

Asking the experts: 50 support group leaders talk about survivorship needs

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Men with prostate cancer have stepped up to provide support to their peers in the community, where the healthcare system is lagging behind. Support group leaders are dedicated volunteers with many years' experience in supporting prostate cancer survivors. A new Australian study has interviewed these experts to hear their priorities for prostate cancer survivorship care.

Support groups for prostate cancer

The Prostate Cancer Foundation of Australia (PCFA) was formed in the 1990s when many Australian support groups linked together. These support groups grew from a need for better support and information for men living with prostate cancer. These prostate cancer survivors wished to help their



peers, raise money for research and advocate for better care and awareness. From these grass-roots beginnings came PCFA's three pillars of Research, Awareness and Support. Prostate cancer support group members should therefore be a driving force in determining the priorities of survivorship care.

Australian prostate cancer support groups consist of people affected by prostate cancer. They may be long term survivors, men with advanced disease or those recently diagnosed. Partners and sometimes family members also attend. They meet on a regular basis to share practical advice, discuss shared experiences and learn more about the



disease and how to manage it. Many groups invite guest speakers such as nurses, doctors, nutritionists, social workers, physiotherapists and pharmacists to provide more information. Support groups also help raise awareness of prostate cancer in their local communities.

“PCFA Support Groups are a grass roots force – working with us hand-in-hand to drive change.” – Prof Jeff Dunn, CEO of PCFA.

The 50 voices study

A [new Australian study](#) has interviewed 50 support groups leaders. The aim of this project was to understand the experience of having prostate cancer and collect information for survivorship guidelines. The lead author of the study is Prof Jeff Dunn, CEO of PCFA.

The study consisted of one-off interviews with 50 support group leaders across Australia. The interviews were semi-structured, which means that open-ended questions were used to stimulate discussion.

The group who volunteered for this project live in cities and regional areas. They included support group leaders for gay and bisexual men, younger men and men with advanced prostate cancer. The average age of these support group leaders was over 71 years. 49 of the 50 people were men whereas one was a female partner of a man with prostate cancer. On average, they had led support groups for 5.9 years.

Examples of the questions used are:

- Define the experience of prostate cancer survivorship from your perspective as a support group leader.



- What are the key prostate cancer survivorship issues facing your support group members?
- What prostate cancer survivorship issues would you tell an audience of politicians, health professionals and everyday Australians to act on?

Analysis of these interviews identified categories and themes within the

discussions. Three themes characterised the perceptions of prostate cancer survivorship.

Theme 1: Experience of diagnosis and treatment

The support group leaders talked about specific challenges associated with diagnosis and treatment. Prostate cancer diagnosis had significant physical, psychological and social effects. Ongoing challenges include coping with multiple side effects from treatments, distress, depression and other psychological challenges, as well as feelings of social isolation.

Prostate cancer treatment affected the ability of men to earn an income. Together with costly treatments this often led to financial pressure.

Men struggled with feelings of lost masculinity, loss of identity and loss of control. Further issues related to treatment and diagnosis include a lack of information on how to manage their problems arising from the cancer and its treatments. They felt lost within the healthcare system and like “just another number”. This made it difficult to make choice between treatments and led to a desire for consistent care, regaining of self and dignity. Many survivors felt like they were in a “forgotten” group.

Theme 2: Survivorship priorities

From the results of this study, 4 priorities for prostate cancer survivorship were identified:

1) *Delivering person-centred and man-centred care*

Men with prostate cancer needed better discussion and education about their treatment options and the associated side effects. They called for a “full explanation” of the treatments and side effects available to them. Patients also wanted support from the healthcare system to be tailored to their own needs and preferences.

2) *Improving communication by health professionals*

Improved communication was needed due to the shock of diagnosis. At this time, men suffered emotional distress, information overload and insufficient time between being informed of their options and needing to choose between treatments. They needed to research and make this choice while still processing a major life event.

3) *Improving access to care*

Support groups leaders wanted improved access to care such as increased availability of allied health services, social workers and psychological care. This was a particular need for regional areas.

4) *Improving care coordination*

Survivors need care coordination such as a survivorship care plan, continual education on treatment options, referrals to a range of health services and use of care coordinators.





Theme 3: Support mechanisms

Numerous forms of support were identified for improving the experiences of diagnosis and treatment. These included:

Peer support such as support groups. Men are able to share and receive ideas and practical advice about living with prostate cancer.

Advocacy to improve care for men living with prostate cancer. This advocacy should support the proactivity of men in looking after their health, improving their health literacy engaging the healthcare system and support services. Support group leaders also cited the need for workplace health promotion programs to reduce the stigma of talking about issues of men's reproductive health.

Prostate Cancer Specialist Nurses were seen as important care coordinators who could link men to community-based care and support.

Communication training for health professionals was called for to improve their skills in helping men with prostate cancer. Clearer communication was also needed around PSA testing and the pros and cons of treatment options.

Conclusions

Speaking about this study, Prof Dunn says “contrary to the traditional view that men are passive about health, our research found many men impacted by prostate cancer are clear about the challenges they face and what is needed to address them. They want a role in policy making to improve diagnosis and care, and we need to enable that in order to meet their needs and improve survivorship outcomes.”

The experience of having prostate cancer often leaves men with feelings of loss and of being disinherited by the healthcare system. There are gaps in health services in Australia that increase the challenges of prostate cancer survivorship. Through their experience supporting their peers, support group leaders identified survivorship priorities: man-centred care, improving healthcare communication, improving access to care and coordination of care.



You might like to read about the implications of this study in a [recent media article](#).

If you are interested in joining a support group, you can find more details from [PCFA's website](#). You can find support groups in your local area using our [support group search tool](#).