

# UPDATES

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



Issue No. 69

**Summer/Autumn  
2020**

Eastbourne Pier, East Sussex  
(Photograph by Christina Cutting)

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Cancer treatment**

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and Exercise**



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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.

## Dorset Branch Committee

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## From the Editor

What a change since the last issue due to the Coronavirus pandemic!

This is our regular 12-page Updates newsletter, but without the back-page list of physical meetings and PSA events, as they have all been cancelled for 2020 due to the pandemic. Some PCaSO committee meetings have been held on Zoom and the PCaSO AGM will be on Zoom (see page 4).

Sussex Branch did manage a talk in July 2020, by - you guessed it - Zoom! Andrew Hart, CNS, gave us an update on how Western Sussex hospitals are coping with cancer care during the pandemic (see page 9). Page 3 has content from Prostate Cancer UK's website about Covid-19 and prostate cancer treatment.

Thanks to Neal Bloom, Dorset Branch, for his Patient Story (see page 6) and to Brian Holden, Brighton Group, for the continuation of his previous story (see page 7).

A new information project is underway, called 'Healthy Living for Survivors of Prostate Cancer'. This includes 'Physical Activity and Exercise' and a short version is on pages 10 to 12. The full version of this should soon be on the PCaSO website. Of course, you might already be very fit after doing daily exercises with Joe Wicks during lockdown!

# Covid 19 and Prostate Cancer Treatment

Below is a summary of information taken from the Prostate Cancer UK website (by Roger Bacon)

If you have had **surgery** to treat prostate cancer in the past and have recovered from the operation, this will not increase your risk of catching coronavirus. It also will not increase your risk of severe illness if you do catch coronavirus.

**External beam radiotherapy** to the prostate should not affect your immune system. So, if you have had – or are currently having – radiotherapy to treat cancer inside your prostate, this will not affect your risk of catching coronavirus. It also will not increase your risk of severe illness if you do catch coronavirus.

However, if you are going into hospital to have radiotherapy, you might catch coronavirus from other people there. Hospitals are taking extra measures to lower the risk of staff or patients catching coronavirus, but talk to your doctor, radiographer or nurse if you're worried.

Some men with **advanced prostate cancer** have radiotherapy to relieve bone pain in parts of the body where the cancer has spread. Depending on the bone that is being treated and the dose of radiotherapy, this might affect the bone marrow, which can cause a temporary drop in the number of blood cells that help fight infection.

If this happens, it might mean you are more likely to get infections. Speak to your doctor, radiographer or nurse if you're having radiotherapy to treat symptoms of advanced prostate cancer and are worried that you might be at increased risk.

If you are having **radium 223** to treat bone pain caused by advanced prostate cancer, this can occasionally affect the bone marrow and increase your risk of getting infections. Speak to your doctor or nurse if you are worried.

If you are on standard **hormone therapy**, this will not increase your risk of catching coronavirus, or of severe illness if you do catch coronavirus. However, remember to think about any other treatments you might be taking, and whether those might increase your risk.

If you are taking **abiraterone** tablets, you will also be taking a steroid called prednisolone or dexamethasone. Most men who take **steroids** as part of their prostate cancer treatment will be having a low-dose steroid. This means the effect on your risk of getting infections should be small. Check with your doctor or nurse if you are not sure about your dose.

If you are taking **enzalutamide**, this could affect the number of white blood cells in your blood. If

this happens, you may be more likely to get infections, including coronavirus. Speak to your doctor or nurse if you are concerned, and always contact your medical team at the hospital straight away if you have signs of an infection.

**Chemotherapy** can increase your risk of catching infections because it can make your immune system weaker. You should follow the government's latest advice on shielding and stay at home as much as possible.

If you decide to spend time outdoors with people from your own household, or outside your household if you live alone, it is still important to follow the government's advice on social distancing. Always contact your medical team at the hospital straight away if you have signs of any infection, even if they are only mild.

We all need to be careful, and particularly if:

- you are 70 or over
- you have a long-term health problem, for example with your lungs or heart, or a weak immune system
- you are having a treatment that puts you at increased risk of infections.

## Knowledge Empowers Information Booklet

### January 2020

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).

