

UPDATES

The Newsletter of PCaSO Prostate Cancer Support Organisation

Dorset • Hampshire • Sussex • and surrounding areas



Issue No. 66

**Summer/Autumn
2019**

High Salvington post mill, Worthing

**2019 NICE Guideline
Chairman's AGM Report
Treasurer's AGM Report
Diet and Lifestyle
Cancer services in Sussex
My Patient Story**

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**Prostate Cancer
Support Organisation**

Content for Updates

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

An updated NICE Guideline (51 pages) for prostate cancer diagnosis and management was published in May 2019 (previous updates were 2014 and 2008). See pages 3 and 4.

We had a good turnout for the PCaSO AGM at Chichester on 3rd July 2019, see Chairman's report page 5 and Treasurer's report page 6. The AGM was followed by an update talk on 'survivorship' by Professor Sara Faithfull see page 6.

We thank Jon Chapman of Eastbourne for his interesting Patient Story, see page 8.

Hampshire Branch funded biodegradable water bottles for prostate cancer radiotherapy patients at QA Hospital, Portsmouth, see page 10. Sussex Branch trials progress with the online booking system for PSA test events, see page 11. As usual the programmes for group meetings and PSA test events are found on the back page.

PCaSO welcomes:- Barry Taylor as a Trustee and Exec Committee, Nicky Annells to the Exec Committee and Peter Johnson as Treasurer of Hampshire Branch. Allan Higgin replaces Jim Davis as Dorset Branch Chairman.

Note: Where we use the words 'man' or 'men' this refers to a person(s) with a prostate gland in their anatomy, irrespective of any gender choices they may make.

The new NICE Guideline - 'Prostate cancer: diagnosis and management'

The National Institute for Health and Care Excellence (NICE) publish a guideline for 'Prostate cancer: diagnosis and management' in secondary care in England and Wales and they update this from time to time (2008, 2014). In May 2019 they published their latest update for prostate cancer. There are a number of changes in the updated guideline, some of which we mention below. Some have already been used in trials and are beginning to be put into practice more widely.

mpMRI – men should be offered **multiparametric MRI scans** as a first-line investigation before biopsy if they are suspected to

have localised prostate cancer. (However it should not be offered routinely to men who are not able to have radical treatment).

Radiotherapy – most men with localised prostate cancer should be given a lower overall dose over a shorter period of time, i.e. a total of 60 Gy in 20 'fractions' of 3 Gy. [this would usually mean four 5-day weeks, with weekends in-between to recover] Those men unsuited to this will continue to receive the previous standard of 74 Gy in 37 fractions of 2 Gy.

Docetaxel chemotherapy – will be offered to men newly diagnosed with advanced prostate cancer, to start within 12 weeks

of starting androgen deprivation therapy.

Bone-targeted therapy – for men with hormone-relapsed metastatic prostate cancer, zoledronic acid should be considered, to prevent or reduce skeletal-related events.

Treatment choices – The comparison table below may help men, and their partners, in considering the implications of the choices on offer. They may wish to discuss their options further with consultants in urology, oncology, specialist cancer nurses and with other men who have already experienced side effects of radical treatments before making their decision.

continued overleaf

Comparison of the three main treatment options:

People with low-risk or intermediate risk Localised Prostate Cancer (for whom radical treatment is suitable) - evidence from a large UK trial	Active Surveillance	Radical Prostatectomy	Radical Radiotherapy
Survival and disease progression at 10 years:	%	%	%
People who had <u>not</u> died of prostate cancer	98	99	99
Disease progression (e.g. evidence of metastases, or T3 or T4 diagnosis)	21	8	8
Development of distant metastases	8	3	3
Urinary problems:			
Urinary problems at 6 months	39	71	38
Urinary problems at 6 years	50	69	49
Moderate to severe urinary problems at 6 months	4	19	6
Moderate to severe urinary problems at 6 years	8	13	5
Erectile Dysfunction (ED):			
Moderate to severe Erectile Dysfunction at 6 months	29	66	48
Moderate to severe Erectile Dysfunction at 6 years	40	50	36
Bowel function problems:			
Problems with faecal incontinence at 6 months	2	1	5
Problems with faecal incontinence at 6 years	3	2	4
Moderate to severe impact of bowel habits on quality of life at 6 months	3	3	10
Moderate to severe impact of bowel habits on quality of life at 6 years	4	3	2

This table has been assembled from information in Table 3 of NICE guideline 'Prostate cancer: diagnosis and management' published 9 May 2019. It is intended to be used for health professionals to discuss benefits and harms with patients.

continued from previous page

Active Surveillance – one of the most significant changes is recognition that active surveillance offers men with low-risk localised prostate cancer the same survival benefit as radiotherapy or surgery.

