

My Prostate Journey

Introduction

Steve, G4OCP, is a member of Thames Amateur Radio Group. He is one of several men (yes, it only applies to men) in our group who has benefited from the experience of others with a prostate problem. One person had an enlarged prostate but it was not cancerous, and the others were diagnosed with cancer at an early stage and are able to tell their story.

Tips for Managing your Prostate Cancer Journey. PART 1

1. **Involve your Partner or friend and get them to come to every appointment with you.**
You will need either or both their advice and help especially post treatment.
2. **Get diagnosed early.** Start having annual PSA blood tests (even if they say you are “too young” – having a history is important). Pay attention to any symptoms and get them checked out by GP, Consultant, Scans (MRI etc). Although my MRI was ‘ambivalent’ my Consultant ordered a **Biopsy** because my dad also had prostate cancer.
3. **Have a Biopsy.** This is a proper operation and can ‘take it out of you’ BUT is currently the best way of finding cancer. It is possible to have the biopsy done ‘privately’ and transfer back to the NHS. If the results are positive you will be offered an appointment with NHS Urology Department to discuss what options you have. My results were positive and included a “4+3” reading but with all the cancer contained within the prostate. Now do some **Research** and get prepared for that appointment
4. **Be Informed: Research & Read** – so you have a clear idea of what you want to have done and why. Use reputable sources of information. **Macmillan Cancer Support** and **Prostate Cancer UK** have lots of information both printed and on-line. Make a list of questions. For me, in my circumstances, I decided that having my prostate surgically removed (Radical Prostatectomy) was the best way to remove the cancer. Two years earlier my golfing buddy with very similar biopsy results decided Radiotherapy was his best way forward. It’s
5. **Attend First Appointment with Urology.** Mine was with a Nurse Specialist who was very well informed. When I told her that my decision was to go for surgery and gave her my reasons, listened careful then focused fully on that treatment option by asking and answering questions. Don’t forget other health conditions may make some treatments unsuitable. She introduced me to an **App called Squeezy for Men** – a Pre and Post treatment **exercise routine DO THEM from now on!** You will now be referred to an appropriate consultant. For me this was at **Broomfield** with a surgeon from **Southend Hospital Urology Unit.**
6. **Attend Appointment with Consultant.** Re-read the information about your chosen treatment and make a list of questions – the Prostate Cancer UK ‘leaflets’ have a list of useful questions at the back of every treatment option. **Tell the consultant** about any existing health conditions – they need to know! My consultant was a surgeon whose CV I had researched but it was one of his colleagues who would be doing my Op – so I asked lots of questions! He explained about the robotically assisted surgery. From here on my focus is only on robotically assisted surgery.
7. **Attend all Pre-Op appointments.** These are invaluable so always take a **Notebook and Pen.** Some are Mini lectures BUT are very practical so always ask for clarification if needed. You may well be placed on the **Enhanced Recovery Programme** – it’s brilliant, with documentation written by nurses and **covers both Pre and Post-Op** – so follow the instructions carefully!
8. **Treatment.** This is where my Journey carries on down the Surgery route. Specifically Robot Assisted Prostatectomy – your decision may well take you in different directions – I wish you well whatever you decide.



Tips for Managing your Prostate Cancer Journey. PART 2 The Surgery route

- A. **Get your body ready.** Do whatever you can to get Op-fit. You may be offered free Gym sessions TAKE THEM. Most importantly DO YOUR SQUEEZY EXERCISES conscientiously – you will recover your bladder control quicker if you do. I am now week 6 post Op, completely dry overnight, dry whilst sitting, getting dryer during activities like walking and only needing to change my incontinence pad once a day. I am hoping to be able to walk and putt 9 holes of a golf course, with manageable ‘leakage’, later this week.
- B. **Plan for Post-Op chores.** Read the Enhanced Recovery Programme Notes – there is lots of practical advice and even includes a list of things to get ready for your hospital visit. **ONE** thing you might miss and has significant implications (especially if you are on your own), is the guidance about **LIFTING** things after the Op – “first week **A MUG**”, “second week **A KETTLE**”. So consider using a ‘hospital’ bag with **wheels** for your belongings, order in lots of ready-meals, plan how you will manage all the other household chores that you normally do without thinking! Nor will you be able to drive for some time after the Op. My neighbours and friends have been fantastic – so don’t be afraid to ask.
- C. **Order-In Personal Care Products.** From Medicated liquid soap (Octenisan Antimicrobial Wash or similar) and disposable wash cloths (Conti Washcloth Large or similar) to Incontinence Pads. I found that women’s pads are far cheaper and fitted just as well as the men’s pads (ASDA got good reviews). I did not find the Vaseline useful, it’s just too ‘sticky’ and difficult to wash off. I was given some INSTILLAGEL (also available over the counter) which was fantastic for looking after my catheter.
- D. **Packing.** Everything you need to pack is detailed in the Urology Enhanced Recovery Programme “**Patients Diary**” – **make sure you pack this document** – Page 4 has a “What you should go home with” checklist – very useful when you are not thinking completely straight!
- E. **Drink the ‘Esure’ drinks and the ‘Pre-Op drinks’ as directed.** I am sure that these played a major part in my rapid recovery from the Op and anaesthetic.
- F. **The ‘BIG’ Day.** Finish the last of the Pre-Op drinks. Arrive early – you will miss the traffic and find parking easy, meaning you will be less stressed! I was admitted at the Elective Admission Lounge and after the paperwork, changing into a theatre gown and putting on **my own dressing gown** I met the Surgeon. After a short wait I was collected by a nurse and walked down to the operating theatre – spot on 9am.
Hopefully, like me, you will not remember anything of the Op itself. When I awoke I had a splitting headache so told the nurse, she gave me something and I went back to sleep. **It’s important to tell the nurses if you are feeling unwell or have pain.** I don’t remember anything more until the next morning!
- G. **Next Day – discharge day.** Make sure that you are issued with everything listed in the “Patients Diary” (ask for some INSTILLAGEL) AND several packets of EXTRA STRONG mints (yes, they really do help to ease the pain from the abdomen inflation gas). If travelling by car, have a **small cushion** ready to protect your abdomen from the seat belt. You will have been shown how to look after your catheter leg and night bags. My one tip is that when you are in bed, **use one of the spare Velcro straps** to anchor the joint between the Leg-Bag valve and the Night-Bag tube to your ankle – it will help prevent the tube ‘kinking’.
- H. **First day at home.** Follow **and** annotate the Diary (NB a “short walk” is only about 10m!). Make extra copies of the last Diary Day (P10 for me), enough copies to last you until the catheter gets removed. **DRINK PLENTY** - Peppermint tea has plenty of flavour and helps banish the ‘inflation gas’ that was used during surgery.
- I. **Everything takes longer.** From start to finish it would take me, with help, an hour to have a shower. Things will gradually improve and you will soon master managing your catheter – I found that wearing the Leg-Bag on the outside of my leg made it easier to monitor when it needed emptying.

