

# UPDATES

The Newsletter of PCaSO Prostate Cancer Support Organisation  
Dorset • Hampshire • Sussex • and surrounding areas



Issue No. 70  
**Winter**  
2020/21

Bluebell Railway, Sussex  
(Photograph by Lance Allen)

**Need for National Screening**  
**HDR Brachytherapy**  
**Proton Beam Therapy**  
**My Patient Story**  
**State of the art Biopsies**

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**Prostate Cancer  
Support Organisation**

## Content for Updates

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The opinions expressed in this newsletter are not necessarily those of PCaSO Prostate Cancer Support Organisation. All men and all cases are different and you should always discuss any changes to your treatments with your doctor and in the light of your own personal circumstances.

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## From the Editor

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The full 15-page version of the 'Physical Activity and Exercise' section of 'Healthy Living for Prostate Cancer Patients and Survivors', can now be viewed or downloaded from the PCaSO website (under 'Publications').

Meetings of our local Groups remain cancelled at present due to the pandemic, however the new live online talks are progressing well, using Zoom. An advantage of online talks is that there is no distance limitation or travel needed for either speakers or audience. Where possible talks are recorded and then placed on the 'Videos' section of the PCaSO website. Videos are also listed on the back page of this newsletter.

Many thanks to Chris and Penny Brewer (Rustington Group) for sharing his Patient Story (see page 6).

There are two requests for participation in studies. One from King's College London about fatigue (see page 7), another (on-line) from the University of Surrey (see page 11) about how people think about their cancer diagnosis. Please help if you can.

Viv Miles, PCaSO's long-time Treasurer, is in hospital with serious problems after an operation and is unlikely to return any time soon. Members will join with the Executive in sending our best wishes for his recovery. Meanwhile, we need a Treasurer if you know of anyone. Details on the website.

# The Need for a National Screening Programme

An on-line talk by Chris Booth, retired consultant urologist. Host IoW PCSG on 20th Oct 2020.

Chris became a specialist urologist in 1980, well before the 'PSA test' era and before the challenges of prostate cancer were widely known, although much work was conducted into prostatic diseases generally. This developed into a more holistic approach to cancers of the kidneys, bladder, testicles and prostate. In 2000 Chris set up CHAPS (Colchester Has Active Prostate Support), now a major Prostate cancer support group, see [www.chaps.uk.com](http://www.chaps.uk.com).

CHAPS arranged talks and produced awareness literature. In 2012, mens' health checkups began, in association with local professional football clubs. These covered PSA, aneurysm risk and diabetes amongst other tests. As with PCaSO, the local Lions, Rotary and Masons were partners in arranging test events.

Increasingly aware of the need for Prostate cancer screening, Chris became more involved at national level, including the clinical advisory board of umbrella charity Tackle, see [www.tackleprostate.org](http://www.tackleprostate.org). His extensive experience of Prostate cancer was very useful at meetings and lobbying up to and including the European Parliament. On PSA testing Chris has worked with the Doctors' Laboratory on employer-sponsored screening events around the country - until curtailed by Covid-19.

However the UK still has no Prostate cancer national screening programme, despite other countries with accessible screening seeing falling death rates. In a survey of English GPs, most were unaware of the Prostate Cancer Risk Management Programme. Starkly, only 1 man in 4 visiting his GP stood a chance of receiving balanced advice. GPs generally will not support screening until the National Screening Committee (NSC) gives

the 'green light'. Frustratingly the NSC, which governs all types of NHS cancer screening, still believes that the risks of over-diagnosis and over-treatment outweigh the benefits of PSA testing. The NSC appears not to have any qualified urologists, oncologists or radiotherapists as advisors!

Most PCaSO members will be aware that Prostate cancer develops quietly without symptoms in its early phases, so by the time a GP agrees to a test, the disease is relatively advanced, possibly into metastases. Yet staggeringly, even the chair of the Royal College of GPs stated on BBC Radio 4 in 2019 that "men only need a PSA test once they have symptoms".

Interestingly the current screening for breast, bowel and cervical cancers are managed by the NHS centrally, not through GP surgeries.

The NSC has produced a draft review on whether PSA testing should be recommended. Chris Booth has provided detailed feedback on behalf of Tackle, and the NSC's outcome is due to be published in December 2020. It is believed that the NSC is too reliant on outdated figures and opinions. For example, the PSA test, although only an indication of the health of the prostate, is now more reliable than previously; men with raised PSA levels now have an Mp-MRI scan before invasive biopsy (Chris called this a "game-changer"), and the rate of over-treatment in the UK has been reducing consistently, now less than 4% and falling. In countries with wider screening, the mortality rate has halved. In the UK this could save 6,000 mens' lives each year.

There is currently no feasible alternative to the PSA test, which costs only at between £8 and £12 per test (laboratory costs). An MRI 'non-contrast' scan could be useful but very difficult to scale up

economically in terms of machines, sites and resources.

Chris did highlight that PSA screening required regular, rather than one-off, tests. If a man's PSA count is in the lower half of his expected range, perhaps once every 5 years. If his count is in the top half of the range, annual tests may be needed. Men with family history of Prostate cancer, or those of Afro Caribbean ethnicity, are at higher than average risk of developing the disease.