Every year thousands of men are diagnosed with prostate cancer that is still contained within the prostate and is considered to have a low risk of causing harm. The NICE guideline now reflects the latest evidence and recommends that Active Surveillance should be offered as a primary option for men with low-risk localised prostate cancer (PSA of 10 or less, and Gleason 6, and T1 or T2a) and also considered for men with intermediate risk localised prostate cancer (PSA 10 to 20, or Gleason 7, or T2b). Active surveillance is a way of monitoring their cancer rather than treating it immediately, allowing men to avoid or delay radical treatment and its associated side effects.

Choosing Active Surveillance in preference to immediate radical treatment such as surgery or

radiotherapy is not an easy decision as it can go against the natural instinct of wanting to get rid of the cancer immediately. However, if a man wishes to move from Active Surveillance to a radical treatment at any stage of their care, they may do so after discussion with their consultant.

The NICE Guideline can be found at www.nice.org.uk/guidance/ng131

Also Prostate Cancer UK have information at <https://prostatecanceruk.org/about-us/news-and-views/2019/5/new-nice-active-surveillance-guidelines>

Active Surveillance Protocol

If a man does choose Active Surveillance the NICE guideline recommends the protocol below:

This has been assembled from information in Table 4 of NICE guideline 'Prostate cancer: diagnosis and management' published 9th May 2019.

Year 1 of active surveillance

- Every 3 to 4 months: measure PSA
- Monitor PSA kinetics (PSA density and velocity)
- At 12 months: DRE (digital rectal examination)
- At 12 to 18 months: multiparametric MRI

Year 2 onwards

- Every 6 months: measure PSA
- Monitor PSA kinetics (PSA density and velocity)
- Every 12 months: DRE (digital rectal examination)

Note: if clinical or PSA changes of concern arise during Active Surveillance mpMRI and/or biopsy may be repeated.

Proton Beam Therapy centres open in England and Wales

Even for those who may only have a passing interest in engineering or science there was a fascinating programme on 22 July 2019 on BBC 2 ('The £250m. Cancer Cure') about the construction of two huge centres for the NHS for proton beam therapy. One in London (at University College London Hospital) due to open in 2020 and one at The Christie, Manchester (already open and treating 10 patients per day). The TV programme showed a child having proton beam therapy in Manchester for a tumour within his brain. These centres involve extensive engineering to generate and focus the proton beams,

which have to be contained much as in a nuclear bunker.

Proton beam therapy uses very high-energy proton beams to treat cancer, rather than the usual radiotherapy X-rays. The proton beam can be specifically targeted to a particular treatment site and the beam made to 'stop' before affecting surrounding healthy cells. Proton beam therapy is particularly suitable for treating cancer in children, also harder to reach tumours can be treated, as well as tumours that are in sensitive locations such as near the spine, in the brain or affecting vital organs such as lungs and liver. It is however significantly more expensive than conventional

radiotherapy and is not currently available on the NHS for those cancers, such as prostate cancer, that can be treated readily with current radiotherapy techniques.

However, for those prostate cancer patients on a self-pay or medical insurance basis, the first proton beam therapy machine in the South of England is due to go live near Reading from August this year, at the Rutherford Cancer Centre, Thames Valley and it can treat prostate cancer patients. A similar centre is already open at the Rutherford Cancer Centre, South Wales and others are planned or are in progress elsewhere in the north of England.



Chairman's Report – from the AGM on 3rd July 2019

We would first like to acknowledge the death in

March this year of David Rowlands, who started and founded PCaSO back in 2002 (see article in our Spring newsletter).

We thank those active members who have decided to retire and stop being involved in running PCaSO activities, they are:-

Jim Davis, who has been chairman of Dorset Branch 'forever' and who has been a huge advocate for detecting prostate cancer early and following that up by enthusiastically organising PSA testing across the county of Dorset, Jim has also been a trustee of PCaSO for several years;

Clive Duddridge, who runs the membership records in Dorset;

John Harmer who organised an unknown number of supermarket collections using his team of volunteers to stand outside supermarkets and other places in both Sussex and Hampshire;

David Harris, who was treasurer of the Hampshire Branch and a trustee of PCaSO. He is currently in the Rowans hospice with bone cancer. (*David sadly died on 19 July – Editor*)

Richard Judd who stepped forward to help the Hampshire Branch as a chair for their branch meetings.

We welcome those who have stepped forward in the past year or so to use their talents to help PCaSO move forward.

Cliff Carter, who has helped us vastly improve our IT services, especially with regard to PSA testing.

Andrew Collett, who has taken our membership records under his wing and, with Cliff, is helping improve the PSA testing services.

Brian Holden, who has taken on the Gift Aid programme and persuaded Her Majesty's Revenue and Customs

to pay us £5,700 over the year in question.

Lance Allen, our data protection officer, who has developed our Data Protection/Privacy Policy.

