



# PROSPECT

Bristol and District Prostate Cancer Support Group

Spring 2020

# Newsletter

## In this issue

- A digital copy
- March meeting
- New booklets
- April meeting
- A member's experience
- Prospect WhatsApp group
- Macmillan podcast
- Gay West calendar
- Fishponds & Downend Rotary
- Trusts merge
- Tackle Talk
- Life-saving scan
- Breast cancer drug
- Fall in p.c. death rates
- Meetings update
- Committee update

PROSPECT is a local support group for prostate cancer patients, their carers and friends. We provide help support and information and our newsletter is published four times a year. Any articles you think would interest our members please email to me, David Casley at: [prospect.bristol@gmail.com](mailto:prospect.bristol@gmail.com)



### A DIGITAL COPY

Ten years ago we published our first newsletter in the spring of 2010. Since then all editions have been printed and posted out to members and friends as we think you prefer to receive a hard copy. We also include the Federations newsletter Prostate Matters in the same envelope to save on duplicate postage.

However the present extraordinary situation we are now living in, thanks to the coronavirus, has forced us to make changes and issue our Spring 2020 newsletter in digital format.

Prostate Matters will not be published this spring.

We hope this is a one off situation and that the Summer 2020 edition will be posted out to you as usual in August.

### MARCH MEETING

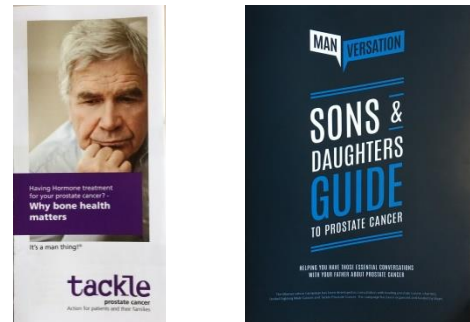
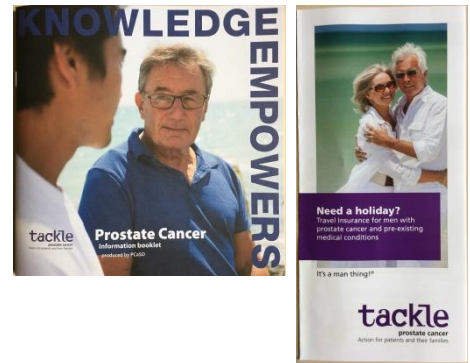
This was one of our informal meetings where we just had a general discussion about our health problems and generally put the world to rights.

Somebody had managed to persuade Paul Williams to start the proceedings with a talk about his own medical experiences and Paul gave a very amusing and emotional talk.

Paul has been a member of Prospect for many years and on numerous occasions has represented the group at the Federation of Prospect Cancer Support Groups "Tackle" annual conference. He has therefore met many men from all parts of the country and confirms that we are all very fortunate to live in the Bristol area, which is a centre of excellence for prostate cancer treatment.

### NEW BOOKLETS

Member Martin Fox responded to the article in the last issue of "Prostate Matters" advertising the updated version of the booklet "Knowledge Empowers". Martin received a large quantity of these booklets together with the Manversation booklet "Sons' & Daughters' Guide to Prostate Cancer" and leaflets on "Why bone health matters" and "Travel Insurance".



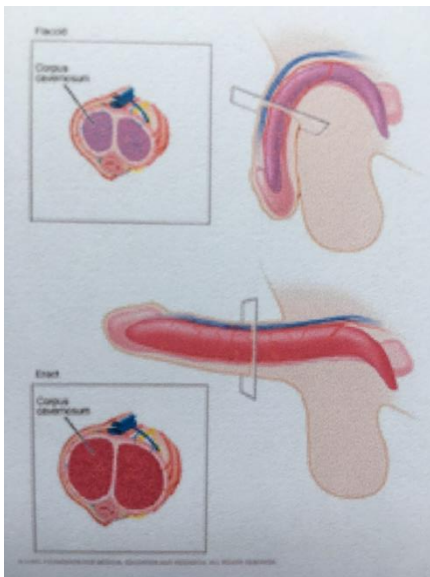
We were going to make these booklets available at our April meeting, which was cancelled. However all of these booklets and leaflets together with others are available to download on the Tackle website.

The following link will take you to the appropriate page. <https://www.tackleprostate.org/info/sheets.php>

## APRIL MEETING

This meeting was to include our annual general meeting, which we have now postponed until later in the year.

Clinical nurse specialist Rachel Skews was going to give us a talk on erectile dysfunction. Rachel has supplied us with a very detailed document covering the topics she would have covered. Some of these topics are listed below. We are very grateful for the time she has taken to produce this document considering the stress all NHS staff has been under during the last few months.