## PCaSO Consolidated Accounts year ended 31st March 2020

	Dorset	Hants	Sussex	Executive	Consol Adjts	Total 2020	Total 2019
<b>Balances as at 1st April 2019</b>							
Current Accounts	19,054	18,035	10,587		1,828	49,505	48,880
CAF Deposit Account			3		3	3	
Virgin Money Deposit Funds	29,678	17,684	23,750	9,692		80,804	57,977
<b>Cash Balances as at 1st April 2019</b>	<b>48,732</b>	<b>35,719</b>	<b>34,337</b>	<b>11,523</b>	<b>0</b>	<b>130,311</b>	<b>106,860</b>
<b>Receipts</b>							
Subscriptions	84	48	108			240	384
Donations - Members	703	1,966	2,947	844	45	6,504	6,646
Donations - Personal		425	113	3,007		3,545	833
Donations - Corporate	3,334	9,348	2,801	1,375	1,200	18,058	12,984
Donations - PSA Testing	5,243	16,825	25,638			47,705	41,047
Fundraising - Public Meetings	235	1,139	5			1,379	486
Fundraising - Collections	1,655	253			239	2,147	3,810
Fundraising - General						0	
Fundraising - Events	9,544				1,557	11,101	5,899
Fundraising - Eastbourne			3,088		-3,088	0	
Interest on Deposits	221	133	178	73		604	326
GiftAid	927	2,234	2,917		48	6,126	5,709
Other	400	150				550	
	<b>22,347</b>	<b>32,521</b>	<b>37,794</b>	<b>5,298</b>	<b>0</b>	<b>97,960</b>	<b>78,125</b>
<b>Payments</b>							
Administration (Note 1)	357	733	389	1,795	-1,025	2,249	2,396
Trustee & Public Liability Insurance				751		751	589
Helpline						0	
Newsletter costs			1,454	1,073		2,528	2,730
Support to members	1,089	926	2,102			4,117	2,154
Awareness	1,044	1,439	2,554			5,038	2,325
Expenses - PSA Testing	10,435	14,675	19,361		1,025	45,496	34,842
Advertising						0	208
Fundraising - collections	65					65	121
Fundraising - Events	324	81	251			657	36
Donations (Note 2)	1,100	19,331	6,996			27,427	8,749
Capital expenditure & software	1,018	1,178	693	816		3,704	524
Inter-Account transfers						0	
	<b>15,433</b>	<b>38,364</b>	<b>33,800</b>	<b>4,436</b>	<b>0</b>	<b>92,032</b>	<b>54,674</b>
<b>Receipts less payments</b>	<b>6,914</b>	<b>-5,842</b>	<b>3,994</b>	<b>862</b>		<b>5,928</b>	<b>23,451</b>
<b>Total Funds</b>	<b>55,646</b>	<b>29,877</b>	<b>38,331</b>	<b>12,385</b>	<b>0</b>	<b>136,240</b>	<b>130,311</b>
<b>Cash &amp; Bank Balances</b>							
Current Accounts	25,747	12,060	14,404	2,618		54,828	49,505
CAF Deposit Account				3		3	3
Virgin Money Charity Deposit A/c	29,899	17,817	23,928	9,765		81,408	80,804
<b>Total Cash Balances as at</b>	<b>55,646</b>	<b>29,877</b>	<b>38,331</b>	<b>12,385</b>	<b>0</b>	<b>136,240</b>	<b>130,311</b>

### Notes

- 1 Exec Admin: \*GFCT Warwick conference £401, TACKLE AGM attendance expenses £374, PO Box £342, Website costs £194, \*PSA IT £92, Exec meeting room hire £135, ICO registration £35, travelling exs £82, AGM notice and room £90, postage £49. \* transferred to PSA costs.
- 2 Donations: Southampton Hospital lithotomy chair £15,665, TACKLE £3,300, Southampton Hospital chairs £1,330, Mary How Trust £1,000, Cancerwise £1,000, Cancer United £1,000, Royal Sussex radiotherapy leaflets £146, Eastbourne DGH £1,780, water bottles for RT patients at QA Portsmouth, Brighton & Eastbourne £1,870, QA Portsmouth TV £226.

## PCaSO AGM on Zoom

Due to Covid-19 risks, this year the AGM will be held remotely as a Zoom video meeting, so you can attend from the comfort and safety of your home, using a laptop, tablet, smartphone or other suitable internet connected device. The AGM will be scheduled to commence at **2.30 pm on 22<sup>nd</sup>**

**September 2020.** If you wish to attend the AGM please email [secretary@pcaso.org](mailto:secretary@pcaso.org) and you will be sent a link and password a few days beforehand which will enable you to join the meeting. Please ensure you join the meeting within the 10-minute period before this scheduled time, i.e. from 2.20 pm. For further information about Zoom please see the article below.

## 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.

*continued on bottom of page 5*

# Changing the way men are diagnosed

## Re-IMAGINE research project

MRI scanning has been around for some time, but it started to get better 12 or 13 years ago, so to a trained eye you can now see where the cancer is in the prostate. This research project aims to take MRI scanning to a new level and change the way prostate cancer is diagnosed.

The vision of Re-IMAGINE is built on recently published research work (PROMIS trial) showing that Magnetic Resonance Imaging (MRI) of the prostate was 100% better at identifying men at risk compared to the standard prostate biopsy, and moreover missed no men with potentially fatal disease. MRI is now certain to become the future cornerstone of the risk-stratification process for men at risk of early prostate cancer. However, little is known about the use of MRI in combination with other markers in the body, the project will investigate the best way of predicting cancer progression, through use of imaging combined with advanced blood/urine/tissue marker analysis. The Re-IMAGINE programme consists of a number of work-strands (WS).

WS1 will create the first group (cohort) of men (around 1000) who have received a prostate cancer diagnosis by means of an MRI-based pathway. These men will, after appropriate consent, donate some tissue, blood and urine for marker analysis. They will be

recruited from a number of major centres in London that have high quality MRI in place.

