

Prostate Cancer Ipswich Prostate Cancer Support Group

Affiliated with the **Prostate Cancer Foundation of Australia**

January 2016 Newsletter

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Report on Meeting held Thursday 21st January 2016

Next Meeting: Thursday 18/02/2016 Guest Speaker: Dr Ali – Urology Consultant Ipswich General Hospital Topic: TBA Venue: Humanities Building; 56 South St. Ipswich Parking: South St & Nicholas Sts and off Roderick St

The normal starting time for the meeting is 7.30pm with coffee, tea and biscuits at the conclusion of the evening.

This meeting was the first for 2016 and designed to be a planning meeting by the members of the Group to plan the activities and active support for 2016. There were 11 members in attendance. Jeff D. acted as Chairperson for the night as Len, though unwell, was in attendance.

Welcome back and the best wishes for 2016! The meeting was not of the normal style as the discussions were to be about planning the support and activities for 2016 so the members present sat around the circle and allowed the conversations to occur. We broke for coffee about half way through.

Madonna Britton from the Ipswich General Hospital spoke to the Group. Madonna is the Nurse Unit Manager in the Urology Ward 4F and has been in various roles and responsibilities in nursing for many years. She spoke passionately about her past interactions with our Group and her desire to ensure that the staff of the Urology Ward were aware of our activities and experiences.

Madonna spoke about the improvements that were occurring in the Urology Ward and with the staffing situation. She spoke about the number of doctors on staff and the introduction of a 'specialist' nurse to concentrate upon the improvement of the patient's experiences through the PCa journey. It was acknowledged by all present that they had experienced knowledge gaps in their journeys and that it was essential that processes be in place to identify and provide mechanisms to make the journey easier.

The 'specialist' urology nurse is Mr Stephen Walker who has been appointed, on a 6 month trial, to be a conduit for the delivery of better support services to PCa patients. This means that Stephen could be regarded as the main support contact person for those patients in the public system. His role will be to be contactable by the patient or family and be able to supply additional non-medical information as necessary – "who can I talk to?, What support services are available in the community?, Who do I talk to about my incontinence?, etc.

As PCa is being diagnosed in younger men, the integration of these younger men into the apparatus of the Support Groups may be difficult and may Groups may need better mechanisms to achieve this. A new learning curve for us, perhaps! We know that we have travelled the journey thus far and our experience is hard-won, but we need to be able to include and assist where possible. Stephen will be able to assist here in that he can be an early voice in the PCa journey.

The matter of the future running of the Group was discussed at length with a view of getting more buy in from the membership. Len has suffered a bout of ill health and needs to wind back his involvement

(however difficult that may be for him) and the Group members must step up or there is the real potential that the Group may lose its momentum and focus. In addition, some members of the past management group will be unavailable for a large portion of 2016 thus complicating the matter. We do have volunteers for the preparation of future monthly newsletter – Thank you John and Robyn G. your help is valued.

Madonna suggested that the roles required to deliver the Group's work could be split into different activities and making each job a more manageable one. Her insights were that 1 in 7 Queensland males are being diagnosed with PCa and that it is being detected in younger males so the demographic profile is changing.

In the initial phases of the Group (way back in the day!!!), a Management Committee met to 'divvy up' the jobs and this operated effectively. Perhaps we need to investigate this again as a mechanism to better operate as a group of volunteers trying to provide some support back to other sufferers of PCa who have just commenced the journey. Please think seriously about this as your help is needed to keep the Group running.

The meeting closed at 9.45pm with a general consensus that the work that the Group did was valuable but little advance into the practicalities of continuing the Group's work. Please get involved and phone Len and let him know what assistance you can supply.

Extract from "The Healthy Male" – Newsletter of Andrology Australia – Summer 2015 Issue 57

"What do men with prostate cancer want other men to know?

A UK study investigated the use of film wherein seven volunteers talked about what they wanted to tell other men about their cancer journey.

The synopsis is:

- "Going into the unknown, it was difficult but I got through it "which highlighted the difficulties and their resilience and determination to get through it, and
- "Only you can do it" was about getting help but ultimately taking control of their own management and decisions, and
- "I haven't changed massively" was about going through difficult experiences but fundamentally remained the same person, and
- "Stay involved" stressed the importance of staying connected to family, friends and community;

The study provides a framework for understanding what men who have been through prostate cancer think would be helpful to other men who are starting on the cancer journey."

Ipswich Prostate Cancer Support Group Meetings				
Ipswich: Third Thursday each month. Meeting starts at 7.30pm				
Humanities Building, Cnr. South and Nicholas Sts. Ipswich				
9:30am on od	d Wednesday (except 1st Wed in August) ld months, 7:00pm on even months 553 Gregory Terrace, Fortitude Valley	Lockyer Valley : Contact Bob Stewart, 23 Wagtail Drive, Gatton, Q 4343		
Program of Events For the Group				
Date	Speaker/Event	Subject		
18/02/2015	Dr Ahmad Ali – Director Urological Ward 4F Ipswich General Hospital	Confirmed		
17/03/2015	TBA	TBA		
21/04/2016	TBA	TBA		