Erectile dysfunction (impotence) is the inability to get and keep an erection firm enough for sex.

Having erection trouble from time to time isn't necessarily a cause for concern. If erectile dysfunction is an ongoing issue, however, it can cause stress, affect your self-confidence and contribute to relationship problems. Problems getting or keeping an erection can also be a sign of an underlying health condition that needs treatment and a risk factor for heart disease.

If you're concerned about erectile dysfunction (ED), talk to your doctor - even if you're

embarrassed. Sometimes, treating an underlying condition is enough to reverse ED. In other cases, medications or other direct treatments might be needed.

### Causes

Male sexual arousal is a complex process that involves the brain, hormones, emotions, nerves, muscles and blood vessels. ED can result from a problem with any of these. Likewise, stress and mental health concerns can cause or worsen ED.

Sometimes a combination of physical and psychological issues causes erectile dysfunction. For instance, a minor physical condition that slows your sexual response might cause anxiety about maintaining an erection. The resulting anxiety can lead to or worsen ED

Treatments for prostate cancer or enlarged prostate often cause erectile dysfunction.

### Diagnosis

For many men, a physical exam and answering questions (medical history) are all that's needed for a doctor to diagnose erectile dysfunction and recommend a treatment. If you have chronic health conditions or your doctor suspects that an underlying condition might be involved, you might need further tests or a consultation with a specialist.

### Treatment

The first thing your doctor will do is to make sure you're getting the right treatment for any health conditions that could be causing or worsening your erectile problems.

Depending on the cause and severity of your ED and any underlying health conditions, you might have various treatment options. Your doctor can explain the risks and benefits of each treatment and will consider your

preferences. Your partner's preferences also might play a role in your treatment choices.

Oral medications are a successful erectile dysfunction treatment for many men. They include:

Sildenafil (Viagra)  
Tadalafil (Adcirca, Cialis)  
Vardenafil (Levitra, Staxyn)  
Avanafil (Stendra)

All four medications enhance the effects of nitric oxide - a natural chemical your body produces that relaxes muscles in the penis. This increases blood flow and allows you to get an erection in response to sexual stimulation.

Other medications for ED include:

Alprostadil self-injection. With this method, you use a fine needle to inject alprostadil (Caverject Impulse, Edex) into the base or side of your penis.

In some cases, medications generally used for other conditions are used for penile injections on their own or in combination. Examples include papaverine, alprostadil and phentolamine. Often these combination medications are known as bimix (if two medications are included) or trimix (if three are included).

Each injection is dosed to create an erection lasting no longer than an hour. Because the needle used is very fine, pain from the injection site is usually minor.

Side effects can include mild bleeding from the injection, prolonged erection (priapism) and, rarely, formation of fibrous tissue at the injection site.

Alprostadil intraurethral (Muse) therapy involves placing a tiny alprostadil suppository inside your penis in the penile urethra. You use a special applicator to insert the suppository into your penile urethra.

The erection usually starts within 10 minutes and, when

effective, lasts between 30 and 60 minutes. Side effects can include pain, minor bleeding in the urethra and formation of fibrous tissue inside your penis.

Other treatments include:

### **Penis pumps.**

A penis pump (vacuum erection device) is a hollow tube with a hand-powered or battery-powered pump. The tube is placed over your penis, and then the pump is used to suck out the air inside the tube. This creates a vacuum that pulls blood into your penis.

Once you get an erection, you slip a tension ring around the base of your penis to hold in the blood and keep it firm. You then remove the vacuum device.

The erection typically lasts long enough for a couple to have sex. You remove the tension ring after intercourse. Bruising of the penis is a possible side effect, and ejaculation will be restricted by the band. Your penis might feel cold to the touch.

If a penis pump is a good treatment choice for you, your doctor might recommend or prescribe a specific model. That way, you can be sure it suits your needs and that it's made by a reputable manufacturer.

### **Penile implants.**

This treatment involves surgically placing devices into both sides of the penis. These implants consist of either inflatable or malleable (bendable) rods. Inflatable devices allow you to control when and how long you have an erection. The malleable rods keep your penis firm but bendable.

Penile implants are usually not recommended until other methods have been tried first. Implants have a high degree of satisfaction among men who have tried and failed more-conservative therapies. As with any surgery, there's a risk of complications, such as infection.

### **Alternative medicine**

Before using any supplement, check with your doctor to make sure it's safe for you - especially if you have chronic health conditions. Some alternative products that claim to work for erectile dysfunction can be dangerous.

