3 CT scans over 3 weeks to try to achieve the best set up for the actual treatment- very important as it is essential to pinpoint the actual point(s) where the high dose needs to be. Getting the liquid intake to provide the correct amount in the bladder is an art form in itself! This was not a nice period as I had to have daily enemas and twice daily laxatives – not a nice experience. These carried on through the SBRT treatment – thank goodness this was only 5 days.

The easiest part of the whole experience was the actual SBRT treatment itself. Painless and quick, excellent professional team and even free car parking outside the oncology suite. After a couple of sessions I noticed my urine flow was weaker and concerned that it might stop altogether so I was prescribed Tamosolin which improved the flow rate.

I have experienced some side effects since SBRT -some of which are more likely to be due to hormone treatment (weight gain; hot flushes and fatigue) whilst others like urinary flow and frequency are more likely due to SBRT. It is impossible to know whether these are better or worse than if I had undergone conventional radiotherapy.

I am now 11 weeks post SBRT . On the positive front my PSA is 0 but so is my testosterone level. Some of the SBRT side effects have either gone or not been encountered (so far!!). I am still experiencing increased frequency and very strong urgency demands which I am advised should improve over the coming weeks. I have just stopped taking the Tamosolin and I have my last Decapeptyl dose on 4th November. My 12 week review is the same week with the next PSA in early January.

One downside of the SBRT trial is that relatively few patients have been through it and so the amount and timescales of any side effects are unknown and like the conventional treatment are experienced differently by one patient to the next.

I would be happy to provide an update to members in due course if it would be useful.

Keith Wilby

One of the topics on the action plan that was discussed in some details after the AGM, is how we as an organisation we can offer effective partner support. Gill very kindly agreed to put the following article together which I'm sure many of you will empathise with:-

Gill Clay - Partner Support

SUPPORTING MY HUSBAND THROUGH PROSTATE CANCER by Gill Clay

Mike and I were both 75 years of age and had been married for 52 very happy years when he was diagnosed last September with prostate cancer. We were both devastated to receive a 'brief' phone call saying that Mike had low grade prostate cancer with no treatment plan other than active surveillance with three monthly PSA blood checks. For the first time in my life, I had to face the frightening fact that Mike's life could end, and I would be a widow sooner than expected. Would Mike be able to cope with his diagnosis and what felt like a death sentence hanging over his head and how best could I support him both physically and emotionally? When would he need other treatments and what would their side effects be? Would we be able to lead a normal life together and would we need to make lifestyle changes? Should I change our diet and encourage him to take more exercise and carry on with life as before? I soon realised that my support would be essential and very important and that I would need to be patient, sensitive, understanding, and strong. I tried to encourage him to do the things he enjoys, albeit hampered by the pandemic, and spending time with the family in a Covid safe manner. I investigated suitable diets for prostate cancer patients and tried to prepare healthy foods that he likes to promote a nutrient-rich diet and support weight maintenance.

Mike is not the type to take his diagnosis lying down. He couldn't cope with knowing that he had cancer growing in his body and do nothing about it. I said I would support him in his search for alternative treatments and their consequences. We both worked as a team trawling the internet for answers and for as much information as we could find that would help us to make informed decisions. We learned so much in a short space of time, but which route of treatment should Mike take? Prostate Cancer UK and the Torbay Prostate Support Association were amazingly supportive and in the case of the TPSA, Mike spoke with Clive. Their discussions and zoom meetings were very reassuring, learning from others' experiences and we both gained a great deal of calm and awareness about prostate cancer from their excellent zoom lectures.

Mike's legal background led him to question all aspects of his diagnosis and turned to the internet. The Focal Therapy Group gave us great hope, but treatment was in Southampton. We went through many highs and lows whilst I supported Mike during our day trips to Southampton which eventually led to his decision to have the tumour removed by cryotherapy in Southampton on 21st December. We had to consider hotel accommodation and food for our overnight stay as Covid was presenting us with many additional issues to overcome.

The whole experience has made us even closer than before because, for the first time in his life, Mike has had to rely on me, and I was determined that I would not let him down. Oh, how much easier life would have been if the treatment was available locally.

Following Mike's cryoablation I had to face the question of what would the future hold? Would this new treatment work? Would I be lucky enough to get my Mike back again as he had been, strong and healthy? I was very worried not knowing what the future might hold and the practical aspects of catheter management and the possibility of complete incontinence. Thankfully Mike's operation was a success and after a couple of months he returned to normal health with no ill effects. He still has around 2/3 of his prostate and with a PSA of under 1.00, we are hopeful of a good future, but my overriding worry is "for how long". However, I am sure this is a concern of every Prostate Cancer sufferer and their families.

