

PROSTRATE FOR THE PROSTATE

Well I've been and had my prostate done.
I can tell you this, it's not much fun.

The Urologist, whose motives were not ulterior
Had his finger probing my posterior!
Between you and me I have to say,
I'm bloody glad that I'm not gay.

Anyhow he says, "I have to tell you mate,
We are going to have to operate."
So they stick a needle in my back,
Then start reaming out my urine tract.

He set about with dextrous hand
Cutting fillets off my prostate gland.
I'm back in the ward when I find out
I've got a pipe stuck up my spout

And on the end they've tied a plastic bag
Which for two days round the ward I drag.
They say the most tender spot is in the eye.
I can tell you now, that's a bloody lie!

Well now I'm all healed up and the stream is
great
But still I have to compensate.
From the trough I'm standing so far, that
I can't see what I'm aiming at!

So boys, if you're born again in another world
And you've got the option - be a girl!

*Written by **Dave Chambers**, an uncle of Michael Meszaros' wife. Dave was nearly blind, hence the reference to not seeing where he was aiming. Michael is a member of Prostate Heidelberg.*

A BIG THANKYOU TO CONTINENCE FOUNDATION of AUSTRALIA

Since our inception about 14 years ago, the Contenance Foundation of Australia have posted out our Newsletter. Though they are not able to continue to do this service for us from 1st January, our Group (Prostate Melbourne) thanks the Foundation for the wonderful support they have provided at no cost over the 14 years.

HOW TO TAKE CONTROL OF YOUR TREATMENT

After finding out you have prostate cancer, you may feel shocked, upset, anxious, inadequate, or confused. These are normal responses.

You will, as a patient, be asked to take control of your treatment and to make the treatment choices along the way. It is up to you as to how involved you want to be in making decisions about your treatment.

To "control" your treatment is very daunting when you are first diagnosed (even later along the journey). Added to the choices is the fact that every cancer is different, with different degrees of aggression.

Why should You take Control, and What Does it Mean?

Along the course of the journey with the cancer, you will meet stages when you (or the specialist, if you allow him) choose options / make decisions. The specialists are experts in "your" disease, but not necessarily in "you". You're the expert in "you". Who you are involves your family and

friends, your financial, emotional and psychological state, and what you value (e.g. is your sex life more important than “getting rid” of the cancer). Only you can tell the specialist who you are and therefore which decision is right for you, the patient.

The best treatment for your prostate cancer depends on your age, general health, and, the grade and stage of your cancer. Treatments for prostate cancer are improving, however side-effects of treatment may affect your lifestyle including sexual function and continence. Therefore at the point of decisions, listen to the specialist about the medical options, and you need to feel comfortable with your choices.

You may have to go back for further appointments to determine which specific “cancer” you have, and which options you are asked to consider. Then you should ask questions until you understand, in your own terms, what each option means. Use your family and friends, support groups, cancer organisations websites to frame your questions. Ask these questions of your specialist - your specialist is the only one who can answer questions about your situation.

Where do you start? Here are some simple, but important, steps you can take as you start the decision-making process.

Take Your Time

Prostate cancer is unusual in that it is slow growing in some men and usually not a threat; and even when it has spread (metastasised) aggressively, there should be still time to do research.

Therefore, take time to research your options.

Choice in Writing

Ask for your pathology reports, biopsy results, Gleason Scores and other staging indicators, and

PSA results. Keep them in a file or a book. Write down your questions before your appointments. Ask for the choices/options in writing, or write them down. Always, if possible, attend appointments with a partner, carer, or close friend. Ask him/her to take notes.

Know your Options and Understand the Goals of Treatment

Don't presume that your cancer will kill you tomorrow. Your doctor may use some treatments to slow, stop, or eliminate the cancer. He or she may also use treatments to manage symptoms and side effects. Ensure your doctor explains to you the goals for your treatment plan and how it will affect you. And make sure it aligns with your personal goals for treatment.

Talk with your doctor about the treatment options for your type and stage of cancer. Some of these options may include:

- Surgery
- Radiation therapy
- Chemotherapy
- Hormone therapy
- “Active Surveillance”
- Palliative care or later stage treatments
- Participating in a clinical trial

Ask your doctor what side-effects to expect and how best to manage these. Sometimes cancer can cause long-term effects, or late effects, that might develop months or even years after treatment. You have more options to keep your fertility if you address this concern before treatment, instead of waiting until after treatment.

Consider the risks and benefits of treatment options

Listed below are some questions you may want to ask of your healthcare professionals about treatment options for prostate cancer:

- What are all the treatment options available?