Lobbying for Prostate cancer screening does continue. The British Association of Urological Surgeons has a cancer committee that liaises with Tackle. Nearly 60% of urologists support screening, but only 25% of GPs. An awareness reception took place at the House of Commons last year (at which PCaSO was represented) but it unfortunately coincided with MPs having to leave the event for important voting on the Brexit Bill. In the Upper House, Lord Libeiro has been an active supporter, particularly on the ethnicity risk.

The Isle of Wight group stated that when they held Prostate cancer awareness and PSA testing events, the public were either very supportive or not at all - there was no halfway house. A number of men were attending PSA tests under instruction from their 'other halves'! Some local clinicians had been quite forcefully negative towards the testing events.

Looking ahead, it is to be hoped that the National Screening Committee will come to realise at last that many lives can be saved, and many mens' quality of life improved, through PSA screening. If the outcome of the NSC's current review is negative, then perhaps more proactive and joined-up lobbying may be required!

*Notes by Lance Allen (PCaSO)*

# High Dose Rate (HDR) Brachytherapy

An on-line talk by Dr. Angus Robinson

Dr. Robinson is a Consultant Oncologist and is Clinical Lead for the Oncology Team, Sussex Hospitals. He has spoken in previous years at PCaSO group meetings. This talk was on 25th November 2020, during pandemic 'lockdown', so a Zoom meeting was held, allowing a wider audience to benefit. There were around 55 participants, plus 8 partners on screen, including members of Support Groups in the Isle of Wight and in Mid-Sussex.

## High Dose Rate (HDR) Brachytherapy

Note: there are two forms of brachytherapy, low dose rate (which has permanent implanted 'seeds') and high dose rate. (The term 'dose-rate' refers to the speed of the radiation source used rather than the dose delivered). The brachytherapy technique described here, as used at Brighton, is High Dose Rate (HDR). [*whereas low dose rate is carried out at Guildford, Surrey*].

HDR Brachytherapy may be used for patients diagnosed with high-risk localised prostate cancer (e.g. possible T3b, or Gleason 8, 9, 10, or PSA 30-40). It may not be suitable for patients with pre-existing urinary problems or those on blood-thinning medication.

A series of slide diagrams and MRI scans were used to clearly indicate how HDR brachytherapy works. This was very useful as few, apart from men who had undergone this treatment, would fully understand the process. There is some similarity with the trans-perineal biopsy, where a template is placed against the perineum - Dr Robinson compared it to playing 'Battleships'!

Unlike external beam radiotherapy (EBRT), with brachytherapy the radiation is delivered directly into the prostate without affecting surrounding organs and tissue. In

some cases patients can receive a combination of both treatments. Brachytherapy may also be used when prostate cancer previously treated by EBRT recurs (this is 'salvage' treatment). Men who have had the prostate removed by surgery cannot be subsequently treated by brachytherapy.

**Planning and Preparation** - The HDR brachytherapy process starts with ensuring the bladder and back passage are empty. The patient then receives both epidural and light general anaesthetic. An ultrasound probe is inserted to the rectum, providing images of the prostate and surrounds, to help with guiding the brachy tubes through the template and into the prostate. Some 15 to 20 tubes are inserted, plus a bladder catheter. Following this preparation, the patient is awakened, although remains in a position that does not disturb the template or tubes. At this stage they carry out scans of the prostate in order to 'map' and prepare the treatment plan before any radioactive source is delivered. The Physics team decide where in each tube the radioactivity needs to be and for how long (a few seconds in each tube).

**Procedure** (*about 45 minutes*) - The open ends of the individual tubes are now connected to the 'radioactive source', being a carefully-managed lead-lined box. The tiny radioactive material then travels down each tube on a wire in turn such that the sites (15 to 20) within the prostate are exposed to radiation. Following withdrawal of the tubes, the catheter is used to ensure no undue bleeding via the bladder. If so, a saline irrigation is used to ensure no clots can form. Nothing remains physically inside the patient or his prostate, i.e. no radioactive 'seeds'.

Usually a day case treatment with a 7.30 am appointment for

the patient. In almost all cases, the patient can go home on the afternoon of the same day.

There can be side effects of the brachytherapy such as the prostate expanding which can narrow the urethra.

Up to two weeks later the patient may have external beam radiotherapy to cover a wider area.

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## RADICALS Trial (is EBRT after surgery beneficial?)

Dr Robinson went on to describe an arm of this important trial, involving patients who had undergone prostatectomy. i.e. surgical removal of the prostate gland. The trial would indicate whether it is more beneficial to follow the operation with external beam radiotherapy (EBRT), or to monitor the patient and provide later 'salvage' radiotherapy only if needed. The trial was worldwide, but mainly UK-focused.

The outcome indicated no difference. Whether men had radiotherapy after prostatectomy or not, some 80% were still in remission, with no bio-chemical recurrence, after 8 years. Neither was there any difference for men who were also on hormone treatment. (For the purpose of the trial biochemical relapse was taken as at a PSA of 0.4).