### ***A MEMBER'S EXPERIENCE***

We gave ourselves the unaccustomed luxury of several hours of afternoon lovemaking, knowing this might be our last time. This knowledge intensified our closeness and matched the excitement of our first encounters nearly thirty years ago. The next day I underwent a radical prostatectomy to treat an aggressive cancer. The procedure removed my prostate and meant that I would no longer have spontaneous erections, and that my orgasms would be 'dry'.

After the operation the effect was dramatic; my penis was totally unresponsive. Charities offered useful guidance about how a cancer diagnosis affects a relationship, but were largely silent about sex. So much attention had been given to treating the cancer that I felt frighteningly ignorant about what would be involved in regaining some function of my penis; I didn't even know whether it is possible to have an orgasm without an erection.

After experimenting unsuccessfully with a vacuum pump, my desire for an erection became greater than my fear of needles, and I decided to try self-injecting with a prescribed treatment. It required training and my first experience of injecting myself was in front of a doctor who explained the process. We had several practice runs at home to incorporate the injecting process into our lovemaking and to find the right dose. Eleven months after my surgery, we've

enjoyed a full return to lovemaking – and all the intimacy that entails.

The diagnosis and treatment of cancer is a life-changing experience. It took determination, medical support and a willingness to relearn how to be sexual to get here - but now my orgasms are a joyous celebration of life fully resumed.

(First published in the Guardian in *My life in sex* series January 2020 – contributed by a member of Prospect.)

### ***PROSPECT WhatsApp GROUP***

One of our members, Nigel Derrett, has set up a Prospect WhatsApp Group and has also volunteered for the role of Account Administrator to ensure its smooth running. We are very grateful to him for taking on this initiative.

The Prospect WhatsApp Group is only available to Prospect members and friends who have registered their email address with us.

If you would like to join the group basic instructions are as follows:

WhatsApp is a program that runs on smartphones to let individuals and groups keep in touch.

If you don't already have WhatsApp installed on your phone, then you need to go to the Apple App Store if you have an iPhone or the Google Play Store if you have an Android phone and install the app.

Once you have the app installed, email your smartphone number to us at [prospect.bristol@gmail.com](mailto:prospect.bristol@gmail.com) and Nigel will contact you with the link to join the group.

The group has now been running for well over a month and is a great aid for patients to ask questions about their condition and get answers based upon our members' own experiences.

### **MACMILLAN PODCAST**

Macmillan has recently released a Talking Cancer Podcast. The third episode in the run is entitled Life After Cancer and is about Prostate Cancer. It's professional in its production and we're sure many of you will find it interesting. The link to the podcast is as follows.

<https://www.macmillan.org.uk/about-us/media-centre/talking-cancer-podcast.html>

### **GAY WEST CALENDAR**

You may recall we published details of the Gay West's Boyz 2020 calendar in our autumn newsletter.

This must have been a very popular Christmas stocking filler as Gay West have made a very generous donation of £600 to Prospect from the proceeds of the sale of these calendars. Many thanks to all who bought a copy and in particular to Colin O'Brien and the members of Gay West for their support of Prospect.

### **FISHPONDS & DOWNEND ROTARY CLUB**

Fishponds & Downend Rotary club held a fundraising event in November of last year in support of Prospect.

Our Mike Broxton was to have given one of his popular Prostate Cancer Talks to their members but this has been delayed until the coronavirus restrictions are lifted.

However the Rotary club have raised a fantastic sum of £1500 to donate to our group. This is tremendous news as like so many charities the donations to us have suffered in recent months.

We are very grateful to Dave Baker of Fishponds and Downend Rotary Club and all of their members for their generosity.

### **TRUSTS MERGE**

From 1 April University Hospitals Bristol NHS Foundation Trust and Weston Area Health NHS Trust have formally merged to become University Hospitals Bristol and Weston NHS Foundation Trust (UHBW). The merger went through a significant governance process, which involved Trust board approval, scrutiny from the regulators (NHSEI), Council of Governors approval and a final approval from the Secretary of State for Health and Social Care.

The new Trust has a workforce of over 13,000 staff and will serve a core population of over half a million people. There are a number of benefits in building on the many years of partnership working between the two Trusts and taking the step to become one organisation. These include:

- A better experience for patients - ensuring people from North Somerset and surrounding areas can be seen and treated in their local hospital, and improving access to specialist services in both Bristol and Weston through use of expanded workforce and facilities.

- Increased diversity, capacity and resilience among staff, allowing for greater training and development opportunities across a much wider portfolio of services, strengthening the knowledge base, peer support, skills and experience of all employees.