WS2 will test the performance of MRI in a random population of men (around 350), where cancer is less common - men who have not had a PSA test. This will allow the project to look at predicting the exact proportion of men at risk within the community.

These work streams will generate a lot of data (clinical information, imaging data, as well as information from markers in blood, tissue, and urine). All this data and information for each patient will be combined using a secure database, in line with the General Data Protection Regulations (GDPR), analysis will include mathematical techniques.

Such a complex project will require high levels of project management and coordination with various expert partners such as – patient organisations, clinicians, image experts, molecular biologists, methodologists and a range of specialist industrial partners. Just a few of the dozen or so commercial partners and what they can bring to the project are listed below. If you wish to see more partners, go to <https://www.reimagine-pca.org/commercial-partners>

### ProteoMedix

ProteoMediX is specialised in developing truly disruptive blood-based tests for the improved diagnosis and management of

prostate cancer. ReIMAGINE presents a unique opportunity to permit a re-calibration of ProteoMediX' tests to be used in the MRI-based imaging era. The collaboration allows for the development of a test-model that can determine a patient's individual risk for developing prostate cancer.

### Minomic

Minomic has developed an in vitro diagnostic blood test called the MiCheck® test for the detection of prostate cancer that also better differentiates aggressive from non-aggressive cancers. As the test has a higher specificity than tests like PSA it is able to reduce the number of men proceeding to biopsy. Minomic is preparing to launch the MiCheck® test in the US this year.

### Lucida Medical

Lucida Medical is the new name for Cambridge AI Health. We develop software to analyse MRI scans using image processing and AI methods, with the goal to make cancer screening accurate, accessible, cost-effective, and quick. We will apply our software to the ReIMAGINE data to validate methods to support prostate cancer screening and diagnosis.

Although this research study will take several years to complete with in-depth analytical analysis, the future of diagnosing prostate cancer could change forever and become a lot more accurate and make decision making about treatment easier.

*Roger Bacon*

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)

Zoom meetings will usually be opened 10 minutes before the scheduled time, to allow for participants to join the meeting before it opens. You will be placed in a 'waiting room' until the meeting host allows you to enter the meeting. To ask a question please use the Zoom "Raise Hand" facility. This can be done by mouse hover at the foot of the screen and clicking on Participants, then at the foot of the popup click "Raise Hand".

This will show a blue raised hand against your name in the participants screen, and white raised hand on a blue background at the top left of the Host's view of your screen. The Host/Chair can then see all who want to ask a question.

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>



# 'Tales of the unexpected'

## Patient Story by Neal Bloom, Dorset Branch

Several years ago, there lived a man who drove a white Rolls Royce, who was seen regularly in the Bournemouth / Poole conurbation. The number plate on his distinctive car began with the letters MB. I am referring, of course, to the well-known family entertainer Max Bygraves- I am showing my age, will be 70 in September! Max, nearly always started his act with the phrase "I wanna to tell you a story". Fellow Prostate Cancer sufferers and others affected by this disease. This is my story so far.

### Diagnosis

One evening in July 2018, I went to pass water and there appeared to be more blood than urine. A repeat performance the following morning, persuaded me to contact my GP who informed me that I probably had a bladder infection and prescribed antibiotics. However, he emphasised that if I became unable to pass urine, I was to go to the local A&E department. The possibility of spending 4 hours at A&E on a lovely hot summer's day did not cheer me up!

I am my wife's carer as she had two operations in 2017 to remove a benign brain tumour and insert a shunt. That afternoon, we had invited friends for tea. I was unable to pass anything and a friend drove me to the A&E Department of the Royal Bournemouth General Hospital, where I was seen very quickly by a Junior Doctor. Following a PSA test, CT scan and various internal examinations, I was told by the Consultant Urologist that my PSA was 907 (normal range was up to 4). I asked him if I should contact the Guinness Book of Records but no reaction- no sense of humour some people! I was told I had Prostate Cancer and that the next morning I would see a cancer nurse.

### Treatment

I cannot account for my immediate

reaction, although my wife, unsurprisingly, was in shock and had only returned home from hospital within the last 6 months herself. The cancer nurse informed us that I was suffering from Advanced Prostate Cancer which had spread to my bones - a rib, pelvis and spine. The CT scan confirmed T4 N1 M1b prostate cancer, no Gleason score was given. My treatment for the first 21 days would consist of 1 pill per day and hormone therapy injections (Prostap). I was supplied with a list of the possible side-effects of hormone therapy and can now sympathise with women going through the menopause! I received the first injection whilst in hospital and subsequent injections have taken place every 3 months at my surgery.

Also, I was invited to join a trial the details or reasons weren't fully explained to me and I declined. Subsequently advised by the Jigsaw cancer treatment department at the hospital I would be having 6 sessions of chemotherapy at 3 weekly intervals and would be taking daily steroids. The day before my first session of chemotherapy, my height and weight were measured. I was told that the day before every session, I was to consume 8 additional steroids - I was beginning to rattle!