**Note:** *an article on the Radicals Trial can be seen in UPDATES, Spring 2020, page 3.*

Dr Robinson answered a number of questions from the online attendees, but of course could not speak specifically with regard to individual men's situations. He was thanked for a very useful and interesting talk.

The talk can be viewed on the PCaSO website under 'Videos'.

*Notes by Lance Allen.*



## 'My patient experience with Proton Beam Therapy'

An on-line talk to PCaSO by Timon Colegrove, 6th October 2020

Timon Colegrove's experience is quite rare, in that following his diagnosis with prostate cancer in 2017, as an otherwise fit and healthy man in his mid 50's, he has undergone Proton Beam Therapy (PBT). He is now sharing his experience with prostate cancer groups throughout the country, raising awareness of the benefits of this new treatment (which is not yet available on the NHS for prostate cancer patients). He summarises the last few years as a journey through diagnosis, dilemma, luck, decisions, treatment and outcomes. Timon has a twitter channel @TimonColegrove, and a Google search of his name produces a variety of articles.

Under the NHS, there is currently only one PBT machine in the UK, at Christie Hospital, Manchester. A second machine is due to open in London at UCLH soon.

Timon had first heard of PBT in 2014 when the news media highlighted the plight of a young boy with a brain tumour, whose parents took him abroad for proton beam treatment, contrary to NHS advice. The youngster is now a cancer-free healthy 11 year old.

In 2017 Timon had a general medical test, at a time of career change. His PSA came out at 5.2, being slightly higher than the norm of 4.0 for his age group. He had no symptoms. His local hospital in Oxford said "Probably nothing but we'll do a scan". This showed a few unidentified shadows. "Probably nothing but we'll do a biopsy". The ensuing transperineal biopsy did lead to alarming [but not abnormal] blood loss and 3 weeks of discomfort.

After his cancer diagnosis was confirmed, Timon was offered a choice of radical prostatectomy (40% chance of lasting nerve damage), or brachytherapy (40% chance of incontinence and/ or impotence). This left him frightened, confused and bemused.

Timon shared his experience with a friend in a similar situation. Prostate cancer was understood to affect 1 man in 8, but 1 in 4 if the father had the disease (as had Timon's own father in his mid 90's). He went to a local prostate cancer support group's meeting, where he was welcomed and learned a lot from others. PBT was referenced as using extremely accurate laser light, which resulted in much less damage to the surrounding healthy tissue. However his hospital consultant dismissed PBT with "There isn't the data to support the use of PBT". This was very deflating! However his oncologist, who was looking to study PBT, provided him with a glimmer of hope.

Timon's scans were sent to the Rutherford Cancer Centre, which is a private medical company with two proton beam centres, one in Newport, South Wales and another recently opened in Thames Valley, Reading. Timon was accepted as a patient and treatment started by reducing the size of his prostate with hormone therapy, with associated side effects such as loss of libido. Prior to the PBT, a gel spacer was inserted between his prostate and rectum, to minimise the risk of damage to the latter. Timon then had 20 fractions of PBT at the Rutherford Centre in South Wales over the course of a month. The only noticeable side effect was the need to pass water more frequently, but this only lasted 3 weeks.

Timon's PSA is now an admirably low 0.02.

PBT machines are incredibly expensive high tech equipment. The Christie and intended London sites are primarily directed to children's cancers, and adult 'difficult to reach' cancers. PBT is not intended for prostate cancer because other treatments are available, albeit at greater risk of side effects and impact upon quality of life. More patients can now be handled by PBT using only 10 sessions at double strength rather than 20.

Treatment by PBT for prostate cancer is not available on the NHS, and to go private is likely to cost 'the same as a new family-size car'. Private health insurers are unlikely to fund PBT, due to the availability of other remedies and the NHS line that there is 'not sufficient data for PBT'.

Timon answered questions from participants in the zoom meeting, advising that his treatment was for the prostate itself, there was no metastatic cancer. Also it is not known if any tissue scarring occurs that would preclude future treatment (as can happen with radiotherapy). Interestingly Timon had recently spoken with his GP who admitted to seeing many prostate cancer patients with side effects from 'traditional' radiotherapy. Only time will tell whether Timon's treatment is 100% successful, there will need to be conclusive evidence from clinical trials before PBT is available on the NHS for prostate patients.

Timon was thanked for giving his time for this very interesting and useful talk. Participants acknowledged his clear content, and delivery style.

*Notes by Lance Allen.*



## My Patient Story

Chris (and Penny) Brewer - Rustington Group

I had been getting up 2 or 3 times a night for several months and put it down to getting old. Then I started to get other problems, weak flow, feeling the bladder hadn't emptied and dribbling. I went to see my GP on 18th January 2018. I told him my symptoms and he performed a DRE. He said the prostate was enlarged and hardened and he suspected prostate cancer. He said he would put me on the fast track programme to see a urologist and sent me for a blood test, which I had the following day at Worthing hospital. A few days later I received an appointment for 1st February to see a consultant at Southlands Hospital. The consultant had seen the test results which gave a PSA reading of 201; he also performed a DRE and confirmed prostate cancer. He told us he had other patients with much higher levels who had lived for 10 years. He then said he would arrange for a bone scan and a CT scan and in the meantime, he prescribed Tamsulosin to aid urination. Unfortunately, these caused a bad allergic rash and the first anti histamine made the rash worse!