Peter Johnson, who, although he has no history of prostate cancer, has agreed to step into David Harris' shoes as Treasurer for the Hampshire Branch.

Roger Smith, who has agreed to take time from his sailing and become the Secretary for the Hampshire Branch.

As we have said many times, we are all volunteers. PCaSO has no offices and no paid staff at all, so we depend on people giving us their time and expertise to help us move forward. PCaSO exists with two primary functions, to promote awareness and support those diagnosed with prostate cancer. We thank all those members who have volunteered their time and efforts to the various committees, events and activities organised by PCaSO

Awareness

Let's talk PSA. This is our major activity and in the calendar year 2018 we tested 4,813 men, finding 359 with raised readings and that's around 7.5%. The Executive Committee are convinced that this is an important contribution on two fronts. One is that it saves lives. We have had letters from men who are now under treatment and who were discovered at one of our events. Indeed, several of those men have now come forward to help us at events after being diagnosed. Secondly, and importantly, it raises awareness of prostate cancer. Men talk about having the test and they persuade others to do it as well. The more that people hear about it, the more that men will come forward early enough to be tested and hopefully cured.

It is obviously important to ensure that all the administration of the tests is done correctly as we have to be sure that the right results go to the right men and this has been a time-consuming process. Luckily, with Cliff Carter and Andrew Collett, we have some IT experts and they have been working to make life easier. We have been testing a system of online booking which has been surprisingly effective in that Roger does not now get more than a few phone calls for each event. Having tested it in Sussex we are now moving it into Hampshire and Dorset over coming months and our friends in Surrey, the Prostate Project, who are about to embark on a testing programme of their own, will also be using online booking. I am pleased to say we hope to be working closer with our Surrey neighbours in the future.

Having all the information online does help the hospital pathology labs by speeding the way they give the results back to us. Likewise, a final spreadsheet with results and all the details of men tested can be entered as one onto the database prior to distributing the results to the individual men. We are taking it slowly as we must make sure it is correct at every stage but we are pleased with how far we have come!

Election of Trustees

The AGM agreed the appointment of the Trustees. The following were standing again as Trustees:

Roger Bacon,
Allan Higgin,
David Hurst,
Vivian Miles,
Derek Pilling
Peter Weir.

Barry Taylor from Dorset Branch was standing for the first time.

Their appointment was agreed unanimously.

PCaSO recognises the need for confidentiality of the personal details of members, and attendees at PSA blood test events. PCaSO has a Privacy Policy that is available on our website, and the new PSA test online booking system also highlights the Privacy Policy. We constantly monitor for regulatory changes from the Information Commissioner's Office as well as the Charity Commission, with regular reports to our Executive Committee. We have had no data protection complaints or breaches.

Support

We realised this year that we should be doing more to help those who have been diagnosed and are living with cancer. So we have partnered with the Penny Brohn organisation, based in Bristol, to offer their course 'Living Well with Cancer' free of charge to any member that wants it. We have run three courses so far, one in Arundel, one in Eastbourne and one in Hayling Island (supported by Genesis Care). All three were very successful and we are looking to run more courses in coming years. These courses offer information and encouragement for couples to look at their overall lifestyle and diet with the intention of helping their bodies fight the cancer.

We run support group meetings where men can come and talk about their worries and problems with prostate cancer. Often there's a visiting expert to discuss aspects of prostate cancer though some groups just provide a place where men can talk to others about those things they can't really mention elsewhere. Also local council health groups or charities like Macmillan will have a day where people can drop in and find out answers and where we have a table to talk and promote prostate cancer.

We also publish booklets and leaflets including our much acclaimed Knowledge Empowers which we are in the final stages of preparing for reprinting.



Treasurer's Report - For the year to the end of March 2019.

Receipts of £78,125 were up by 42 per cent from £55,045 the previous year.

Donations at PSA testing events of £41,048 increased by £17,635. Corporate donations of £12,984 were up by £5,487. Collections and events income was up by £1400 and Gift Aid reclaimed from HMRC through the work of Brian Holden reached £5,709.

Payments of £54,149 were down by some £10,000 on 2018.

PSA testing costs were up by £8,168 to £34,842 making this by far the largest element of the charity's work. It is worth saying that the huge amount of work done by our IT experts in automating the administration of the PSA testing is not charged because we are all volunteers.

Donations by PCaSO were down from £26,500 to £8,750 as there had been no major project in the year.

Donations made comprised TACKLE (our national federation) £3,400, Cancerwise (Chichester) £1,000, Cancer United (Angmering) £1,000, Mary How Trust (Pulborough) £1,000, Sussex Cancer Fund (Brighton) £500, Eastbourne hospital ward equipment £900, radiotherapy leaflets for Brighton and Eastbourne hospitals £120 and water bottles for radiotherapy patients at Queen Alexandra Hospital, Portsmouth, £830.