The first session of chemotherapy wasn't too traumatic. I had no adverse reactions until session 3 when I noticed that not only was my hair falling out in bundles from my head but rapidly disappearing from other areas of my body- I know, too much information! In my last 3 sessions, I noticed different side-effects, for example: bleeding fingers; pins and needles in my fingers which spread to my toes; and finger nails turning a funny colour. However, thankfully I did not experience nausea. My last session of chemotherapy was in January 2019.



### Today

The pins and needles disappeared from my fingers, replaced by neuropathy, a kind of nerve damage that can cause tingling or numbness, in my toes and feet. My consultant told me this may be permanent so they had no objections to me trying alternative medicine [if you wish to try alternative medicine, please ensure that you have a conversation with your doctor to ensure that you do it safely]. I have had 6 sessions of acupuncture (on a private basis) and 6 sessions of reflexology (free provided by a local cancer charity). To date the flare ups are not as bad, but my balance is a problem.

At the moment my wife, Rosamunde, and I cannot due to our conditions make any long-term plans. I have to survive long enough to ensure that she would be self-sufficient and hope that the private sector can obtain a cure as soon as possible. I no longer concern myself (as far as possible) with what might happen within the next 3 years and know at the moment, apart from the neuropathy, my physical condition is OK.

I discovered in January 2020 that there was a Prostate Cancer Support Group in my area, at the end of that month attended my first meeting and joined in February, next meeting etc., all cancelled.

In the past, cancers or the big "C" were a taboo subject with exclusive membership. Today they let anybody join, even me! To paraphrase the late American comedian Groucho Marx, "would I want to join a club where they would accept me as a member?" I wish you all a good and long life and hope that you stay as positive as possible.

# Brian's Lucky Journey Continues

**A story of persistence! by Brian Holden, Brighton Group**

Following my article in PCaSO Updates Winter 2018, Issue No 64, titled "Brian's Lucky Journey", unfortunately and unexpectedly my journey continued.

It is best to go on the PCaSO website and read the full previous article but, put very simply, in October 2016 at a free PCaSO testing day my PSA was found to be 5.4, by 2017 I had PSA 6.9, Gleason of 4+3 and staging T3A N0 M0, locally advanced prostate cancer. I was treated initially by hormone therapy, prior to HDR brachytherapy and external beam radiotherapy, resulting in a PSA of 1.33.

Fortunately, thanks to my participation in the Add Aspirin clinical trial, I was having my PSA checked every few months after treatment, and was also seeing my treatment consultant, who was the lead consultant for the AA trial in Brighton.

For several months my PSA rose steadily. This was initially attributed to 'the bounce', a short-term rise in PSA which is apparently known and quite common after treatment. However, in 2018, nine months after treatment, my PSA reading was up to 3.96, and my consultant decided to start further investigation.

First was a negative MRI scan.

Second was a negative choline PET scan.

But my PSA was still not stabilising. My consultant was unsure if this was 'the bounce' or not.

Third was another negative choline PET scan.

In between scans I started to see blood in my stools and, after a flexible sigmoidoscopy (rectal camera examination), was diagnosed with radiation proctitis. This is a known, possible side-effect of my treatment, due to

radiotherapy damage in the rectum, but is nothing sinister.

Fourth came a bone scan, which showed no signs of the cancer.

But my PSA was still showing no sign of dropping, and I discussed what to do next with my consultant.

Luckily, at this stage in early 2019, my oncology registrar daughter pointed me to clinical trials of a PSMA scan at UCLH London.

This scan is currently generally unavailable for NHS patients, as it is still being evaluated as a tool for prostate cancer diagnosis. After my numerous emails with the lead radiographer, and due to a breakdown of communication with my treatment team, I was not accepted onto the trial. Amazingly, however, and probably because I became a nuisance with my emails, I was nevertheless offered a free scan! Hooray! A day-trip to London for the scan in June 2019 ensued.

As keen sailors, we had already decided to take our summer holiday sailing the north coast of France. One hot evening at about 2000 French time I had a phone call from an unknown number and, being a couple of glasses of red wine down, I made the unusual decision to answer it. It was my consultant, who informed me that the PSMA scan had successfully picked up cancer cells in the pelvic lymph nodes. He now knew where the cancer cells which were causing the rising PSA were located, and could thus treat them. The multi-disciplinary team had already formulated a plan, and I should start treatment straight away!

Oh! Our sailing plans were cancelled, and it took us a week to get back to England, initially to restart hormone treatment with bicalutamide tablets and then, hey ho, another course of monthly Zoladex injections. Treatment

begun, we did return straight back to France for a few weeks, but our sailing plans were very much scuppered.

Back on the treatment path again, Zoladex injections have continued, followed by 23 two-Gray sessions of external beam radiotherapy. Fortunately, because the treatment was higher up the pelvic area, I did not have to take the 'enemy' (enema) before each session.