At this time neither Penny nor I appreciated the significance of a PSA level of 201, nor had the consultant elaborated. All we had heard was that most men die with prostate cancer rather than from it.

When we got home, we "googled" prostate cancer and found the

Prostate Cancer UK website. This was very useful but distressing as we found out the normal level for a man of my age was 5.

On 16th February I had a bone scan at St Richards, Chichester. On 19th February I had a CT scan at Worthing Hospital. On 2nd March we saw the consultant who advised us the bone scan was clear but there was an anomaly on the CT scan which showed an enlarged lymph node. He said he would arrange for a PET scan but this would be carried out at the Clinical Imaging Science Centre, University of Sussex Brighton. He explained that as this was an outside body it was outside the fast track programme; he could not start any treatment as this might affected the scan results.

As we had heard nothing by 10th April, I rang the urology department at Worthing Hospital and spoke to Andrew Hart. He said the wait was normally 4-6 weeks as they had to get the choline specially and normally waited until they had a number of patients. As I couldn't start my treatment until after the scan, he said he would contact Brighton Hospital. Six days later I received an appointment for the 25th April at the Clinical Imaging Science Centre, University of Sussex, Falmer. I also had an appointment to see Andrew Hart on 26th April for my initial dose of Degarelix. Degarelix had been chosen because of my previous adverse reactions to tablets.

On May 4th we saw a Urologist who gave us the results of the PET scan which was positive (T3b N1 M1b) He also gave me a revised prognosis of 5 to 8 years before referring me on to the Oncology Department and arranging for a biopsy. As it happened both appointments fell on the same

day, 24th May 2018. We saw Dr Plataniotis at 10.30am at Worthing Hospital and the biopsy at Southlands Hospital at 14.20. At the appointment with Dr Plataniotis we discussed early Chemotherapy and the side effects of Docetaxel. Because of these, my allergies and the compromisation of quality of life (which is now 3 to 5 years) we mutually decided not to have Chemotherapy and to continue with the Degarelix. My PSA was now down to 69.7ng/mL

On Monday 18th June 2018 Penny and I attended a Hormone Information Session at Worthing Hospital which also included the importance of diet and exercise. The exercise session was presented by a representative of Albion In The Community who offered 10 weeks free in a cancer rehabilitation class; I duly filled in an application form and 2 weeks later met the same representative at the Amex stadium, Brighton who explained that they organise the classes on behalf of Macmillan Cancer Support and the Worthing classes are held at Bandana Health and Fitness studio in Tarring. I then filled in a questionnaire and committed to returning every 3 months for the next year. I contacted Bandana and have regularly attended the Cancer Rehabilitation course on a Monday morning ever since, treatment permitting.

On 30th May 2018 I had my first injection of Degarelix administered by a Practice Nurse at my local surgery. I had to obtain Degarelix on prescription before the appointment. Degarelix comes as a powder and separate solution which the nurse has to mix together slowly and carefully without shaking, until the solution is clear. It is then injected slowly into the subcutaneous fat layer of the stomach. My reactions to

this injection were a red swelling, a lump and hot flushes. It was 4 days before I could get out of bed, and a further 6 days before I could bear anything around my waist and stomach.

I then continued to have similar reactions each month until August when the injection was given when the mixture was still cloudy. The injection site immediately came up with a bright red swelling that spread across my stomach. It was suggested that I took an anti-histamine before the next injection which I duly did and there was no reaction for two days and a lump and swelling appeared which lasted for three weeks. I saw a different nurse for the next two months and on the third month she noticed that the needle was different. I had a four hour hot flush and uncontrollable shivering that evening and overnight. A lump the size of my fist came up and I couldn't dress for 12 days. I phoned Andrew Hart who said he thought she might have

injected into a lymph node. I saw Dr George Plataniotis three weeks later who said try Degarelix once more and if it happens again, he would change the medication. I had no problems over the next four months but in May 2019 I had another very bad reaction.

On the 21st June 2019 I saw "Dr George" who said PSA was now down to 0.38 and testosterone down to 0.61. He said we are now looking at the long term so I must lose some weight as I now need 30% less calories. I continued with the monthly injections but in May and June 2020 I had very bad reactions, and was unable to dress for 3 weeks. On 1st July I had a phone consultation with Paula Ford, an oncology nurse and explained the situation who immediately rang my Doctors surgery to cancel the next injection and issued me a prescription for Bicalutamide which I had to take prior to the change in medication, she also told me my PSA was now 0.63 and

testosterone 0.64. On 17th July I had my first Prostav injection in the arm, no reaction whatsoever; my next injection was 14th August and then every 3 months from then. I have noticed, however, that the hot flushes and fatigue have worsened.