Finally, facing such a diagnosis serves as a reminder of how valuable time with loved ones is. We walk a little further on our evening stroll, enjoy the simpler things of life together and appreciate the time spent with family and friends. We are grateful for the past and look forward to some more future good times together. In short, we ensure we make the most of every minute.

The above articles by Keith & Gill highlight how we differ in our approach to being offered 'Active Surveillance'. I found Richard's article in the last newsletter, on this subject, thought provoking & it is still available on our website (as are previous newsletters)

Clive Richoux

Previous Zoom Meetings

The Zoom logo is a blue square with the word "zoom" in white lowercase letters.

Our Zoom meetings are continuing to prove popular with both our local supporters but also from people around the UK. In October we were pleased to welcome back a stalwart supporter of TPSA Andrew Gabriel, who covered in a very informative and interesting way how to deal with the side effects of Hormone treatments. I'm sure like me, on diagnosis you look at all the treatment options presented, together with the potential side effects and it is certainly a mine field. So information from people like Andrew is most welcome.

Fund Raising

We reported previously that we had set up an online donating site via Virgin Money Giving. Unfortunately as many of you will know VMG have decided to close their site with effect from 31st November 2021. This is as a result of their cessation of their association with the London Marathon. **Peter Hosking's Daughter and Granddaughter currently have a cycle challenge on our donate page if you know of anyone who want to make a final donation.** We have been looking at other potential providers and have selected CAF (Charity Action Foundation) As a charity themselves they are in an ideal position to understand the needs of small charities like ours. (Mark are you able to put their logo in here please)

Also in October we received a donation of just over **£49.00 from Tim Rowe and his wife** for which we are very grateful.

TPSA also our thanks to the customers of **the Coach & Horses Pub in Markfield Leicester from whom we received £40.29** from a collection bucket.

You will have received details of the Movember challenge that Keith Wilby is doing, if you would like to make a last minute donation please make this to the Rotary Club of Preston(Torbay) Charity account **(sort code 30-88-04 a/c no 36842968) ref "MOV"** - who will collect all donations and present Torbay Prostate Support Association with, I hope, a brilliant amount to help their work.

TPSA Action Plan

Following on from the AGM we shared with the group our action plan for the future detailed below. This was under the banner of **Reset, Rebuild, Reignite.** The continued success of TPSA will only happen if we can enlist the help of people like yourselves. As they say "many hands make light work". Whilst any help you can give us is of course appreciated, we could really do with help on media interface and specific fund raising initiatives. If you do have even a small amount of time to on these or other matter please contact Ian Nightingale or any of the Trustees.

Publicity Material Update

Revamp at general TPSA leaflet (similar to the 8 page A5 one we have)?

Produce a simple A5 flyer to be able to hand out. See what Tackle ha

Awareness Raising

Consider Workplace Presentations, Men's Health Group

Arrange for the A4 laminated posters be made available to members for them to arrange local display

Make contact with Rotary , Round Table, Lions and Probus Clubs

Social Media

Agree what our social Media presence should be, recognising that posts will need to be monitored and responded to to make it worthwhile

Meetings

Look at appropriate venues for Trustee & Members meeting, considering suitability for confidential discussions, location ease of access cost etc

Frequency of meeting and type. Proposal for 10 members meetings a year. Winter months via zoom summer face to face

Consider how we involve partners. Specific partner sessions ?

Proposal to join resources with Tamar & Plymouth for winter zoom meetings to maximise speakers potential

Timing of Face to Face meetings

Building Relations with Health Professionals

Torbay Hospital

Identify and send out emails to key consultants/contacts at Torbay Hospital

Other Health Care Providers GP's etc

Devon Cancer Alliance

Developing additional links with Exeter Hospital (Recognising some consultants worked between both)

TPSA Structure/Support

Consider on how we attract people (members and others) to support and run the Association.

Fund Raising

Consider how we raise funds given the shift away from cash

Our next meeting will again be via zoom on 24th November commencing at 6pm for members and 6.30 for the speaker. This will be Hayley Luxton Research Impact Officer from Prostate Cancer UK.

The Trustees would like to thank you all for your support over the past year and look forward to more face to face meetings in 2022. We wish you and your families a very Merry Christmas and a Healthy New Year.

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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.