It was at Preston Park radiotherapy centre that I met fellow sufferers Rob and Brian. I have always believed in the benefits of sharing experiences and comparing notes on side effects and progress. Brian and Rob have both become good friends, and we keep in touch regularly, mainly through our love of off-road cycling - but that's another story.

Fitness has played a major role in staying healthy and psychologically positive. Cycling, walking and upper body strengthening now play a key part in my life. You cannot beat the outside 'green gym' to lift your spirits!

*continued overleaf*



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Throughout the treatment years my wife and I have continued to follow a healthy diet on the basis of everything in moderation, and this works for both of us – no special diet required. We have cut out processed meats, greatly reduced red meat and consumption of other processed foods, and eaten more fruit, vegetables, chicken and fish - sometimes called the Mediterranean diet. My minder buys fresh, locally sourced ingredients where possible, and we home cook to get the best benefits.

Friday 13th December 2019 – radiotherapy treatment finished, blood test for Add Aspirin trial. PSA 0.03.

After celebrating my 65th birthday with my family in early January 2020, we decided to escape the winter for a couple of weeks to the sun. Whilst sitting on a sunbed I noticed that my ankles had swollen badly, so I researched on the NHS and Macmillan websites and found information that suggested oedema. Holding a finger on the ankle left an indentation, which was subsequently confirmed as pitting oedema.

In March 2020, Coronavirus hits the world, but cancer patients are still fully supported by the NHS.

I had a post-treatment CT scan, then a call from my consultant on 6 June 2020 in lieu of a face-to-

face consultation. CT scan all clear! Brilliant news, and a good virtual family celebration that evening.

Despite the oedema being an ongoing problem, it is not life-threatening, and is being resolved mainly with self-help – diuretic tablets to reduce water content, compression stockings, exercise, moisturisation and self-massage.

Having received my final three-month Zoladex injection in May 2020, it is now a case of waiting for its effects to gradually wane and for my testosterone levels to rise again. A further PSA test and consultation are planned for December 2020.

## Sussex Branch hosts first ever talk on Zoom

As you will be aware our Group meetings were cancelled due to the Coronavirus pandemic. Resumption of all of these in the usual manner is unlikely for some time, due to the higher risk of our, mostly elderly, members contracting Covid-19. It was therefore decided to try out a virtual meeting, open to members across Sussex (rather than just a single Group). We were then fortunate in Roger Bacon securing a speaker to give us a talk using Zoom (see following article).

We do not have email addresses for all our Sussex members, but for those we did have we invited them to let us know if they wished to participate. The technology showed that only about 55% of those PCaSO emails to members were opened! Those that responded were sent details by email. For the talk itself we then had 18 persons in the 'virtual' audience on Zoom. One member commented that it was his first experience of using Zoom, but he was glad he had made the effort and thanked Cliff Carter for

his help in understanding how to use Zoom.

The speaker was excellent and in the usual manner there were some questions and answers after the talk. As a concept it has been shown that using Zoom for talks can be successful and obviously keeps members safe from Covid-19 contacts during these unusual times. It also means the talk can be seen across our 'connected' membership from the safety and comfort of their own homes, not just by those attending a particular local Group. It was, however, disappointing that there was not a greater 'virtual turnout' as those that either did not participate, or could not get on Zoom, missed a good informative talk.

Sussex Branch plan to screen other Zoom talks and already a couple of potential further speakers have expressed a willingness to talk to PCaSO members in this way. We will let members know in due course about these events to be held in the Autumn. This is a new

experience for our speakers as well as our members and Cliff and Roger deserve credit for making this happen. We just need to work at it to get increased benefit.

PCaSO pays a subscription to Zoom that ensures unlimited time for up to 100 participants and some committee meetings have been hosted in this way. There is also a very easy free version of Zoom, and for those members interested we strongly recommend you download Zoom to your pc, laptop, or tablet well in advance of a scheduled meeting and get some practice in using it if you can. It will work on smartphones as well, but a larger screen can be preferable.

To download Zoom to your particular device, go to [zoom.us](https://zoom.us)

*Tony Ball*

**For more information see 'How to Join a Zoom Meeting' on page 4/5**



# Talk to Sussex Branch

by Andrew Hart, Uro-oncology Cancer Nurse Specialist,  
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Following an invitation from Roger Bacon, Andrew Hart presented a talk using Zoom to PCaSO Sussex Branch members on 22<sup>nd</sup> July 2020 and answered several questions. He explained that because of Covid-19 the use of video-conferencing software had increased in the NHS, either by medical staff working from home and/or working at their offices, but not travelling between hospitals, e.g. Microsoft Teams video-conferencing software being used for MDT (multi-disciplinary team) meetings.