As can be seen from the above, our lives narrowed to revolve around my treatment and the side effects. Life became a series of daily adjustments. In the Update of Spring 2019, we read about a charity called Penny Brohn UK who were going to run a two-day non- residential course called "Living Well with Prostate Cancer". We subsequently attended the course which explored the various aspects of the Penny Brohn Whole Life approach and can thoroughly recommend it. Also, having been caravanners for over 18 years, we could no longer cope with the caravan so changed to a small motorhome which enables us to squeeze in short breaks whenever possible. It is also something that Penny can and does drive. ■



## FLEXIBLE BRAIN TRAINING



### A novel online program for fatigue: a feasibility study



**Do you have prostate cancer?**

**Do you also experience persistent fatigue?**

**We are investigating the effect of persistent fatigue on how we process information and would love your help to research this!**

#### **What does participating involve?**

- 10 minute screening questionnaire
- 10 minute phone call with a researcher
- 12x 20 minute online sessions for 3 weeks (4 sessions/week)
- Online follow-up questionnaires at 1 and 3 months

#### **You can take part in this survey if:**

- You experience persistent fatigue
- You are at least 18 years old
- You are fluent in English
- Able to use and have access to a computer with internet connection
- Not undergoing CGT or psychological therapies

#### **Interested?**

If you would like to find out more about this study please contact the team at [flexprotect@kcl.ac.uk](mailto:flexprotect@kcl.ac.uk) or **07950 214 560**

Or register your interest on the study website [www.flexproject.co.uk](http://www.flexproject.co.uk)



**Please note that enquiring about participation and registering your interest does not commit you in any way.**



# State of the art biopsies

## State of the Art Prostate Biopsies - using the 'Schmitz-soehne Medi-matic® 715' Urology examination & treatment chair enabled by a generous PCaSO (Hampshire Branch) donation.

By Samantha Oxford and Ellyse Webb, Prostate Diagnostic Nurse Practitioners, University Hospital Southampton.



Biopsies are an important integral tool in the diagnosis of prostate cancer. Receiving histopathology in the form of biopsy cores enables us in reaching a helpful and meaningful diagnosis, which in turn guides treatment options. Ultimately our goal is to ensure the patient receives an accurate diagnosis, prognosis and treatment in a timely manner. Our facility for performing transrectal ultrasound (TRUS) biopsies became unsuitable during the COVID-19 pandemic due to the relocation and redeployment of staff. Further, the risk of developing severe infection and sepsis with the traditional TRUS biopsied forced us to reconsider it as the treatment of choice. Therefore, at University Hospital Southampton (UHS) we have used the COVID-19 era to accelerate our programme to eliminate TRUS biopsy as the initial strategy for obtaining a tissue diagnosis in men suspected of having prostate cancer.

This acceleration allowed us to switch our first line biopsy from TRUS to transperineal PrecisionPoint prostate biopsies (TP), as part of the TREXIT initiative encouraged by the South East London Cancer Network,

by performing local anesthetic outpatient biopsies in our designated Urology Centre. The benefit of this is; TRUS biopsies risk missing cancer, particularly in the anterior part of the prostate gland and increase the risk of infection and sepsis. Given the COVID crisis this was something we, more than ever, wanted to avoid as it would pose further risks for our patients if admission for sepsis was needed.

Data from Public Health England reports that TRUS biopsies carry a reported risk of post biopsy infection of between 0-8 % and that prostate biopsy related sepsis accounts for 10% of hospital admissions for sepsis nationally. Evidence for the TREXIT initiative found that a Meta-analysis of 6609 patients found only 5 hospitalisations for sepsis post TP biopsy (1). Antibiotic resistance has significantly increased nationally over the last decade (2) and the standard protocol for TRUS biopsies at UHS requires patient's to have three days of ciprofloxacin starting the night before the biopsy.

By performing TP biopsies it reduces, with the view to eliminate, the need for prophylactic antibiotics pre-prostate biopsy. This will minimise the future risks of developing antibiotic resistance without compromising the risks of infection and sepsis. The Schmitz-soehne Medi-matic® 715 urology examination & treatment chair allows us to continue of diagnostic pathway in the outpatient setting, reducing the need for theatre space and time as well as reducing the number of patient's requiring general anesthetic. This new diagnostic pathway has only been made possible by the generous donations of funds from PCaSO to purchase this state of the art 'biopsy chair' (see photo on page 9 opposite).

During the height of COVID-19 between the months of April and June 2020, when most elective procedures were cancelled, the urology department performed 14 TP biopsies. Although this number may seem small, the number of GP referrals for men with suspected prostate cancer, in this timeframe was significantly lower than historic levels and represents a large proportion of men proceeding to their first biopsy after diagnostic MRI scans. Undertaking these biopsies would have not been possible without the generous donation from PCaSO. We have received excellent feedback from the patients who have had biopsies taken on the Schmitz-soehne Medi-matic® 715. It is important to us that patients are physically comfortable during the procedure.

The feedback which we have received from our patients is that they find it comfortable and well tolerable. Ensuring that the patient is comfortable reduces anxieties and makes the process more bearable for the patient. Evidence taken from work with kidney stones highlight that pain tolerance is better with the use of music therapy and light therapy (3); an approach we have adopted during the biopsy procedure. In addition to this, as practitioners, it's fit for purpose and enables us to adjust the patient positioning to ensure the comfort of both the patient and the practitioner undertaking the procedure. The variety of positions that the chair allows, makes it more tolerable for both the patient and the practitioner when compared to TRUS biopsies and also allows us to accommodate patients of all different builds.

