



Issue 2: Winter 2020

“The Faucet”

Welcome to the second issue of “The Faucet”, the TAPS quarterly newsletter. The contents of this issue include:

- a. Running Taps: Feedback from your Steering Group’s discussions with members
- b. Open Taps: Some brief notes on the open November Zoom session on “What if my prostate cancer comes back?” led by Pat Smith of PCUK
- c. Outside Taps: Research and other activities around the PCa world
- d. Mixer Taps: Members Forum
- e. Closing Taps: Future meetings

RUNNING TAPS

Many thanks to all of you for taking the time to give feedback on your health and your views on TAPS activities. The calls appeared to be welcomed and nearly everyone seemed to be in good form. We gained considerable insight into your views and that was really helpful.

1. Overall responses

Sadly we know of 3 members who have died in the past year, 2 of whom died from their prostate cancer and we have been in touch with their families. As a result in November there were 39 members of the TAPS group of whom we were able to talk to 30. That is a 77% response which gives us a sound basis from which to understand the group.

2. Health of members

The prostate cancer health of almost everyone (the full 30) was either good, good as could be expected or at least bearable! For quite a few, their treatment was years ago which was very positive news. Some people were still in mid-treatment, mainly radio therapy and/or hormone therapy. Some people had varying or rising PSA scores which can be worrying (see Outside Taps below) and a few had other health issues (mainly cardiovascular). In general it seems that TAPS is a healthy population.

The Covid pandemic seems to have had limited impact on TAPS members. Only one person contracted it and most have managed the lockdown periods without difficulty (or fun) albeit constrained in their activities. Nobody was seeking assistance from TAPS. Everyone who responded on whether to have a vaccine agreed that they would. Hopefully this will help us all to meet in the Spring!

3. Zoom meetings

There were very mixed views on attending Zoom meetings. Just under half were comfortable with meeting by Zoom but attendance depended on the content. For the other half, members either did

not have the technology, or found it difficult, or did not like video conferencing. Most of these members looked forward to returning to face-to-face meetings. This shows that we must expect to have lower attendances at our Zoom meetings whatever the content.

4. Meeting content

This was an informative question! Five people were specifically interested in medical speakers and then only if it related to their condition. Another six would attend on any topic provided it looked interesting, so not necessarily medical. However ten people were not interested in any meetings mostly because they felt that they have progressed on from their cancer and often do not wish to be reminded of it. This is very understandable but interestingly they wish to remain on the mailing list. This question also indicates that we can expect that about half of the membership will be active in TAPS to some degree.

5. Social activities

At least half of the members are unlikely to take part in additional social activities. A few were interested in walks or in fishing trips, and a number would meet in a pub occasionally post-pandemic.

6. Do you wish to stay on the TAPS list?

Very encouragingly, all bar one wished to stay on the list and to receive our various mailings including notices and reports of meetings, the newsletter, and forwarded emails on other groups' meetings, and from PCUK and Tackle. Twelve members would be reasonably active and another twelve said that they would like to remain as "dormant" members which is fine.

Conclusions for the future

About half our members are actively engaged and will attend meetings when they can and when it is interesting. The other half take a watching brief but know where to come should their interests change. Attendance will probably improve once we can return to the Town Hall and there were no requests to change the venue or timings. The SG will continue to a) try to provide a varied menu of meetings, b) provide a supportive social environment, c) attract new members who are beginning their prostate journey, and d) raise awareness among the public about prostate cancer.

OPEN TAPS

The speaker at our open Zoom meeting on 25 November was Pat Smith, a specialist nurse from PCUK. We opened invitations to several other groups and as a result there were 44 attendees including 8 from TAPS. People came from Reading, Purley, North Devon, Torbay, Plymouth and Truro. The topic must have hit a chord! This is a summary of her talk as interpreted by me and therefore please do not take it as totally correct!. The topic was:

"What happens if my prostate cancer comes back?"

Pre-treatment diagnosis: Based on PSA, Gleason score and scans.

Treatments: Mostly surgery or radiotherapy (RT). Sometimes PSA does not fall after surgery as far as expected because some cancer cells had already escaped the prostate envelope.

Post-treatment PSA: Expected changes in PSA depend on treatment.

- PSA after Surgery normally drops to 0.0 to 0.4 but further checks may be made if it is >0.2.
- PSA after RT without subsequent hormone therapy (HT) normally takes up to 18 months to reach its base level and it may bounce around a bit.
- PSA after RT and with HT normally drops almost immediately to near zero but, once HT stops, it may rise a little. Its new base level is an indicator of how successful RT was in clearing the cancer. Either way after RT, the threshold for further checks is normally base

level + 2.0. Note that many GP surgeries apply a pre-treatment PSA threshold anywhere from 4.0 upwards but this is too high and misleading.

Recurrence: A high Gleason score will raise the risk of recurrence because it indicated an aggressive cancer. It may recur locally in the prostate area or bed, or it may have spread outside to lymph nodes or further, ie metastasis.