## Impact of Covid-19

West Sussex has many elderly residents, Worthing for instance has the second highest elderly population in the country after Blackpool. Surprisingly, however, locally there were a relatively low number of patients requiring prolonged hospitalisation for Covid-19 and now the 'red Covid' zone within the hospital has been reduced. Masks are worn at all times in clinics/hospitals and supply of PPE has always been good. Unlike elsewhere in the NHS there was less need for staff to be redeployed to deal with the virus, so cancer staff mostly retained their usual duties but some were working from home. Services are restarting, but there is a considerable backlog, e.g. of template biopsies, radiotherapy, cystoscopies, chemotherapy and routine scans. Both radiotherapy and surgery have been restarted now. Some treatments had been altered due to the delays caused by Covid-19, e.g. bicalutamide or LHRH hormone therapy has been given to patients forced to wait for surgery, whereas hormone therapy has been extended for radiotherapy.

A 30-40% reduction in prostate cancer referrals has been experienced due to the pandemic.

## Novel Anti-Androgens

Abiraterone or Enzalutamide are being prescribed for patients with metastatic hormone -resistant prostate cancer (mHRPC).

Abiraterone has recently been denied by NICE for metastatic hormone-sensitive prostate cancer (mHSPC). [Roger Bacon mentioned that PCaSO, Tackle and Prostate Cancer UK have submitted an appeal against this decision].

Enzalutamide has been used up-front in metastatic hormone-sensitive prostate cancer (mHSPC), during Covid-19, instead of chemotherapy. NICE will review this.

Apalutamide has a UK licence, but is not approved by NICE yet. Darolutamide does not have a UK licence yet, but NICE appraisal is expected in November 2020. *(These two drugs are new 'second generation' drugs to Abiraterone and Enzalutamide).*

Enzalutamide is denied by NICE for non-metastatic hormone-resistant prostate cancer (nmHRPC).

In the non-metastatic setting clinicians are only permitted to prescribe Casodex (Bicalutamide) or a steroid such as Dexamethasone, not the newer, much more expensive drugs. If, however, it can be demonstrated the cancer has started to spread they may prescribe more advanced drugs.

There is a backlog of reviews within NICE.

## Other developments

It is becoming increasingly possible to use scanning technology to identify the spread of smaller tumours (known as 'micro-metastases'), and PSMA PET-CT scans can be more sensitive for this than the Choline PET-CT scans. However, PSMA PET-CT scans are not yet readily available within the NHS. [PCaSO member Brian Holden mentioned that he had

a rising PSA that had not shown up any metastatic spread on (choline) PET-CT scans. He had personally managed, with great difficulty, to get a free PSMA PET-CT scan at UCLH in London which revealed cancer spread to his pelvic lymph nodes, so his consultant then knew where cancer cells causing his rising PSA were located. - Andrew suggested patients in similar situations could try asking their oncologist if they could be referred, on the NHS, for PSMA scans]. *(See also Brian's article in this issue of Updates).*

Immunotherapy - is still developing for prostate cancer. Some drugs only have a low response rate amongst patients, however those that do respond often do so very well. There is a need to find out the criteria for selecting the best responders, so that immunotherapy treatments can be targeted at those most likely to respond well.

PARP inhibitors - such as Olaparib, which is a precision medicine treatment that has shown to be effective against cancers with mutations in genes, are also being used and developed further. (for more information see page 65 of our Knowledge Empowers Information Booklet)

## Supported Self-Management

Andrew is a member of a working group started at Worthing and Chichester hospitals for developing 'supported self-management'. Patients will be invited to use an online system called 'Patients Know Best'. They will be aiming for a group education session for those patients who will be self-maintaining. Patients will only request appointments with clinicians where the patient deems it necessary. Such appointments may be virtual consultations. **[Roger Bacon requested that a patient representative be considered as a member of the working party, PCaSO would be willing to ask for a volunteer from amongst its members].**

Andrew Hart was thanked for his excellent presentation with a 'virtual clap' by the Zoom audience!

# Healthy Living for Survivors of Prostate Cancer

An information guide is being developed by members, commencing with 'Physical Activity and Exercise'. A short 'taster' is below, if you find it interesting then the full version is coming shortly on the website. In future there will be other sections to the guide.

*Note: Some activities will be limited by any applicable Covid-19 restrictions.*

## Physical Activity and Exercise

### The Benefits of Exercise

Moderate activity can reduce fatigue, improve mood, psychological well-being and benefit body composition. Exercise may, if combined with other lifestyle changes, show a reduced rate of PSA progression in men on Active Surveillance, and a reduced risk of relapse after radical treatments.

Regular exercise over the long term changes your energy metabolism, lowers inflammation and improves immune response. Studies have shown that faster-paced walking or vigorous exercise significantly reduced the risk of prostate cancer recurrence or prostate cancer death.

Being fitter is beneficial for men before treatment as well as for 'survivors' of prostate cancer. The fitter you are before treatment the better the recovery time/outcome, especially for chemotherapy or surgery, but also other treatments such as brachytherapy, EBRT or hormone therapy.

The World Health Organisation recommends at least 150 minutes of moderate intensity physical activity per week (or 75 minutes of vigorous intensity) see <https://www.who.int/news-room/fact-sheets/detail/physical-activity> The NHS recommend a similar amount, see <https://www.nhs.uk/live-well/exercise/>.