In practice, the biopsy chair's award winning ergonomic design allows for a very rapid set up and ease of cleaning are important

factors when scheduling lists given time constraints. Since the commencement of local anesthetic PrecisionPoint biopsies in April, we have been able to perform biopsies for 85 patients.

Being able to perform biopsies in our own centre has enabled us to arrange biopsy lists with ease as we no longer require another department's facilities. Furthermore, the ease of communication between the team has allowed us to perform ad-hoc inpatient biopsies; this reduces hospital visits, lowers waiting times and improves the patient pathway. All of which are important in the COVID-19 era

In addition to offering prostate biopsies we are now also able to offer men having radiotherapy SpaceOAR® insertion. The insertion of SpaceOAR® is administered to help avoid some of the bowel toxicity associated with radiotherapy treatment. The insertion of SpaceOAR® would have previously been performed under general anaesthetic which would require theatre space, time and additional staffing. The Schmitz-soehne Medi-

matic® 715 chair has meant that we can now perform the procedure under local anaesthetic in our urology centre, an outpatient setting.

We are very grateful to PCaSO for making this all possible and, having had the chair in the department for coming up to a year we are certainly making the most of its high-tech features. We are looking to further develop the types of biopsies performed using this technique and in the near

future hope to be able to offer prostate fusion biopsies under a local anaesthetic. This further specialist biopsy allows us, in selected men, to use the MRI scan merged with real-time ultrasound pictures to more accurately target lesions seen on the MRI scan. At present we are only able to offer this in a theatre setting under general anaesthetic but our aim is to offer this as part of our biopsy repertoire in the outpatient setting under local anaesthetic. ■



## Brighter Outlook and keeping active through and beyond prostate cancer

Being physically active, or simply moving your body, on a regular basis is one of the best things you can do for your health and wellbeing. Not only does it help to lower your risk of developing health problems in the future, including cancer recurrence, but it can help you to manage some of the side effects of treatment for prostate cancer. It can help you to maintain muscle strength, reach a healthy weight, improve bone strength, manage fatigue, and deal with feelings of anxiety and depression.

Albion in the Community, the official charity of Brighton & Hove Albion Football Club, offers free specialist one-to-one support and group classes to help anyone with a

cancer diagnosis to get more active. The programme, called Brighter Outlook, helps people to prepare physically and mentally for cancer treatment, manage side effects of treatment and support recovery.

Brian, age 67 was diagnosed with prostate cancer in March 2020 and his Macmillan nurse referred him to Brighter Outlook. "I wanted to fight the cancer and improve my mental health. Doing the classes through Brighter Outlook has been life changing. I can do exercises now that seemed impossible three months ago. I can now bend down, get in and out of the car easily, and feel positive to continue cancer treatment. I am now able to walk more, it has built up my strength, and I

have already lost a few pounds through exercise and diet."

The programme is funded by the local NHS and Cancer Alliance and is available to anyone living in Brighton and Hove and East Sussex. You can find out more at: <https://www.albioninthecommunity.org.uk/brighter-outlook>.

Rosie Sadler from the Brighter Outlook programme will be joining the January Zoom Talk to discuss more about getting active, why it is so important, and what you can do to move more and feel good in a way that is right for you.

*Rosie Sadler  
Cancer Activity Project Coordinator  
Albion in the Community*

## Erectile Dysfunction

On 14th October 2021, in an online Zoom meeting, Dr Steve Allen, ably assisted by Lorraine Grover, an independent Psychosexual Nurse Specialist, presented a talk on Erectile Dysfunction to members of Mid-Sussex Prostate Cancer Support Group and PCaSO (25 participants). A 63-minute recording of this talk is on the PCaSO website under 'Videos'.

Steve is the Patient Representative for 'Tackle' (National Federation of Prostate Cancer Support Groups) and is involved with regulatory bodies such as NICE (more details in 'Prostate Matters' November 2019). Steve also assisted PCaSO by commenting on drafts of our revision of the Knowledge Empowers information booklet (issued January 2020).

Erectile Dysfunction (ED) to some degree or other can affect many patients who undergo prostate cancer treatment, whether surgery, radiotherapy or hormone treatment (and for some patients more than one such treatment). For those that suffer from ED it can be both a physical and an emotional matter and can affect relationships with partners. However, most men are reticent as they feel it is a very personal and private matter that is little

talked about openly in public, even with fellow prostate cancer patients. We are therefore thankful to Dr Allen for his remarkably open talk on the subject as he is a sufferer of ED too, following an open radical prostatectomy 12 years ago.

This wide-ranging talk on ED commences with a description of the anatomical aspects, but progresses to treatments, aids and emotional aspects. (If you had problems before prostate cancer treatment, prostate cancer will never make it better!). If you suffer from ED then for many patients there are options other than total avoidance of sexual activity, but it will be a different experience requiring a degree of adjustment and patience. An understanding partner helps. Some men will just need a little help such as a Viagra, Levitra or Cialis tablet. For those severely impacted by ED who cannot get an erection then there are still ways of sexual activity. It is possible to have an orgasm without an erection.