- Greater opportunities to share expertise and best practice, particularly in the development of new models of frailty and ambulatory care, collaborating with others to provide more services at home or close to home.

- Accelerated roll-out of new information technology to support consistent delivery of care across the new organisation.

- Support for innovation and research, empowering teams to

design new pathways at the forefront of medical and surgical ambulatory care.

Commenting on the final milestone in the merger process, Robert Woolley, chief executive of UHBW, said:

"This is a momentous occasion in the history of two proud hospital Trusts and one that wouldn't have been possible without the support of our dedicated workforce in Weston and in Bristol.

I am immensely grateful for their hard work to help us achieve this merger but particularly for everything they are doing for our patients at this unprecedented time.

Uniting the Trusts increases our diversity, capacity and resilience, and provides a unique opportunity to bring together the things that make both the Weston and Bristol hospitals great places to work and to receive care, in order to create an even better and stronger organisation for the future.

It's important to reassure our service users that, while the name of the Trust may have changed, they will continue to receive care from the same staff in the same location that they do now.

The names of the component hospitals, including Weston General Hospital and the Bristol Royal Infirmary, will remain unchanged.

From 2 April, the new website will be [www.uhbw.nhs.uk](http://www.uhbw.nhs.uk)

This is where all corporate information about the Trust will be stored, as well as up-to-date information about access to our hospitals during the current situation.

We will still be using our existing UH Bristol and Weston Area Health NHS Trust websites where people can access information about our services in Bristol and Weston respectively."

## tackle talk

Ken Mastris, chairman of Tackle, has sent us the following update.

"I trust that you are keeping well during these extraordinary times.

We know that many of you may well have some concerns about how the coronavirus (COVID-19) might affect you and we recommend you view the Prostate Cancer UK website, which has some excellent information.

I am sure that many of you will want to keep in touch with each other. We held our recent Board meeting virtually using Skype but many people are using Zoom. It's a great way to keep connected.

Here at Tackle, like many other organisations, we are putting things on hold:

**AGM & Conference.** We had scheduled this in for June at the same venue in Birmingham as last year. We are reviewing the date with the venue at the moment with a view to holding it in September. We will keep you posted.

**Prostate Matters.** The next issue of our quarterly newsletter will now not be on 1 May but will be postponed until the summer.

I am very pleased to report that we have appointed two new Trustees: Julian Burgess and Roshani Perera. Finally, please keep safe and well."

Ken Mastris

### LIFE-SAVING SCAN

Scientists have found using a radioactive molecule which sticks to prostate cancer cells and lights them up in a scan is 27 per cent more accurate than the methods which are routinely used.

The technique detects when prostate cancer has spread further into the pelvis or beyond and, therefore, identifies the men who

need more powerful radiotherapy, or wider surgery.

Researchers found the scan, called a PSMA-PET/CT scan, correctly detected whether prostate cancer cells had spread or not in 92 per cent of men.

Conventional CT and bone scans, often used on the NHS in England, produced accurate results in just under two-thirds.

The results were taken from 295 men newly diagnosed with high-risk, more aggressive prostate cancer, from ten Australian hospitals.

Professor Declan Murphy, senior author of the study from Peter MacCallum Cancer Centre, said: "Around one in three prostate cancer patients will experience a disease relapse after surgery or radiotherapy.

This is partly because current medical imaging techniques often fail to detect when the cancer has spread."

The study, published in the Lancet journal, gave 150 men conventional scans and 145 the PSMA-PET/CT scan first, then swapped to compare.

The latter was more accurate; showing those whose cancer had spread so much that it was incurable, sparing them unnecessary surgery.

It also highlighted those whose cancer had spread into their pelvis, allowing 7 per cent to have further surgery. Another 7 per cent were given more powerful radiotherapy or radiotherapy over a wider area of their body.

The researchers were able to see the scans were accurate based on biopsies and follow-up imaging six months later.

The study was funded by men's health charity Movember. Dr Mark Buzza said: "There is now solid evidence that PSMA-PET/CT scans are the gold standard first-line imaging test for staging high-risk prostate cancer."

(Daily Mail)

### BREAST CANCER DRUG

A breast cancer drug is on the verge of being approved as a ground breaking treatment for prostate cancer, following the success of a clinical trial.

Scientists are confident that olaparib, a breast cancer drug, will prove "revolutionary for men who have prostate cancer and faulty DNA repair genes as it stops cancer cells repairing and eventually kills them without damaging healthy cells.

Up to a third of men with aggressive prostate cancer are set to benefit from olaparib, which researchers say is more effective at slowing the disease than hormone treatments.