Muscle strength is also very important. As we age our muscles get weaker, especially if we have high cancer risk, or are on hormone therapy. Include resistance

exercises at least two days a week, for upper-body, lower-body and core muscle strength. Strength, endurance and balance training, even into our 70's, 80's and 90's, can counteract some of the loss of muscle mass, providing some protection against falls and frailty.

### Physical Activity - develop an active lifestyle

Without some physical activity you might experience a 'spiral of decline' leading to frailty. If you cannot stand up for long there are exercises you can do whilst seated. Finding ways to incorporate more movement into your daily life will help keep your muscles engaged. Physical activity improves the flow of blood supply, even gardening or cleaning the house can be beneficial. Try to spend less time sitting down and limit it to 20-30 minutes before getting up for a break. Don't forget to stand up regularly if you sit down to work.

### Choosing Exercise activities

Find a sport or activity you enjoy. You may get more benefit from a mix of activities than just one. Build up gradually. You might find it more fun to exercise with other people. Join a sports team, a walking or a running group.

Choose activities and activity levels you can manage safely. Individuals with pre-existing health issues or injuries should check with their GP before starting any new exercise. If you are on hormone therapy or have cancer that has spread to your bones, check with your doctor

before doing high impact exercises such as running or contact sports, as you are more likely to break a bone if you fall. If you cannot do some activities or sports because of your prostate cancer treatments or other health conditions you might be able to do another one instead, e.g. swimming or cycling.

If you have recently had surgery to remove your prostate take the advice of your doctor as to when and what activities you can safely do. Any exercise following surgery should be light and gentle so that your body can heal properly. You will probably be advised by your doctor to avoid any heavy physical activity for several weeks.

After prostate cancer treatment you could ask your GP for a referral to a local municipal gym on the National Exercise Referral Scheme for a 12-week supervised programme. Charities such as Macmillan Cancer Support can also assist your rehabilitation.

Remember to warm up before you exercise and cool down with some stretches afterwards.

Drink plenty of water, as you must keep well-hydrated.

### Setting Goals

For personal motivation set achievable goals and measure your progress towards these against time. With a fitness tracker you can count your steps and measure your heart rate.

Interval training brings further benefits to cardiovascular health and has been shown to benefit cancer survivors on chemotherapy. It involves alternating short periods (e.g. 2 minutes) of intense exercise (65-80% of MHR) with periods of easy/moderate recovery, e.g. run for 2 minutes, then walk for 1 minute, repeat 6 times.

Have a rest day once or twice a week, to allow your body to recover. Also try and get 7-8 hours of sleep each night.

## Walking

Walking can be an enjoyable and beneficial exercise. Purposeful brisk walking, say at about 3 miles/hour, 30-minutes daily, is excellent. It can increase cardiovascular fitness and endurance. It is also a weight-bearing exercise so can help to build bone strength and muscle in the lower-body.

## Nordic walking

Nordic walking provides all the benefits of a brisk walk, but also exercises the upper body, thus helping to meet prostate cancer rehabilitation recommendations for aerobic exercise and regaining muscle strength in arms, back and shoulders. It doesn't involve the same constant pounding as running, so you can reap the cardio and muscular endurance benefits by using poles, with less impact on your knees and other joints.

You do need to be properly trained. The technique needs to be learnt to be effective and safe.

## Cycling

Dust off that old bike, give it an oil, and get pedalling! Cycling is a great aerobic exercise, burns calories, gets the heart working, and is very low impact on dodgy knees and joints. However, it does not have much upper-body benefit, so a suspension system or exercise bands should be used to complement cycling and give balance to your fitness regime.

Main road cycling is not to be encouraged unless there are dedicated cycle lanes. Try to find quiet roads or lanes. If your bike has suitable tyres, take it to off-road bridleways and tracks. Remember you can cycle on bridleways, but not on footpaths. Try not to push hard gears early on, use an easy gear, this will build muscle strength and increase endurance.

Don't ride the bike within 48 hours of a forthcoming PSA test!! (It can massage the prostate and so may cause your PSA reading to be unusually high).



## Running

Running is a very flexible outdoor activity. You set your own goals, or just run for fun.

Good footwear is essential though - trainers that fit properly, have good cushioning and good grip. Man-made fibre clothing is preferable to cotton, as it wicks perspiration and feels drier.

So how to start running? We suggest you follow NHS guidelines, see link: <https://www.nhs.uk/live-well/exercise/get-running-with-couch-to-5k/> this is a brilliant guide you download to your smartphone/headphones, etc. It is free and designed to take you from absolute zero to 'hero' in about 8 - 10 weeks.

After a run, do walk around for a few minutes to help avoid muscle stiffness in the legs and carry out stretches recommended on the above NHS website.

Compared with walking running puts more force onto the bones. This can promote bone growth and strengthen the muscles that absorb more force, as well as associated ligaments and tendons. Rest days are important, your bones need a recovery period to create new cells and adapt to the loads experienced, otherwise stress fractures can occur.

As a regular aerobic activity, running will improve your levels of energy and vitality, body mass, self-confidence and general positivity. It is best to balance running with resistance training such as gym workouts, Yoga or Pilates.