Please watch the video on the PCaSO website. PCaSO Chairman Roger Bacon describes it as 'one of, if not the best, talks on this important topic for men who have had surgery or radiotherapy'.

*Notes by Tony Ball.*

## STOP PRESS!

### Brian's Lucky Journey - Finale

After four years of treatment for locally advanced prostate cancer and subsequent pelvic lymph node cancer, I am glad to say that I now have a PSA reading of less than 0.01!

(For the full story of my lucky journey, please read Updates 64 and Updates 69.)

My sincere thanks are given to my family for their support, our fantastic NHS and, in particular, my treatment team headed by Dr Angus Robinson.

PCaSO and our wonderful volunteer army of men and women made early detection of my cancer possible through our free PSA testing scheme. Roger Bacon's encouraging and enduring statement to me that "It's treatable and beatable" is now an often-used phrase of mine too.

So, stay positive, keep fit, eat and drink everything in moderation

Happy New Year everyone,

*Brian Holden*

## Sussex member Mark Giddings appears on Chris Woollams' online show

Chris Woollams is a well-known author and online publisher of health awareness and choices to help combat cancer. He hosts an online Sunday Show and recently featured PCaSO member and volunteer Mark Giddings.

Following his diagnosis in 2014 and being told he had 'up to' 3 years to live, Mark was determined

to use self-help and lifestyle choices as a positive strategy to improve his chances against his prostate cancer. In addition to a healthy natural diet and exercise such as running, Mark has used elements such as meditation, acupuncture, osmotic water filtration, and even kite-surfing in as far-flung places as Brazil,

Morocco and Mauritius. He has read widely on health choices, including Chris Woollams' books such as "The Rainbow Diet".

Delightfully Mark is still with us and remains very fit and healthy!

*You can read Marks Patient Story in UPDATES Issue No 63 Summer 2018*

## Participate in a new online study in 2021!

The University of Surrey is to investigate the role that 'thinking styles' may have in the wellbeing of those diagnosed with cancer. The project aims to gain a better understanding of factors that influence how people cope after a diagnosis of cancer, and develop better support for those recently

diagnosed. The Study group is looking for those diagnosed with prostate cancer within the last 24 months, to complete a 20-minute online survey, with shorter follow-ups 3 and 6 months later.

PCaSO has been asked if any members would be interested in

taking part, the survey is at:

[https://surreyfaqs.eu.qualtrics.com/jfe/form/SV\\_e2tDvQrWtSx5xBj](https://surreyfaqs.eu.qualtrics.com/jfe/form/SV_e2tDvQrWtSx5xBj).

*The participant information sheet and consent form are on this link. Participants will be recruited until February 2021.*

## PCaSO AGM

PCaSO's AGM was held on Tuesday 22nd September and, in common with many other charities and others, it was held online using Zoom. The Constitution requires that we have a minimum of 20 members attending and we managed to have 24.

There were two actions required. The first was to approve the annual

accounts which were displayed in the summer edition of Updates and the second was to re-elect the trustees for the next year. Both of these were achieved and **Roger Bacon, Allan Higgin, David Hurst, Vivian Miles, Derek Pilling, Barry Taylor and Peter Weir** were elected.

PCaSO can have a maximum of 12

trustees and a minimum of three at any one time.

Following the formal part the meeting was opened for any questions that anyone might like to raise and there was discussion of self-administered PSA tests and suggestions for future Zoom lectures and meetings that might be of interest to members.

## BOOK REVIEW • BOOK REVIEW • BOOK REVIEW • BOOK REVIEW • BOOK REVIEW

### How to Live

by Professor Robert Thomas

This isn't Professor Thomas's first book but it is an approachable volume for the non-medical reader. Some may have seen extracts published in the Daily Mail in September 2020.

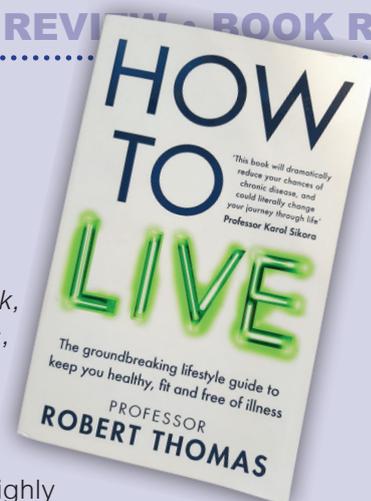
Prof. Thomas has clearly worked hard to distill the outcomes from medical trials around the world, and presents these in terms of how our diet and lifestyle can affect our susceptibility to diseases including cancers and even the new challenge of Covid-19. The book demonstrates how to help maintain our metabolisms and immune systems.

In these enlightened times there is no escape from the mantra

that a healthy diet and regular exercise, will help make us more resistant to disease, or help us to recover from illness or surgical interventions. But 'How to Live' highlights what complex biological machines we are. To function well, the human body needs a wide range of organic compounds, phytochemicals and enzymes - not just vitamins - most of which we have never heard of! These are derived from a healthy diet, but also through good 'gut health' so the body can absorb all the nutrients it needs. Pre-biotic and pro-biotic foods such as live-culture yoghurt, kefir and sauerkraut will help this. Prof. Thomas is clear on what foods should be avoided and which should be embraced.