Cash flow for the year showed an income of £23,452 with bank balances rising to £130,313. The

Treasurer repeated his view that PCaSO was not here to hoard money, but publicised donations to good causes seemed to attract more money.

The Accounts were unanimously accepted at the AGM on 3rd July 2019.

Diet and Lifestyle Factors for Improving Prostate Cancer Survivorship.

Talk by
Professor
Sara Faithfull,
Professor
of Cancer
Nursing
Practice,
University of
Surrey



Professor Sara Faithfull who is from the University of Surrey and has many years of experience in oncology, updated PCaSO at a talk following our AGM.

Treatment solutions for prostate cancer have improved significantly in recent years, with 10-year survivorship now at 84% of diagnosed men. As part of a recent multi-country trial on a variety of prostate cancer related topics, called TrueNorth (TrueNTH), the University of Surrey chose to focus on improving physical exercise by 3 hours per week. The benefits are more marked for men with previously sedentary lifestyles, but can help all with prostate cancer by reducing the likelihood of recurrence after treatment (by up to 49%); reducing the risk of cardiovascular disease, and by minimising the side effects of hormone treatment, such as fatigue and muscle mass loss.

Hormone therapy suppresses testosterone and leads to a reduction of muscle mass and also an increase in fat mass, particularly around mid-body organs. A healthy 70-year old loses muscle mass at around 1% per annum, but long-term hormone therapy increases the loss rate to 5% p.a. Typically this means thinner

arms and legs and a larger belly. A further impact of hormone treatment is an accelerated 'ageing' process, that can be countered by lifestyle changes in exercise and diet.

Being overweight or obese can increase the likelihood of various other medical conditions, e.g. diabetes and cardiovascular disease, not just cancer.

Portsmouth was chosen for this TrueNTH Phase 2 trial, funded by Prostate Cancer UK's Movember fund, and delivered via community pharmacies. Each man in the trial was given a clinical assessment and a personalised Lifestyle Prescription. This was followed up with a 'motivational call' after 1 and 7 weeks, ending with a re-assessment after 12 weeks. The outcome was significant reduction in weight, blood pressure and cholesterol levels, and increased upper body and lower body strength. The cohort of 116 men with prostate cancer diagnoses had a median age of 71. The results of the Phase II trial were published in a BMJ paper in June 2019, see link: <https://bmjopen.bmj.com/content/9/6/e025114.info>

Men in the trial did remark on it having made a real positive difference to their lifestyles - however there was a noticeable tendency to lapse into old ways afterwards. For aerobic exercise to be worthwhile, it must involve at least 150 minutes per week of vigorous 'breathless' exercise.

For participants in the trial the University of Surrey / TrueNTH produced in 2016 a useful booklet and DVD titled "The Man-ual", on exercise and diet after prostate cancer treatment. An updated version (in e-book format only) is under preparation. PCaSO is interested in helping to sponsor the cost of a printed version.

Beyond the TrueNTH trial, a new high-intensity exercise regime is on trial at the University of Surrey for men with metastatic disease, to help control the spread of secondary cancers.

Changes to the organisation and delivery of cancer services in Sussex / Surrey

Rustington Group heard an interesting talk on 11th June 2019 by Andrew Hart, Uro-Oncology Clinical Nurse Specialist at Worthing Hospital, on the theme of "Changes in the Organisation and Delivery of Cancer Services in the Western Sussex Hospitals NHS Foundation Trust". Trusts in Sussex and Surrey are working together as one of 44 'Cancer Alliances' in England - these replace the previous Cancer Networks. Aims will include earlier diagnosis, and patient holistic needs assessments for living with and beyond cancer. A 'Be Clear on Cancer' campaign covering various types of cancer will involve new diagnostic tests and models of care.

New Treatment Summaries will be used by patients and their GPs, recognising the ongoing or long term need for primary care. This gives patients the ability to co-ordinate their own care, and positive lifestyle.

Specifically for prostate cancer, care will be more focused on individual needs, and the frequency of appointments. Emerging technology will include video consultations and an app for PSA monitoring - each being for patients with access to such channels and GPs who offer the technology. Concerns were raised by Rustington attendees about difficulties experienced in obtaining PSA tests at GP surgeries that seem to be ever busier with limited resources.

Andrew then outlined new and emerging treatments for prostate cancer. Many patients will already have experienced 3D tomotherapy radiotherapy, that reduces the risk of damage to surrounding tissue. Stereotactic radiotherapy, also known as 'cyberknife', targets small specific areas, whilst Proton Beam therapy is very high intensity, with potentially few side effects. The first Proton Beam machine in the south of England is due to go live in

Reading in August 2019 (see story on page 4). Brachytherapy is now delivered as a single high-dose procedure. For metastatic cancers, radio isotopes such as Radium 223, and Lutetium 177 (still being trialled), can be effective. A new therapy, Irreversible Electroporation, uses electric probes to kill cancer cells. This is also known as 'nanoknife' and has been developed in Germany, but is not yet available in the UK.