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- J. **Do everything it tells you in the Diary** - and annotate. You will need your notes when your nurse phones to ask how you have been getting on.
- K. **Catheter Removal Day.** Go prepared with cushion, pads, change of clothes etc to manage any leakage. The chances are that you will be issued with some pads and heavy duty 'pull-ups' to see you through the journey and for a while after.
- L. **Recovery and beyond.** Again **FOLLOW THE ADVICE GIVEN** you will make better progress if you do AND contact your nurse if you need any help.
Arrange and have your 6 week PSA Blood test.
The next milestone is the follow-up appointment (6 to 8 weeks Post-Op) with the surgeon who will discuss the results of your PSA blood test, the Histopathology results of your Prostate and what needs doing as a consequence of those results. My PSA results were fine but the Histopathology showed a very small positive margin meaning that cancer might have spread outside the prostate – luckily it is Gleason level 3 so is likely to be very slow growing and very unlikely to metastasise. This means that at the moment no further treatment is required BUT my PSA levels will be monitored for the next 10 years. All of which is reassuring.
For now it's just a case of re-introducing my normal activities and getting myself fully 'dry'.

I do hope you find these notes helpful, if not for you, then for someone you know. If you do happen to develop Prostate Cancer then I wish you well, whatever treatment route you decide upon and DON'T BE SILENT – whatever the issue TALK TO YOUR NURSES they are brilliant!

Further reading:

1. Prostate Cancer UK. <https://prostatecanceruk.org> Use the **Menu** button to access **Prostate Information and Support**. You will be offered the opportunity to download all articles or as printed articles that can be ordered. You can also order (FOC) a Surgery Support Pack that includes both publications, a selection of pads and other useful items.

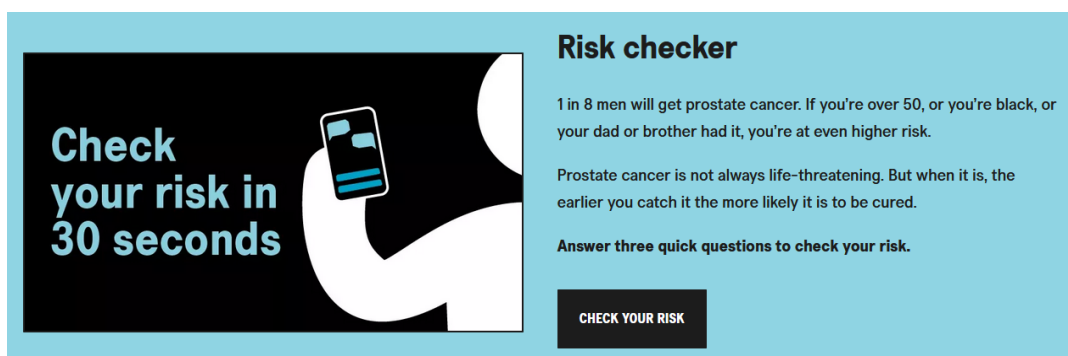
The articles clearly state the risks of individual treatments and can be quite scary to read but DO NOT be overwhelmed – the sooner you are treated the better the likely outcome.

2. Macmillan Cancer Support. www.macmillan.org.uk who provide support for a wide range of cancers – not just Prostate Cancer. Click **Search** and select **Cancer A to Z**. In the new search bar, search for **Prostate** and select your type of cancer – hopefully either **Early (localised) Prostate Cancer** or **Locally Advanced Prostate Cancer** will be all you need. Clicking either of these will take you to a new page, then scroll down until you find them and then you will be able to order physical copies. Another publication worth having is: **Holistic Needs Assessment – Planning your care and support**.

If you are able, please support either or both of these charities with a donation.

Very Best Wishes for a happy, active and healthy future.

Steve G4OCP, May 2024



Check your risk in 30 seconds

Risk checker

1 in 8 men will get prostate cancer. If you're over 50, or you're black, or your dad or brother had it, you're at even higher risk.

Prostate cancer is not always life-threatening. But when it is, the earlier you catch it the more likely it is to be cured.

Answer three quick questions to check your risk.

CHECK YOUR RISK