



Issue 3: Spring 2021

“The Faucet”

It is time for the Spring edition of “The Faucet”, the TAPS quarterly newsletter. The contents of this issue include:

- a. Running Taps: Feedback from your Steering Group’s March catch up call with members
- b. Open Taps: Brief notes on some open Zoom sessions we have had in the last quarter.
- c. Outside Taps: Research and other activities around the PCa world
- d. Mixer Taps: Members Forum
- e. Closing Taps

RUNNING TAPS

This March the Steering Group rang round those members they had spoken to last November to find out how you were getting on during lockdowns.

1. Overall responses

Of the 39 members listed in the TAPS group, we were only able to talk to 24 which is a 62% response. Just over half deem themselves to be actively engaged while the remainder are in the watching brief group. It was not possible to obtain answers for each question and so responses rarely add to 24!

2. Health of members

The majority (16) of members’ prostate health remains the same while 4 felt better and 4 had complications of which 2 suffered delays in treatment due to Covid pressures. Everyone who responded to the Covid vaccination question (22) had had their first one.

3. Update on IT usage

As before just under half were happy to use Zoom for our meetings while most others have IT access at least by tablet or phone and can read, and perhaps print, emails and newsletters. Overall 85% of those responding to this question are receiving our emails and so, since the date for starting to meet again seems some way off, we shall have to continue communicating with you electronically.

4. Views on Future Meetings

Given that only half use Zoom, unsurprisingly views were evenly split on whether they wished to join meetings organised by other groups. Since it is increasingly difficult to obtain speakers for our meetings, we are going to share that responsibility with the Plymouth group on an alternating month basis. Plymouth meetings are on the 4th Thursday of the month and we shall begin with them for the April meeting. We do hope that you will support these joint meetings.

5. Other matters

Faucet newsletter: 85% of respondents stated that they enjoyed the read and found it interesting. Unfortunately 15% had no recollection of it!

Willingness to contribute to the of running TAPS: In addition to the existing Steering Group, 2 other members offered to help with either marketing or fundraising.

OPEN TAPS

Jan 2021: Andrew Gabriel

Topic: Living with and surviving Hormone Therapy

There are various types of hormone therapy (HT) but essentially they reduce testosterone levels which is the food for the growth of prostate cancer cells – no food stops or slows growth but does not remove the cells! The effect of HT is to reduce the size of the prostate, to improve the outcomes from low power radiotherapy, to improve life expectancy for incurable cancer and to put PCa on hold while waiting for treatment perhaps because of Covid.

Andrew concentrated on the possible side effects from HT and how to live or deal with them. He listed non-exhaustively 21 possible side effects – who knew (or was warned) that there could be so many! The most well known are hot flushes and night sweats, loss of libido and erectile problems, fatigue, swelling and tender breasts, loss of body hair, etc. Less well-known positive effects include loss of body odour, reversal of head hair balding, and possible but unproven reduced risk of Covid. Most patients undergo a limited time on HT (normally max 3 years) and the side effects will then generally dissipate over the next 12 -18 months. Hot sweats are one of the last to go and may take even longer. Andrew took each of the main side effect areas in turn and gave some guide as to how to alleviate them, eg for hot sweats, strip off in layers, take iced drinks or just wait for them to stop - in about 2 mins! For some there are physical aids and for others there are medical treatments. As ever one of the most effective methods is to take plenty of exercise and eat a sensible diet.

Feb 2021: Sarah Gray, National Support Manager, Tackle Prostate Cancer

Topic: Working together to support people living with and beyond Prostate Cancer

Sarah talked about the role of Tackle as the national federation of prostate support groups (PSG). It aims to help new groups become established (eg TAPS received a start-up grant) and existing groups to grow/develop. Tackle provides a telephone service to members of PSGs who wish to discuss their condition with another male who has already been through PCa treatment. Tackle funds small research projects and works closely with Prostate Cancer Research and PCUK. To date Tackle has been a largely voluntary operation and Sarah has been appointed recently as the only full-time member of staff. Her remit is to expand the services available to support groups.

Mar 2021: Robert Butler, Partner Estate Planning, Gard & Co

Title: Updates on financial estate planning

This session covered the latest options for reviewing areas such as our wills, inheritance tax planning, trusts, tax reduction schemes, powers of attorney, etc. The major objectives of estate planning are to ensure that, on death, one's assets pass to those people and organisations that you wish to benefit from them while at the same time legally minimising the amount of inheritance tax payable to the State. Wills and trusts are the main instruments for achieving this. Even today much of the wills law is based on the 1837 Wills Act.

If one dies without a will, one dies intestate and the distribution of assets is governed by the Intestacy Rules which state that the spouse receives up to £270k plus personal possessions plus half the remaining estate, the other half being split equally between one's natural children. This may be fine in simple situations but with so many second marriages, stepchildren and perhaps dependants with special needs, it is essential to be able to specify who should get what. A will can be written using a template but it is wiser to use a lawyer and it is not an expensive process. A will is advisable even

for young people just starting a family to ensure that the spouse and children are properly provided for and that, for example, guardians are named should both parents unfortunately die.

Wills should ensure that maximum use is made of Inheritance Tax allowances – the Nil-Rate Band of £350k plus the Residence Nil-Rate Band of £175K (providing there is a residence to leave to one's children). On death of the first partner and after specified bequests have been made, that estate passes to the survivor along with any unused IHT allowances. In effect this means that the partnership has a total IHT allowance of £1M. If this is likely to be insufficient, there are other ways of reducing IHT such as investing in business property for Business Property Relief or in Discretionary Trusts. You can make as many gifts each year of up to £250 as you wish but only £3000 as larger gifts otherwise these still count as part of the estate for 7 years and so remain subject to IHT. However you can gift out of your income, but not capital, without it counting for IHT.