Olaparib is already approved for some breast or ovarian cancers and could be a further weapon against prostate cancer [this was highlighted in the national press a few days earlier]. Andrew showed a very complex flow chart that would determine where Olaparib could be effective.

As regards hormone therapy, the existing Prostag and Zoladex are joined by Firmagon, as a further way to suppress testosterone and oestrogen. Where non-metastatic cancers cease to respond to the above, Apalutamide can now be the next line of defence, where the existing Enzalutamide stops working, or the patient's condition becomes resistant.

For chemotherapy, Docetaxel remains the main solution, and is increasingly used soon after diagnosis, in tandem with hormone therapy, but in advance of radiotherapy. Where the cancer is later seen to return, Cabazitaxel can be used rather than further courses of Docetaxel.

Much of the above is extremely expensive to the NHS. Patients are increasingly encouraged to help by maintaining healthy lifestyles. Andrew highlighted some simple actions such as reducing the use of factory-processed foods, sugar, salt, red meat and dairy.

Lance Allen PCaSO (Sussex)

My Patient Story

by Jon Chapman, Eastbourne Group

My story started about ten years ago when I was diagnosed with an enlarged prostate. After trying various drugs I opted to have a TURP (*transurethral resection* of the prostate) procedure which was successful and involved cutting away a section of the prostate. Biopsies at the time indicated that there were no further problems. However, by 2014 my PSA had risen to 8.8 and a physical examination suggested that I could have cancer. Within two weeks I had had an MRI scan which pretty much confirmed the initial diagnosis. There followed biopsies which showed I had locally advanced cancer. The news did not come entirely as a surprise, as I think from the earliest examination I knew I had cancer.

The consultants letter after the results of the biopsy stated: "Shown a Gleason 4+3=7 adenocarcinoma of the prostate on both sides of the gland. A recent MRI shows extension into the seminal vesicles and some extra capsular extension anteriorly making him a pT3b"

At this time my oncologist proposed hormone treatment along with external beam radiotherapy (37 sessions). I was asked to join the Patch Trial which was set up to compare two types of hormone treatment – conventional anti-hormone treatment and female hormone oestrogen. If I agreed to join I would be randomly selected for one or other treatment. Both treatments are considered to be effective, but there is already some evidence that there are fewer side effects with oestrogen treatment. The patch trial is a randomised controlled trial with over 2000 patients participating. Agreeing to the trial, I was selected to be treated with the anti-hormone drug Zoladex and started on three

monthly injections. There were additional blood and urine tests compared to the tests carried out on patients not taking part in the trial. I stopped having the Zoladex injections in early 2017.

Shortly after starting on hormone treatment, my oncologist suggested that I may be a suitable candidate for a fairly new treatment known as brachytherapy. I was invited to discuss the procedure at the Cancer Centre at the Royal Sussex County Hospital in Brighton. I trained as a chemist many years ago and found the discussion of the treatment rather interesting. It was agreed that I should have the High Dose Rate (HDR) brachytherapy which uses Iridium-192 and is delivered through needles placed into the cancer cells for a very short time.

The delivery of the HDR treatment was quite complicated and required an overnight stay in hospital. It started with the insertion of a large number of plastic needles into the prostate via the perineum. I forget the actual number, but it was around 15. This was done under an epidural and a general anaesthetic. When I came round from the anaesthetic the lower part of my body was still paralysed from the epidural and with a lot of needles protruding from between my legs! There followed two CT scans to check that the needles were correctly positioned in the prostate as the radioactive material will be passed down these needles to the areas to be treated. A couple of hours later I was taken to the Brachytherapy Suite where the needles were connected by tubes to the delivery machine containing the radioactive material. Everyone waved goodbye and you and the machine, which looked like a large vacuum cleaner and went by the name Elektra



Flexitron, were left in a lead lined room for about an hour! The machine delivered the radioactive material for a few minutes down each needle to the appropriate part of the prostate. After this the needles were removed and I was transferred to a ward overnight and went home the following morning once the nurses were happy I could pass urine.

I had the Brachytherapy mid July 2015 followed by 15 sessions (3weeks) of external beam radiotherapy from the beginning of August 2015. Both treatments were carried out at the Cancer Centre at The Royal Sussex County Hospital.

The treatment has proved to be very successful as my PSA has remained very low (around 0.05). As with most things in life there have been side effects. My bladder is weaker and about three years ago I underwent an operation to remove a urethral stricture. I am very grateful to all the staff who have treated me and given me emotional support. The NHS has been superb and I cannot thank them enough.