- What is the standard treatment of my stage of prostate cancer?
- What do the treatments do? (Do they aim to remove or just contain the cancer?)
- What are the treatment procedures?
- What are the benefits and how likely are they?
- What are the potential short- and long-term side effects
- What are the effects on my quality of life and independence
- What is the likelihood the cancer will come back after treatment
- What are the chances of living longer with or without treatment
- What do I have to do and how may it affect my day-to-day life? (e.g. travel to a treatment centre, time off work, changes in responsibilities)
- How will the treatments be monitored?
- What are the costs involved with the treatments?
- How may the treatments affect other health conditions I may have?

You will likely think of other questions too. It may take several visits with your doctor before you feel you have all the answers you need to make a decision.

To Treat or to Monitor

Cancer treatments all have side effects. You may want to get rid of the cancer as soon as you hear you have it, but the treatment (e.g. surgery, radiation, chemotherapy, hormone therapy, etc.) may not be a “cure” of the cancer. Can the treatment be deferred? “Active Surveillance”, where you are “staged” at the start, at about a year later (“re-staged”) and then as the PSA indicates, is increasingly seen as the most appropriate treatment option. Ninety percent of men will die with prostate cancer rather than of it.

Discuss your decision with people you trust

Use cancer support groups, Cancer Councils, PCFA, etc. to help with asking the right (for you) questions. Remember that the internet, friends and support groups will help ask the right questions. The answers come from the right specialist.

Every Cancer is Different

This difference in cancers (researchers have identified about 28 types of prostate cancer, but are still trying to work out what this means) means that you will hear from family and friends about someone they know who had prostate cancer and that person did “such-and-such” or “something” worked for them. You can use all this advice to frame questions of the health specialist, but should not accept this advice as necessarily applying yourself.

Consult guidelines or other decision-making tools

The American Society of Clinical Oncology (ASCO) and other cancer organizations publish guidelines and treatment decision-making tools. These tools help doctors and patients understand various treatment options. Find summaries of recent guidelines from ASCO and talk with your health care team to see if any apply to your situation.

Multidisciplinary Care Team

Ask your specialist if your case will be discussed by a Multidisciplinary Care Team. If it is, ask for the team’s opinion. If it is not, go to second opinion and ask that specialist if your case will be discussed by a Multidisciplinary Care Team.

Second Opinions

Prostate cancer is usually a slow growth cancer and you should have a while to make the decision. Because your options usually involve different specialists, you should get at least an opinion of a specialist in another discipline - if you see a

surgeon / urologist, then get a referral to see a radiation oncologist. Most specialists are able to help you get a second opinion either in the same field (e.g. urological surgery), or a different field (e.g. medical oncologist re chemotherapy).

Check with your insurance company to find out if your policy covers a specific doctor or health care option.

Advanced Care Plan

Prepare an Advanced Care Plan - it forces you to write down what you value in life and in reference to your health. Hospitals and other health professionals can help you in this process. You don't need to be dying to find the document useful.

After understanding all the information about treatment options, talking with members of your healthcare team, partner, families and friends, and taking into account your personal beliefs, you may choose not to have any treatment. This is a valid choice.

Your Physical and Emotional Wellness?

Eating a healthy diet including a variety of foods, will ensure you have what your body needs to cope with treatment and recovery. Regular physical activity can improve your cancer recovery and reduce side-effects such as fatigue.

- Don't be afraid to ask for professional, financial and emotional support.
- Consider joining a cancer support group.
- Learn to ignore unwanted advice and 'horror stories'.
- Live day-to-day and remember that every day is likely to be different.

Complementary Therapies

Complementary therapies can work alongside medical treatments, and some have been shown to improve quality of life or reduce pain. There

is no evidence that these therapies can cure or prevent cancer. Some have not been tested for side-effects, may work against other medical treatments and may be expensive. Talk to your doctor about using complementary therapies.

Find help managing the cost of cancer care

The cost of cancer care is often high, and you may have unanticipated expenses. Your health care team can help you identify costs related to your treatment options or suggest ways to manage medical and associated costs. They can also refer you to support services that address the financial concerns of people living with cancer.

Beware the Internet

But be careful when doing research online. Many sites can be frightening, inaccurate, or misleading. Your doctor or nurse can suggest reputable websites. If you come across unfamiliar words while researching online, ask a member of your health care team to explain or use a medical dictionary.

Understand the role of statistics - a Warning

Your doctor may mention statistics when describing treatment options. These may include relative survival rates, disease-free survival rates, and progression-free survival rates. These numbers may be a good way to learn how the treatment options differ. But they can't predict how well the treatment will work for you. Your doctor or another member of your health care team can explain how these statistics relate to your treatment.

