The Walnut January 2016 Newsletter of the Prostate Cancer Support Group ACT Region Inc. Affiliated with the Prostate Cancer Foundation of Australia

Postal address Prostate Cancer Support Group - ACT Region Inc. PO Box 717, Mawson, ACT 2607

Personal support

For general information please call SHOUT (Self Help Organisations United Together) who will arrange for someone from the group to contact you. They are available during normal office hours on (02) 6290 1984.

If you would like immediate support, advice or assistance contact:

President: Graham Erickson

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Walnut editor: Aidan Moore

Contact Editor at http://tinyurl.com/mgw9rbp

Monthly meetings

Meetings of our support group are held on 3rd Wednesday of each month except December. The next general members' meeting is on Wed 20 January 2016

Usual Location and Time:

Room 22, Building 1, Pearce Community Centre, Collett Place, Pearce, ACT 2607. 6:30 for 7:00 pm See our web site http://tinyurl.com/bjoyczu for details and map showing the location, and other useful information. Instructive personal stories of survivors can be found on our website: prostate-cancer-support-act.net

Last monthly meeting

Members' Monthly (Christmas) Meeting on 18th November.

The Chair, Committee Members and attending Members wish to express their appreciation and thanks to all members and spouses who contributed to the Christmas food and party atmosphere for the Christmas Meeting on 18th November.

The ladies in particular support the Group quietly all year and get insufficient recognition for their valuable contribution. Members are usually too busy discussing medical conditions, treatments and experience, and often counsel new members to adequately express their appreciation of the ladies' contributions and support, which we now warmly and gratefully express.

PRESIDENT'S REPORT

As you know I was elected as your new President in 2015. Chris Hansen held the position for many years and we owe him our gratitude for keeping the PCSG active in the ACT. Over those years Chris tirelessly promoted awareness of prostate cancer throughout the ACT region. Unfortunately due to travel commitments I have not been available for the past few months. Hopefully in 2016 I will be able to devote more time and energy to the PCSG. I would especially like to welcome any new members.

The PCSG has struggled to keep going over the last year and it was difficult to get members to take up an executive role. Thankfully, this has now happened and we look forward to helping men and their families again in 2016. At our next meeting to be held on 20 January 2016 I will be asking members to volunteer some of their time to take on some minor roles. In doing so this will greatly help our Group to have an active role in the community to promote awareness of prostate cancer. As in the past I hope that we are able to secure guest speakers for each of our meetings.

The main role of the PCSG is to provide a forum where men and their families can come together to share with others their experiences of dealing with prostate cancer. I found that this certainly helped with my fears and expectations when I was first diagnosed with prostate cancer 4 years ago.

I look forward to meeting as many of you as possible at our next meeting and subsequent meetings throughout 2016. I will endeavour to keep the business part of the meetings very brief so that members can enjoy some quality time sharing experiences with each other. I wish you all the very best for 2016.

Graham Erickson
President, PCSG - ACT Region

Articles of interest

<u>The following articles</u> from the medical and general press were contributed by members. All have been edited (shortened) and some have been kept for possible inclusion in future issues of The Walnut. Increasingly, this newsletter is respecting members' privacy by reducing naming except where needed, eg the names of office holders or when requested.

Library Acquisitions, Notices and Reviews.

The following from our Librarian, UN Bhati These books are now in our library and can be borrowed.

| Facing the tiger: a guide for men with prostate cancer and the people who love them | Professor Suzanne Chambers, a health psychologist from Griffith University | | January 2013 | Australian Academic Press, Level 5, Toowong Tower, 9 Sherwood Road, Toowong Qld 4066 | 1 | ISBN 978192211 7052 (pbk). xii+138 pages |
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Below the Belt: Experiences with Prostate Cancer

Busybird Publishing, PO Box 855, Eltham Victoria 3095.

Publication Date: 21 February 2015

Price: \$30.00. Format: Paperback (153x234mm, 205 pages)

ISBN: 978 0 9925547 3 6 Category: Nonfiction

Below the Belt: Experiences with Prostate Cancer is filled with stories and poetry from those who have been courageous enough to share their experiences – a library of information that is educational, but also shows the importance of seeking support, of opening up to reveal that it's not a fight that need be undertaken alone.

And that strength and resilience can come through sharing.

The production of Below the Belt was proudly sponsored by <u>Hire A Hubby</u>. Five dollars from the sale of each book will go to the <u>Prostate Cancer Foundation</u>.

Selling points:

Poems and stories from people who have experience with prostate cancer.

Information about Prostate Cancer.

Resources for prostate cancer diagnosis and care.

Will raise money for the Prostate Cancer Foundation of Australia.

About the Authors

With approximately 30 contributors in the book, the reader gains a variety of information about different aspects of the disease – the physical, mental and technical – in an easy to read, non-medical language.

Review by the Editor Dr O'Malley-Ford,

'Below the Belt, Experiences with Prostate Cancer' is a publication and initiative of Busybird Publications. It is filled with stories and poetry from those who have been courageous enough to share their experiences – a library of information that is educational, but also shows the importance of seeking support. It's about opening up to reveal that it's not a disease to be taken on alone. The book has been written to share concern about the fact that prostate cancer kills more men than breast cancer does women. Men are stoic but often solitary when it comes to health. They not infrequently combine a lack of knowledge, fear, and solitude to make the battle more difficult. A Joint Project between Hire a Hubby Australia and Busybird Publishing, \$5 from every book sold will be donated to the Prostate cancer Foundation of Australia. The book can be purchased here.