I believe keeping physically fit and eating well is important. I swim regularly and my wife and I walk a reasonable distance most days. We're fortunate to live on the "sunshine coast" so can often be found on the downs or along the seafront. I'm sure this

has helped my recovery. In the beginning I think I coped quite well mentally, but worries as to my long-term health did begin to surface. My oncology nurse suggested I contact the Macmillan Counselling Service. I had a number of one to one sessions which I found very helpful. My wife and I were then offered a Mindfulness course also run by Macmillan where we learnt to build strategies to deal with our thoughts and emotions. We are so fortunate to have this service.

We also joined PCaSO about three years ago and started helping with the fundraising. We were able to furnish the waiting room at the new Radiotherapy Centre at The Eastbourne District General Hospital. PCaSO has been a great place to learn about the latest developments in treatment and

to share experiences with other cancer patients.

Survival and recovery is also about the everyday support from everyone around you. I've been very lucky with support from my family and friends, particularly my wife and children and the many people I know.

A couple of months ago my wife and I, together with others from the Eastbourne PCaSO group, were given the opportunity to attend a two day Living Well course run by the Penny Brohn charity otherwise known as the Bristol Whole Life Approach. Their vision is to care for the mind, the spirit, the emotions, the heart and the soul as well as the body, paying particular attention to healthy eating, physical activity and stress management.

We learnt about relaxation, self-help techniques, meditation and mindfulness and the last session was a wonderful mindful walk along the seafront focussing on the sounds, sights and smells that surround us. The two excellent facilitators took us through a programme to strengthen our immune system which can help the body heal and repair itself. It was also great to hear other people's stories and share experiences in a supportive environment. We left feeling very positive and knowing now that there are many ways to help ourselves to overcome cancer and live a fulfilling life.

In early 2017 our son moved to Miami so trips there now feature regularly in the diary - something we never thought we would be doing!

Opportunities to donate to PCaSO

Online shopping

Most people now do some shopping online, such as purchasing items or holidays. There are increasing numbers of ways to give to charities while doing so. The majority of these don't cost you anything as the retailer pays a small percentage of your order.

If you use Amazon and register for **Amazon Smile** – you only have to do it once – you can choose PCaSO as your charity. Every time you buy through Amazon, PCaSO gets 0.5%. Sign up here <https://smile.amazon.co.uk/ch/1170536-0>

We had a cheque for £30 from **PayPal**. So sign up for that one as well if you use them.

Easyfundraising have gone to hundreds of retailers and signed them up. If you register with [easyfundraising.org.uk](https://www.easyfundraising.org.uk) once, download the app and choose PCaSO, every time you go to the retailer's website you are offered the chance to 'Activate the Donation' so if you then order something, PCaSO gets a little.

If you want to use another retailer with charity giving and find that PCaSO isn't listed, then tell us.

Online Fundraising

Most people have heard of Just Giving as a way of someone raising money when running a marathon or whatever. There are others, such as Virgin Money Giving, CAF Donate, Wonderful Organisation etc. Most of these will take a percentage of the money raised. Just Giving, for instance, takes 5%, Virgin takes 2% CAF 3.6% but Wonderful is FREE. We are registered with Just Giving, Virgin, CAF Donate and Wonderful, so you can choose. There's a Donation link on our website. Other platforms may be reached via your browser.

Gift Aid

And don't forget Gift Aid. If you are a UK taxpayer, sign a Gift Aid declaration and PCaSO will get 25% extra from Her Majesty's Revenue and Customs. During the last financial year we received £4,655.

Donate your time and experience

Donation is not just about money, it is also about having the human resource to do the many things PCaSO does. We have members on four committees (the Exec and three Branch Committees), but there are many other members who help out in various ways, such as running aspects of PCaSO operations or helping out at PSA testing events. We estimate we have probably around 70 active volunteers across the three Branches, out of around 1000 PCaSO members.

So why not Step Forward and offer a little of your time to helping out PCaSO and other prostate cancer patients in some way? You may have useful background skills from work and life experience you can apply, or even just your energy, commitment or prostate cancer experience to donate. Have a chat with a committee member, they are listed on page 2.

Dorset Branch

Our erstwhile Chairman, Jim Davis, resigned suddenly and unexpectedly in April, well before our AGM, relinquishing all his positions in PCaSO.

Fortunately, Allan Higgin stepped into the breach and volunteered to be acting Chairman until the AGM and to serve for one year thereafter if elected. He also agreed to take over the running of a PSA Test day at Weymouth which had already

been advertised and was to be run on June 1st in conjunction with the New-Man Group. This was accomplished successfully.

A temporary halt was called on further PSA Testing until the Branch Committee had a chance to fully investigate the PCaSO on-line booking system being trialled in Sussex.