## Resistance band exercises

Resistance bands are so beneficial and easy to work with. Gentle resistance exercises with the bands are particularly good if you are on hormone therapy and are at risk of bone thinning. The bands are 2-metre lengths of latex. The bands are usually available from sports shops or online and are colour-coded for different strengths of resistance. A basic set of 3 bands, being low, moderate or high resistance, is all that is needed.

Regular use of resistance bands for upper body, say for 5 minutes twice each day, can soon tone and strengthen a range of muscles in the arms, shoulders, neck, back and abdomen. This improves posture and provides a sense of greater general health.

A wide range of suggested exercises are available online. It may seem difficult at first so don't over-exert yourself. - but to be effective the exercise should increase the heart rate and breathing.



## Resistance training – suspension systems (e.g. TRX)

Suspension training is a system comprising strong webbing straps which can be attached to a suitable fixed hook on the wall or slid down the gap between a suitable door and its frame. You're in control because you are able to adjust your body position to add or decrease resistance. It is ideal when you are undertaking rehabilitation from treatment, or when preparing for it.



To start off chose a few different exercises that suit your specific fitness level and needs, do 10 repetitions of each. Remember 10 minutes of activity is much better than nothing at all.

### Swimming

Regular swimming is a great fitness activity that exercises a wide range of muscles. If there is a pool near you, there will probably be lessons for all abilities, and aqua-aerobics or aqua-fit sessions also. Lessons would help to build confidence in the water, if needed.

Swimming builds cardiovascular strength and improves all the major muscles, without causing undue stress to bones and joints. If you have trouble with walking or running then swimming might be a good alternative for you. You can complement swimming with resistance band exercises at home.



### Walking Football

Walking football can keep people aged over 50 involved with football, either to safely get back to playing or to introduce the sport to people who have never played it before. The sport can be played both indoors and outdoors. It is a unique sport, different to regular Association Football in many ways.

Teams' are either 5 or 6-a-side, dependent on the size of pitch. Games are played at a slower pace, often on artificial grass pitches (which include some rubber), thus reducing the threat of pain, discomfort and injury, with players

briskly walking through matches, maintaining contact with the ground at all times.

Played on a regular basis it is surprising how much fitter you can become. A match can last anything from 10 minutes to half an hour, and you are constantly moving and turning in different directions, this does challenge you physically. It must surely be one of the best cardiovascular exercise regimes with a competitive edge.

### Pilates

Pilates will develop a range of posture muscles for a healthy back and, importantly for prostate cancer patients, strong abdominal muscles.

By working to balance both sides of the body, areas of weakness are identified, and those muscles will become stronger with progress. The exercises are easily built into daily life, and can be complementary to other aerobic activities such as walking, running or cycling.

Look for a beginners' class if you haven't tried Pilates before, and let the instructor know about your condition and any injuries or weak areas. They'll be happy to tailor the stretches to suit your ability. Demonstration videos can be seen on YouTube, and an internet search will identify Pilates groups in your area.

### Yoga

Yoga is not just for women; many men attend the same classes. Yoga, as exercise, is a physical activity consisting mainly of postures, flowing sequences, and breathing exercises, ending with relaxation lying down. Yoga helps to relieve fatigue, build muscle strength and core stability. Flexibility and stamina improve, and it helps sleep quality. The overall purpose of yoga is to connect body and mind so as to engender peace, power and clarity.

To learn correct technique and postures, it is best to attend local classes before doing postures at home. A good instructor is essential, and an excellent source for finding one, and much more detailed information on yoga, can be found at the British Wheel of Yoga, <https://www.bwy.org.uk/>

### Tai Chi

Tai Chi works so well both on and in your whole body - it exercises deep into your muscles, tissues, fibres and ultimately deep into the cells of your body. It is also proven to help reduce stress, mental anxiety and has many therapeutic qualities too. It may help reduce the risk of dementia! It is fantastic for maintaining flexibility, balance and keeping all your joints 'well-oiled'. See <https://www.nhs.uk/live-well/exercise/guide-to-tai-chi/>

## Meetings go 'online'

All PSA events and physical ('face-to-face') meetings of Groups have been cancelled during the remainder of 2020 due to the Covid-19 pandemic.

PCaSO have been using Zoom for its committee meetings. The PCaSO AGM, open to all members, will be held on 22nd September in a video meeting online, using Zoom (see page 4).

Sussex Branch have already successfully tried one Zoom meeting with a speaker (see page 8) and PCaSO plan further online speakers, etc. These will be advertised to members via email and will also be listed on the PCaSO website. See page 4 of this newsletter for 'How to Join a Zoom Meeting'.

**STOP PRESS:** The first such PCaSO-wide online speaker will be Timon Colegrove, from Oxford Prostate Cancer Support Group, to talk about his experience of having Proton Beam Therapy to treat his prostate cancer. The date of this Zoom meeting will be Tuesday 6th October at 7pm. Open to all PCaSO members to log into. Email [info@pcaso.org](mailto:info@pcaso.org) if interested.