Symptoms: Rising PSA; and possibly progressive urinary problems or bone/back pain although these could be due to other causes. Note that HT can cause reduction in bone density. These can be tested by bone scans and PET CT scans.

“Salvage” treatments: What a horrible word! For local recurrence, it depends on initial treatment.

- After RT, surgery or cryotherapy or ultra-sound are unlikely to be recommended and it is usually a course of HT or a watching brief initially.
- After surgery, RT to the prostate bed may be recommended and HT.
- After initial cryotherapy, either surgery or RT plus HT are possible.
- If the cancer has spread, then either HT or chemotherapy may be recommended. As resistance to these increases, other drugs such as abiraterone or enzalutamide may be used.

Conclusion: The science is developing at pace and it is possible for recurring prostate cancer to be controlled with a reasonable quality of life for long periods. We may still hope to die with it **but not of it!**

OUTSIDE TAPS

In this section of the newsletter we will 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 blood tests for early detection of a range of cancers, NICE approval of use of enzalutamide for post chemo treatment of prostate cancer, and improving the use of Fast MRI scans to improve the efficacy of PCa diagnosis.

An innovative blood test that may spot more than 50 types of cancer will be piloted by the NHS in a world-leading programme. The Galleri blood test can detect early-stage cancers through a simple blood test and will be piloted with 165,000 patients in a world-first deal struck by NHS England. Research on patients with signs of cancer has already found that the test, which checks for molecular changes, can identify many types that are difficult to diagnose early, such as head and neck, ovarian, pancreatic, oesophageal and some blood cancers. If the NHS programme shows the test also works as expected for people without symptoms it will be rolled out to become routinely available. The test could help meet the NHS Long Term Plan goal of increasing the proportion of cancers caught early, which can be the key to reducing cancer mortality. Patients whose condition is diagnosed at ‘stage one’ typically have between five and 10 times the chance of surviving compared with those found at ‘stage four’.

NICE has released its final guidance on using enzalutamide in England and Wales, approving it for use on the NHS for men with PCa who have already been treated with the chemotherapy drug docetaxel – and removing a restriction around its use after abiraterone. In October NICE had provisionally approved enzalutamide, a life-extending cancer drug, for men with advanced prostate cancer who have stopped responding to hormone therapy and chemotherapy. However, NICE has revised that draft decision, and says that enzalutamide should only be made available post chemotherapy to those men who have not already been treated with abiraterone – the only other available treatment for men at this stage of the disease. Enzalutamide is a treatment for advanced prostate cancer. It is most commonly offered to men whose cancer has stopped responding to other

types of hormone therapy. You may hear this called hormone-relapsed or castrate-resistant prostate cancer. You can have enzalutamide before or after chemotherapy. Your hospital doctor may offer you enzalutamide if you cannot have chemotherapy, or you do not want to have it yet.

In addition to the “Fast MRI scan” work being undertaken at Imperial College (See last issue) Joseph Norris, of University College of London reports his work on the same theme:

"MRI scans detect over 80-90% of the most important prostate cancers, even before a biopsy is performed. However, 10-20% of important prostate cancers can be “invisible” on MRI. The aim of my research is to improve how we diagnose prostate cancer with MRI scans, so that the disease can be detected in a more accurate and timely manner. This would enable the most effective and appropriate treatment to be given to each patient. My particular interest is to explore the “invisible” prostate cancers that we cannot see on MRI – at present, we do not know much about these tumours and I hope my work will change this. The first element of my research has been focused on improving the way in which we take samples (biopsies) of prostate cancers. The second is to examine the true nature of prostate cancers that are invisible on MRI scans. By precisely comparing tumour appearances on MRI scans to how they look under the microscope, I hope to develop instructions for surgeons on how best to obtain samples from tumours, so that we don't miss invisible cancers."

As you can see, there is a lot of work going on in medical research, and with these three stories just the tip of an iceberg, this is good news for us all.

MIXER TAPS

Normally in this section of the newsletter we will welcome new members, provide a forum for contributions from you, and spotlight any story from one or two members that may strike a chord amongst you. For space reasons, this section will be held over to the Spring edition.

CLOSING TAPS

Following your feedback, your Steering Group will continue to plan meetings on Zoom until it is safe to meet again in the Town Hall. We will aim to have medical speakers where possible but, if not, with other speakers or just social sessions. Since we do not expect large numbers of TAPS members to Zoom meetings, we shall probably invite other groups to join us. We shall also continue to circulate notice of other groups' meetings which you will be welcome to join at whatever day and time they meet. Our Zoom meetings will be held on the 4th Wednesday of the month at 6.00pm for a speaker at 6.15pm. Sometimes it may be necessary to change day/times to meet availability of speakers. The standard time schedule will apply once we return to Callington Town Hall when we hope to welcome back many more of you

As ever we would welcome your contributions to future editions of The Faucet with anything you feel could be of interest to the TAPS community. Please send your articles or information to tapsinfo555@gmail.com for the attention of The Faucet.

Happy Christmas and a healthy New Year.

From the TAPS editorial team.

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