<http://www.cancer.net/navigating-cancer-care/how-cancer-treated/making-decisions-about-cancer-treatment>

<http://www.cancer.org.au/about-cancer/after-a-diagnosis/after-a-diagnosis-of-prostate-cancer.html>

<http://www.cancer.net/cancer-types/prostate-cancer/treatment-options>

PROSTATE CANCER RESEARCH -

EXERCISE AND NUTRITION STUDY

Deakin University is conducting a study investigating the benefits of a new exercise and nutrition program for men with prostate cancer (aged between 50 and 85 years; and being treated with hormone therapy). If interested, contact Deakin University, Burwood, on (03) 9426 8347 or 0425 891 782 or www.deakin.edu.au/research/ipan/participate-in-our-studies.

PCFA'S MAX GARDNER SUPPORT

AND OUTREACH AWARDS 2016

Prostate Heidelberg congratulate the 2016 winners of the awards: Jim Marshall, Gabrielle Moran OAM, and Ian Fisk. Details are on <http://www.pcfa.org.au/about-us/awards/max-gardner-award/>.

MEETING FEBRUARY 2017

Prostate Heidelberg's **MEETING VENUE** is the Ivanhoe Uniting Church Meeting Room, Seddon Street Ivanhoe (Melways 31 F8) - behind the Commonwealth Bank in Upper Heidelberg Rd. Car parking off Waterdale Rd behind the Ivanhoe Hotel.

- The **NEXT MEETING**: **10:00 am to 12.30 pm, Wednesday 8th February 2017.**

2017 SUBSCRIPTIONS \$10

The 2017 annual subscriptions are due from 1st January 2017. The rate is \$10 per individual, couple or family. The subscriptions are payable to the Treasurer or directly into our bank account- "Prostate Heidelberg Community Group Acct". BSB 083 256 Account 5832 44292

FINANCIALS FEBRUARY 2017

As of 31st December 2016, Prostate Heidelberg had \$2,948 (26th November: \$3,008) in its NAB bank account and \$100 as a petty cash float.

PLEASE RETURN BOOKS or DVDs

BORROWED from the LIBRARY

Prostate Heidelberg currently has a significant number of books and DVDs that have not been returned. The usual borrowing period is one month. There are other people who would like to use these library resources on their cancer journey. Please return them at the next available meeting. If you borrowed a book and since lost it, please send a note to that effect to prostateheidelberg@gmail.com. If the material is still in print, we can replace it.

Prostate Heidelberg provides information, education and support for those affected by prostate cancer. At the meetings, we:-

- *Show respect to members and speakers;*
- *Allow people to speak and we listen;*
- *Respect confidentiality;*
- *Allow new ideas to be shared.*

We meet on the 2nd Wednesday of each month (except January) from 10:00am -12:30pm at the Uniting Church Meeting Room, Seddon St, Ivanhoe (behind the Commonwealth Bank in Upper Heidelberg Rd). Free parking is available in a large public parking area at rear of the church. Ivanhoe railway station and various bus routes are nearby.

Meetings are open to anyone interested in getting support or information on a prostate cancer journey. Partners or carers are welcome to all meetings.

There is no charge for attending. But we ask for **\$10 annual subscription** per individual, couple or family due from 1st January 2017 to contribute toward meeting costs, if you can afford it.

After the meeting you are welcome to join us for lunch in a local Thai restaurant.

If you can't attend daytime meetings, the Diamond Valley Prostate Cancer Support Group has evening meetings: <http://www.dvpcsg.org.au/>

COMMITTEE

Max Shub, Facilitator 0413 777 342
 Paul Hobson, Secretary 0405 086 869
 Chris Ellis
 Spiros Haldas
 Janis Kinne
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 Patrick Woodlock, Newsletter 0438 380 131

Please contact attention, Patrick Woodlock, to redirect or cancel receipt of this Newsletter.

CALENDAR Meetings: 10:00am -12:30pm

Wed 8 February 2017
 Wed 8 March 2017
 Wed 12 April 2017
 Wed 10 May 2017
 Wed 14 June 2017
 Wed 12 July 2017
 Wed 9 August 2017
 Wed 13 September 2017
 Wed 11 October 2017
 Wed 8 November 2017
 Wed 13 December 2017 (Christmas lunch)

CORRESPONDENCE

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DISCLAIMER: Information in this newsletter is not intended to take the place of medical advice. You should obtain advice from your doctor relevant to your specific situation before acting or relying on anything in this newsletter. We have no liability whatsoever to you in connection with this newsletter.