Allan Higgin was duly elected Branch Chairman at the Dorset

AGM, also our Treasurer, Barry Taylor, was elected to replace Jim Davis as one of the Branch's representatives at Executive Committee meetings. The reps are Messrs Higgin, Pilling and Taylor.

Clive Duddridge, who has long been our Membership Secretary, did not want to stand for re-election at the Dorset AGM but has kindly deferred his departure from the committee until a replacement can be found or some way of covering his tasks has been worked out.

Hampshire Branch

PCaSO Hampshire purchase biodegradable water bottles for the Radiotherapy Department, Queen Alexandra Hospital, Portsmouth

Earlier this year, I unfortunately needed to undergo radiotherapy at Queen Alexandra Hospital. When attending my appointments, accompanied by my husband Graham, we were shocked at the number of men from the local area including Chichester and the Isle of Wight that were undergoing radiotherapy for prostate cancer, by far the greatest number of all the Cancer patients that we encountered.

The prostate cancer patients were easily identifiable as the gentlemen drinking endless cups of water prior to their treatment. We witnessed the large amount of discarded plastic disposable cups that accumulated every day. One gentleman was filling five separate cups so he would not forget how many he had drunk!

The prostate cancer patients all spoke very highly of the care and treatment they were receiving from the staff of the radiotherapy department and it occurred to me that the department might welcome a donation from PCaSO Hampshire to help prostate cancer patients.

Mrs. Kim Sanderson, Radiotherapy Department Manager, said that her department were very aware of the environmental impact the use of non-recyclable plastic water cups was having and one of her staff, Planning Superintendent Radiographer Clare Murphy, had therefore come up with the suggestion to buy biodegradable 500ml water bottles that could be issued to the men for their personal use for the period of their radiotherapy and retained

by them afterwards. This would then negate the need for the plastic cups. It would also ensure that the men would know exactly how much they had drunk and treatment would not be delayed due to men not consuming enough water.

PCaSO Hampshire Committee members considered that this was a simple but ingenious project that we could support as it would be a "win win situation" for prostate cancer patients as well as the environment. The cost of the bottles was £830 for 500 bottles and it was agreed that Hampshire will also fund a further 500 bottles when required. This latter batch of bottles will carry the PCaSO logo in addition to the hospital logo, thus publicising further the work of PCaSO.



Left: Clare Murphy with example of Disposable Plastic Bottle given to each man.

Right: East Hampshire MP Damian Hinds, has blood taken for a PSA at a PCaSO PSA testing session in Petersfield.

Far Right: Geoff Bailey and Peter Weir of Hampshire Branch meet Eastleigh MP, Mims Davies, at the One Community Charity Awareness Event in Eastleigh.



Sussex Branch

Sussex Branch have run three PSA testing sessions at Uckfield, Chichester and Horsham trialling the new online booking system developed by members Cliff Carter and Andrew Collett.

Previously men applying for PSA testing had to telephone a volunteer who wrote the man's basic details onto paper and told him his reporting time. Then, on arrival at the event, the man had to fill in a Consent Form with more details.

With the online system the man can choose a time and then complete the details of the consent form at home online and print out a 'Ticket' to take to the event. The Ticket barcode is scanned by a PCaSO volunteer. The details are thus available for the administration.

After the event the pathology lab gets a spreadsheet with printed details of each man to ensure that the vial of blood can be matched to the right individual. The spreadsheet helps the lab which means the results are likely to be available sooner.

In Horsham there were 41 no-shows, so from the next event men booking online will get a reminder email three days before the event. Further improvements to the online system are also in hand.

Following introductory trials by Sussex the system is now being used by Hampshire Branch. Dorset may follow as their testing restarts.

Chairman Roger Bacon, who runs the events across Sussex, said "The new online system saves time for myself and my wife as we now only get a few phone calls for each event. It also saves time for our volunteers on the day because men are arriving with their details and consent form already completed so they spend less time hanging around."



Eastbourne Group

Elaine and Tom Chapman held their 3rd Annual Golf day at Willingdon Golf Course on the 24th May. It was a successful and well attended day; 96 golfers including six women. Fortunately, the sun shone brightly which kept the ladies looking after the half-way house busy handing out refreshments. The golfers had a full round of golf followed by an evening meal and an auction. Staff from the Eastbourne Urology Department joined the golfers for the evening meal. It was particularly good to see consultant urological surgeon Peter Rimington as he performed the successful operation on Tom three years ago. The final amount raised on the day was £4,200 bringing the total raised to date to over £12,000. The money raised on the day will be split between Prostate Cancer UK (£3,000) and £1,200 being donated to the Eastbourne branch of PCaSO to be spent on equipment for the Urology Investigation Suite at the District General Hospital.