It is the first genetically targeted treatment for prostate cancer and could be available through the NHS within 2 years.

Prof Johann de Bono of the Institute of Cancer Research in London and a consultant at the Royal Marsden Foundation Trust, who co-led the study, said "The next step is to assess combining olaparib with other treatments to help men with prostate cancer and faulty DNA repair genes live even longer."

The trial involved 387 men with advanced cancer who had alterations in one or more of 15 DNA repair genes. The results were published in the New England Journal of Medicine.

Olaparib significantly delayed the disease, taking 5.8 months to progress compared with 3.5 months for those taking hormone treatments enzalutamide and abiraterone. Men with faulty BRCA1, BRCA2 or ATM genes benefited the most from olaparib with progression delayed by 7.4 months.

Dr David Montgomery, director of research at Prostate Cancer UK, said "This result represents a revolution in the treatment of prostate cancer."

(Daily Telegraph 29 April 2020)

### FALL IN P.C. DEATH RATES

Prostate cancer death rates are expected to fall in the UK and across nearly all EU countries this year thanks to better diagnosis and treatment, analyst suggests.

The mortality rate in the EU is predicted this year to have fallen by 7.1 per cent since 2015, with 78,800 men expected to die from the disease in 2020.

The age-adjusted death rate is 9.95 per 100,000 men for this year, compared with 10.71 per 100,000 in 2015.

In the UK the researchers forecast that there would be 11.99 prostate cancer deaths per 100,000 men in 2020, compared with 13.25 per 100,000 in 2015.

The calculations are based on figures from the World Health Organisation and Eurostat databases for 1970-2015 and have been age standardised, a technique epidemiologists use to allow populations to be compared.

Poland is the only country where the prostate cancer death rate is rising with a predicted death toll of 6,100 men by the end of 2020.

Prof Carlo La Vecchia, of the University of Milan's School of Medicine in Italy, who led the study, said "Across the EU as a whole, the key message from these prostate cancer death rates is to adopt up-to-date surgery and radiotherapy techniques, together with newer androgen deprivation therapy.

This may have a relevant impact on prostate cancer mortality even in the absence of cure, since a proportion of elderly men may survive long enough to die from other causes."

Prostate cancer is the most common cancer in men in the UK; around one in eight men will get the disease.

While prostate cancer death rates, the ratio of deaths to the population, are falling, the

number of men dying from the disease is predicted to increase as the ageing population grows.

In 2015, 74,998 men died from the disease in the EU compared with the 78,800 forecast to die in 2020.

In the UK, 11,827 men died in 2015 compared with 12,000 predicted to die from prostate cancer this year, a drop of 9.5 per cent when adjusted for age.

Dr Matthew Hobbs, deputy director of research at Prostate Cancer UK, said: "We know that research carried out over the past 20 years has led to improvements in diagnosis and treatment. It is great to see that research has reduced the death rate.

However, with incidence of prostate cancer rising in the UK, and the number of men reaching an age that increases their risk, combined with faster progress in other diseases, we need much bigger and quicker reductions in the death rate to stop the number of prostate deaths continuing to rise every year."

The findings are published in the journal *Annals of Oncology*. (Daily Telegraph 20 April 2020)

### MEETINGSS UPDATE

We have cancelled all of our members meetings and Macmillan coffee mornings until the government advises on the lifting of restrictions.

Our spring walk around Ashton Court estate was the first of our meetings to be cancelled.

Look at what we missed:



Bluebells in the wood.



Deer in the park

(These photos were taken after the government relaxed restrictions on short travelling journeys to a place of exercise.)

Unless there is a sudden change of regulations the June Bristol Docks walk will be cancelled as is the Penny Brohn lunch. Penny Brohn has been closed since early March.

We will send an email regarding the September BAWA meeting closer to the date.

A bonus of circulating this newsletter by email is that we do not have the printing restrictions of limiting the number of pages to four. We hope you enjoy the extra information.

### COMMITTEE UPDATE

Our end of March committee meeting was also cancelled and it's unlikely we will be able to meet in July.

However we need to make decisions to assist in the continued smooth running of our group. To do this we have just held a committee meeting via Zoom and will do so again in July.

If you have any comments or suggestions to make, or you require advice about prostate cancer, please make contact using our email at [prospect.bristol@gmail.com](mailto:prospect.bristol@gmail.com)

For all of the latest prostate cancer news and information regarding our group check our website

[www.prostatecancerbristol.org.uk](http://www.prostatecancerbristol.org.uk)

You can also contact us by telephone on our Tackle helpline of 0800 035 5302.