Men are commonly reluctant to talk about their experiences with PrC let alone share the intimate details of their disease, and the feared possible outcomes with a reading audience.

Perhaps the tide is starting to turn. The first few tentative steps have been taken in sharing and normalising discussion about PrC and the possible side-effects that may follow operations, including incontinence and erectile dysfunction. The importance of developing a pre-operative plan for dealing with these possible post-operative problems is now a routine part of pre-operative preparation. The presence of a plan helps to reduce pre-operative anxiety and encourages a holistic approach to treatment and recovery.

Congratulations to Busybird Publications for setting the ball rolling just a little more.

Developments and items of interest

The following article was submitted by Mike F-S, our Secretary

Physical Fitness. Keep Moving or Grow roots 6 Feet Deep.

Whether it is for general health, preparation for treatment or recovery after treatment, or for cancer prevention, physical health is essential and should be optimised. Generally it means keep moving or physical activity.

Examples of moderate- and vigorous-intensity physical activities can be found on the Centres for Disease Control and Prevention (CDC) Physical Activity Web site at

http://www.cdc.gov/nccdphp/dnpa/physical/pdf/PA_Intensity_table_2_1.pdf on the Internet [Editorial comment: Their recommendations are for medically-fit people, and may not suit you or I. Get a referral to an exercise physiologist. AM (ed.)]

Free ACT Health Exercise Programme:

The Canberra Hospital provides a free Exercise Physiology (EP) Programme to aid various patients including those in post cancer treatment recovery. The programme involves two, one hour, supervised sessions per week. EP provides free sessions for 2-3 months periods. Entry to the programme is by referral from your GP, cancer specialist or cancer nurse. Unfortunately, there is a waiting list of about 2-3 months. [I avoided the delay by getting a referral to a very good local physiologist in Belconnen (AM, ed.)] EP will design a routine specific to your needs and ability and get you in the habit. The secret is not to stop when the programme expires, but to continue. One solution is to join [a fitness club. Another, my choice, is a hill behind my house which I aim to climb three times a week (Editor)]

Another article submitted by Mike F-S.

How One Might Proceed [After a diagnosis of prostate cancer (PC)]:

Don't be anxious and don't stress yourself or your family. It is no big deal. Firstly you are not alone and secondly, many peers, even friends have experienced this and they are still with us and in the PC Support Group (PCSG). Be thankful that you have not been diagnosed with brain, lungs GI tract or pancreas cancer, [these generally have much worse prognoses (outlooks)(ed.).

Gather information, not just from expert websites, GPs, counsellors, and specialists, but also from those that have had recent experience of diagnosis and treatment [the PCSG is a natural place to seek these people].

Explore the many treatment options.

Seek second opinions. Remember that you probably didn't marry the first lady you met, so shop around and find a treatment or surgeon that suits you, your health and your condition. One who communicates clearly and answers questions. One in whom you have confidence. Take written questions and maybe a friend with you to consultations.

Compare surgical with non-surgical methods and listen to persuasion from both camps before deciding. [Most of our members have views on these which they will exchange with you (Ed.)]

If you are over loaded with information, confused or scared, my suggestion is the Prostate Cancer Support Group [whose members can give you non-professional accounts based on their personal experience (AM, ed). Chat with them over a cup of tea and a biscuit at our monthly meeting (time and place above). You will not feel intimidated or anxious that you are wasting their valuable time or seeming foolish by asking irrelevant questions, as you might with prestigious professionals. If nothing else our members will sympathise with you and show you that others have been where you are now and have worked through it.

You will find diagnosis of prostate cancer (PC) a learning and growing experience and you will probably value life more. [Let your health professional/specialist tell you how aggressive it is or isn't. Mine was moderately aggressive (Gleeson score 7) and I just wanted rid of it (Ed.) I found a surgeon whose competence I trusted. I don't regret it.]

Qualification:

The above is not medical advice, it is rather advice to seek, evaluate and consider advice [and the personal experience of survivors] before prioritising and deciding a treatment that will suit you. The above is based on my personal experience.

Michael F-S., PhD Psyc., member of the PCSG-ACT.

[Editorial note: Michael F-S sent more material. Some of it is kept for possible inclusion in a later newsletter. I have added my own comments.]

Upcoming Events

Next monthly meeting
Wednesday 20 Jan 2016 at the usual time and location - see details here:
http://tinyurl.com/ley8grl

Disclaimer

From time to time in our newsletters we provide information about developments in the diagnosis and treatment of prostate cancer, research articles, documents, audiovisual products, presentations and other interesting materials. However, the Group's Executive and the editor of this newsletter do not have the medical expertise required to make an informed evaluation of the conclusions and recommendations presented in such materials, and we have not verified such conclusions and recommendations through appropriately qualified medical professionals. The information presented in this newsletter must not be interpreted as being endorsed or recommended by the Executive or the editor. Any recommendations made in such materials may not be applicable in your particular case. Before implementing any recommendations made in the materials that are reported, it is essential that you obtain advice from appropriately qualified medical professionals. The view of the Group's Executive is that no two prostate cancer cases are alike and that no single treatment option is better than any other in all cases. While the information in this newsletter should be of interest, there is no substitute for getting informed medical advice from your own GP, specialists and other medical professionals.