Debbie Hatfield who runs the Eastbourne PCaSO group with Chris Cutting, recently graduated with a PhD undertaken at Brighton & Sussex Medical School. Debbie researched patient and public engagement and involvement in clinical commissioning, i.e. how patients and the public are involved in making decisions about what should be purchased and provided in the way of NHS services for communities defined by a 'Clinical Commissioning

Elaine and Tom Chapman (left with the Urology staff including Peter Rimington].

Group'. The research was sponsored by the former Higher Education Academy and the title of her thesis is: Patient and public engagement and involvement in clinical commissioning; socio-material pedagogies of partnership.

Bexhill



Our June meeting was well attended. We had Nadine an Ambassador and three service users from the Sara Lee Trust to tell us the services they offer to local people. We also had Dr Sue Catt from Sussex Health Outcomes Research & Education in Cancer (SHORE-C) at Brighton & Sussex Medical School to talk about the research she is doing about hot flushes and acupuncture and its effect. The men and their wives were involved in discussions and made a lively meeting. The President of the Bexhill Rotary Club came and presented a cheque for £1000 to support our group locally. Our next meeting is on the 2nd September when Mr R Plail consultant urologist at the Conquest Hospital will come to talk to us.

LOCAL SUPPORT MEETINGS *See inside front cover for contacts.*

September 2019

2nd (Mon) Bexhill	Roger Plail , Consultant Urologist
3rd (Tues) Otterbourne	Edmund CP Chedgy , Consultant Robotic and Urological Surgeon, University Hospital Southampton. 'New Southampton Urology Centre and New Prostate Cancer Diagnostic Pathway.'
5th (Thur) Eastbourne	Simon Tyler-Murphy , Lead Urology Nurse. ED treatment after prostate cancer treatment: are we getting it right?
10th (Tues) Pulborough	Discussion of symptoms, treatments, clinicians, hospitals
11th (Wed) Brighton	Patient Forum
17th (Tues) Rustington	Dr George Plataniotis - Systemic treatments for metastatic prostate cancers.
25th (Wed) Bournemouth	Tbc

October

2nd (Wed) Chichester	Patient Forum
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November

4th (Mon) Bexhill	Tbc
14th (Thur) Eastbourne	Tbc
20th (Wed) Chichester	Patient Forum
26th (Tues) Rustington	Patient Forum
27th (Wed) Bournemouth	Tbc

December

4th (Wed) Brighton	Patient Forum
4th (Wed) Pulborough	Discussion of symptoms, treatments, clinicians, hospitals

2020

January

6th (Mon) Bexhill	Tbc
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VENUES

Dorset

Bournemouth: 7.30pm start
St Marks Church Hall,
Talbot Woods,
BH10 4HY,

Hampshire

Otterbourne: 7.30pm start
Otterbourne Village Hall,
Cranbourne Drive,
SO21 2ET

Waterlooville: 7pm start
Church of the Sacred Heart,
London Road,
PO7 7SR

Sussex

Bexhill: 7pm start
Health Centre, Bexhill Hospital,
Holliers Hill, Bexhill,
TN40 2DZ

Brighton: 7pm start
Macmillan Horizon Centre,
Bristol Gate, Brighton
BN2 5BD

Chichester: 7pm start
Chichester Baptist Church,
Sherbourne Road,
PO19 3AW

Eastbourne: 7pm start
Postgraduate Centre,
Eastbourne District
General Hospital,

Pulborough: 7pm start
Pulborough Village Hall,
Swan View (off Lower Street),
RH20 2BF,

Rustington: 7pm start
John de Bohun Room,
Woodlands Centre,
Woodlands Avenue,
BN16 3HB,

PSA Testing Events:

Check our website www.pcaso.org for the latest details

PSA testing is by booked appointment only. To register online go to either www.psatesting.org or for those not able to book online, contact phone numbers for telephone booking will be displayed on PCaSO's website www.pcaso.org 3 to 4 weeks before the scheduled date of the event (if you do not have a computer ask a family member or friend to check online for you).

August	24th	Pyecombe (north of Brighton) (Sussex)
Sept.	7th	Worthing (Sussex)
	7th	Emsworth (Hampshire)
	21st	Southampton (Hampshire)
	28th	Hove (Sussex)
Oct.	5th	Alton (Hampshire)
	12th	Burgess Hill (Sussex)
	19th	Gosport (Hampshire)
	19th	Bournemouth (Dorset)
Nov.	2nd	Bridport (Dorset)
	9th	Bordon (Hampshire)
	23rd	East Grinstead (Sussex)
Dec	7th	Peacehaven (Sussex)

PCaSO Members

At most events we need help to make them run smoothly. Checking men in at the door, calling them forward and pre-briefing.

Most events are on a Saturday and usually finished by mid-afternoon. If you are available on any of the dates stated you will be most welcome! Please call:

Roger Bacon (Sussex)
01903 775783

Peter Weir (Hampshire)
01489 892168

Allan Higgin (Dorset)
01202 691710