One casualty of a poor diet would be the immune system, which

(Paperback,  
464 pages,  
£14.99)



would not thrive on highly processed 'factory' food, heavy on saturated fats, salt and sugars. This reviewer makes comparison to trying to drive a Ferrari with cheap paraffin in the tank. Not too wise!

'How to Live' includes useful sections including exercise, smoking, skin health, sleep and mental health. Much of the book's information is relevant to prostate cancer, and is recommended reading.

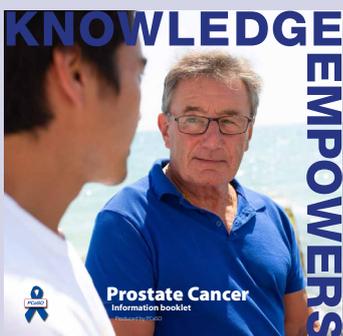
Lance Allen

## BOOK REVIEW • BOOK REVIEW • BOOK REVIEW • BOOK REVIEW • BOOK REVIEW

## Knowledge Empowers Information Booklet

### Version 8

Building on the work of the previous version from 2016 this new edition has been completely revised and updated with the latest information. It has been expanded to 76 pages and presented in a new and hopefully more user-friendly style. The information booklet sets out to provide a comprehensive guide, from a patient's perspective, to most aspects of prostate cancer. It aims to help men diagnosed with the disease (and their partners, friends and family) to understand about prostate cancer and its effects in order to have sufficient knowledge to give them confidence when talking to GPs, hospital consultants and specialist nurses. *It is available to view or download at our website [www.pcaso.org](http://www.pcaso.org)*



*If you would like a free copy of the booklet sent to you by post, either email: [info@pcaso.org](mailto:info@pcaso.org) or phone 0845 650 2555 (call rate will vary).*

## Videos on the PCaSO website

### PCaSO and Prostate Cancer (4 min)

Produced by PCaSO in 2020. Introduced by Professor Christopher Eden, MBBS, MS, FRCS (Urol), Professor of Urology and Consultant Urological Surgeon at The Royal Surrey County Hospital, Guildford. Followed by an introduction to PCaSO and the work it does in spreading awareness of prostate cancer and holding PSA testing sessions around Sussex, Hampshire and Dorset.

### PCaSO – What happens at a PSA Test (5 min)

Produced by PCaSO in 2020, includes footage from a PSA testing event held by PCaSO at Hove in 2019. In this video Consultant Urologist Professor Christopher Eden discusses prostate cancer and the PSA test.

### Erectile Dysfunction – a presentation by Dr. Steve Allen (63 min)

Organised by the Mid-Sussex Prostate Cancer Support Group and recorded on 14th October 2020. A presentation about Steve Allen's personal story of erectile dysfunction after a radical prostatectomy.

### Brachytherapy – a presentation by Dr Angus Robinson (23 min)

Organised by PCaSO, with guests from the Isle of Wight PCaSO and from Mid-Sussex PCaSO. Recorded on 25th November 2020.

### RADICALS-RT Trial – a presentation by Dr Angus Robinson (33 min)

Recorded on 26th. November 2020. First results from the RADICALS-RT Randomised Controlled Trial with detailed slides. The essence of this trial is the timing of any post-prostatectomy radiotherapy.

### How to join a Zoom Meeting

The meeting host will send out a link to the meeting - following this link will take you straight to the meeting, unless you have not used Zoom before when this link will download the relevant Zoom app for your device, take you through the installation, and then join the meeting.

If Zoom is not installed on your device then to save time on the meeting day and give time to resolve any issues with the installation please go to:

**<https://zoom.us/download>** and download and install "Zoom Client for Meetings".

If you have difficulty with this please email Cliff Carter at: **[webmaster@pcaso.org](mailto:webmaster@pcaso.org)**.

For more information please see this short tutorial on how join a meeting **<https://support.zoom.us/hc/en-us/articles/201362193-Joining-a-Meeting>**

**Please note that due to the ongoing Covid-19 situation, many intended events may be changed or cancelled. See PCaSO website under Support - Our Groups for latest details.**

### PCaSO Zoom Events:

Check our website [www.pcaso.org](http://www.pcaso.org) for the latest details

For details of the Zoom events please email [info@pcaso.org](mailto:info@pcaso.org). Details of further zoom meetings will be sent by email. If you are not on PCaSO's email list but wish to be included please email [info@pcaso.org](mailto:info@pcaso.org)

<b>January</b>	<b>14th</b>	Sussex Groups	Thursday 2.30pm	<b>Zoom:</b> "Brighter Outlook and keeping active through and beyond prostate cancer". Rosie Sadler, Albion in the Community.  Sussex members who have provided email addresses will be advised of Zoom details by approx 7 January.
<b>February</b>	<b>18th</b>	All PCaSO and IoW	Thursday 2.30pm	<b>Zoom:</b> Exercise and healthy living. Joint event with Mid Sussex Prostate Cancer Support Group.
<b>March</b>	<b>18th</b>	All PCaSO	Thursday 2.30pm	<b>Zoom:</b> Incontinence as a side effect of prostate cancer treatment. Dr Steve Allen