All clear? No, then get the advice of a lawyer!

Feedback from a Torbay member: What a great session that was last evening. Really useful and so well presented. Thank you for setting it up.

OUTSIDE TAPS

In this section we aim to cover any news from further afield, for example from Prostate Cancer UK (PCUK), Tackle, other support groups, and any medical or scientific news that might be of general interest. This month Nigel Allam has been trawling for recent research news and he writes about Detection Dogs.

“Dogs have been trained to sniff out the most lethal form of prostate cancer, a development that could inspire the creation of a ‘robot nose’ to identify the disease before symptoms appear. The dogs (a labrador and a vizsla) were taught to identify volatile organic compounds in the urine of patients with Gleason 9 prostate cancer. In tests, they showed 71% sensitivity (the rate at which they correctly identified positive samples), and 70-76% specificity (the rate at which they correctly ignored negative samples) including those from men with other prostate diseases. These results, say the researchers, compared favourably with those of the PSA blood test for PCa. Using dogs to screen for cancer is not scalable but they hope to develop a device that can mimic the dogs’ olfactory processes, maybe even via a phone app. Dr Mershin of MIT says “Imagine a day when smartphones can send an alert for potentially being at risk for highly aggressive prostate cancer, years before a doctor notices a rise in PSA levels.” Reprinted from The Week

Nigel has also found a new publication from Prostate Cancer Research which is an excellent explanation of the formation of prostate cancer, its diagnosis, possible treatments and their side effects. The publication is available in the Information section of the TAPS website.

MIXER TAPS

In this edition, we are giving updates on two of our members stories in which there are lessons for many of us!

Nigel Allam writes: “In the first issue last Autumn I encouraged everyone to monitor their PSA history because it helps determine what is going on inside our bodies, and to see if treatments are being effective. In my own case my rising PSA indicated that despite having my prostate removed in 2016, cancer cells had escaped and, since the surgery, were being held in check by one of the common hormone therapies, Decapeptyl. In a chance discussion with one of the guys from Tackle, he encouraged me to seek advice from an oncologist rather than just relying on my urologist, and as a result I met Peter Sankey at Derriford. He arranged for 3 scans which showed small developments of prostate cancer lesions in a couple of places, and I am now on an additional hormone therapy

treatment called Enzalutamide, which is for men like me who have metastatic cancer and are becoming resistant to other hormone treatments. I am still getting Decapeptyl because that works by reducing our testosterone, the seed bed for PCa. Testosterone is made in our testicles, where Decapeptyl is most effective, but can also be made in our adrenal glands. Enzalutamide blocks testosterone from reaching PCa cells elsewhere in your body, and thus curtails their ability to divide and spread. For me, this new regime started in February, and so far so good, I feel well, with no worrying side effects. The learning point for me is to realise there is always a second opinion to be found and that medical science is working hard not only to help diagnose and treat active cancers but to help those of us who have longer term conditions. If any of you are also taking Enzalutamide and want to compare notes, just send an email to TAPS info and I'll get in touch."

Harry Lawson writes: **Hot Flashes and Sweating**

Some of us only suffer minor sweats and flushes while others have the full treatment but, whichever way they affect us, they are not pleasant. I seem to have been unlucky in the sense that my body sweats were heavy all over and combined with a flushed face which I found embarrassing especially in public. Having approached my consultant on the matter I was told "Give it a couple more months and they should fade out". This I found not very helpful!

Fortunately I had to speak to my GP on another matter and we touched on the problem of hot flushes, which then led to a chat with one of the PCUK specialist nurses who recommended taking Medroxy. She also informed me that you can get menopause cooling pillows or towels which help enhance sleep at night. On the internet I found the pillows but also a cooling towel called COOL TOWEL, a Stormfront Product which comes in a pack of three, and I found very useful for night sweats. The Medroxy dose was originally two 10mg pills daily but soon dropped down to one pill for two weeks. Despite some side effects, I am happy to say that that my sweats and hot flushes stopped.



WHEN YOU NEED TO GO YOU NEED TO GO

Existing Prostate problems and treatments leaves us with the urge to wee a lot. With the demise of public toilets and the cleanliness of some, I thought you might be interested in the following two solutions.

1. Carry a PCUK toilet card (at no cost) which is helpful to gain access to toilets in shops and eateries.
2. Disabled Toilet (RADAR) Key available from local council or from Amazon at £1.99.



CLOSING TAPS

As you will understand, it is not easy to hold a support group together when we cannot actually meet! So the Steering Group is very appreciative of members coming to our Zoom meetings and also letting us know through our periodic phone calls that you like us being there. Nigel Allam and I sit on the PCUK support group leaders forum from which we learn that most other groups have similar issues to us in that meeting numbers are typically half or less than for face-to-face meetings. Indeed some groups have not met at all for a year! We went to the annual conference/ networking event by Zoom in mid March where many issues were (hot) aired and some solutions put forward. We will try to give you a summary in the next Faucet issue.

Meanwhile take care of yourselves. Please contact us if you have any issues you would like to raise at tapsinfo555@gmail.com or for more information.

From the TAPS editorial team. Web address: www.tamarareaprostatesupport.org