

# Prostate cancer survivorship of Australian men living with prostate cancer: Patient support programs in Australia

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## Background

Treatment for prostate cancer (PC) is associated with adverse effects, especially in patients receiving androgen deprivation therapy (ADT). The Australian Government, non-governmental organisations and pharmaceutical companies responsible for marketing ADT have initiated and sponsored various strategic support programs for patients diagnosed with PC.

## Objective

This professional article provides an overview of available PC patient support programs in Australia to assist general practitioners (GPs) to direct patient referrals and optimise clinical care.

## Discussion

These PC support programs provide useful assistance on educational materials, decision support, clinical care management and referral to specialised services (eg continence advice, sexual health counselling and psychological support). More concerted efforts and smarter investment in PC survivorship programs are necessary to engage, educate and improve the lives of men living with PC more effectively.

**PROSTATE CANCER** (PC) is the most diagnosed cancer among Australian men<sup>1</sup> and androgen deprivation therapy (ADT) remains a standard of care for locally advanced and metastatic diseases.<sup>2</sup> Although ADT has been shown to improve PC-specific survival and minimise direct PC-related complications,<sup>3,4</sup> it is not without adverse effects such as physical, cardiometabolic and psychosexual dysfunctions.<sup>5</sup> These ADT adverse effects, coupled with known complications related to surgery or radiation therapy, pose unique challenges, and there is a need to improve the health and wellbeing of patients living with and beyond PC.<sup>6</sup> Hence, there is an increasing emphasis on addressing these short-term and long-term unmet needs of men with PC and improving the quality of life of men on ADT as part of PC survivorship programs.<sup>7</sup>

Patient support programs were defined as any form of support or intervention program aimed to improve and address adverse effects related to PC treatment. The Australian Government Department of Health and other non-governmental organisations have provided numerous strategic support programs for PC patients over the years. Similarly, various pharmaceutical companies responsible for producing or marketing ADT have recognised the adverse impact of ADT on patients and have initiated and sponsored many patient support programs. Although these referrals are often driven by specialists rather than the general practitioner (GP) or patient themselves, GPs should be more proactive in directing patients to relevant supportive care interventions.

## Aim

This study aims to provide an overview of PC patient support programs available in Australia, with additional information on pharmaceutical companies' programs for those on ADT, and also assist GPs in providing appropriate referrals to optimise clinical care for Australian men living with PC.

## Prostate cancer survivorship programs

Available patient support programs on offer by the Australian Government, non-governmental organisations and pharmaceutical companies currently available for patients with PC were reviewed and summarised from various patient support PC websites and pharmaceutical companies (Table 1).

## Government and non-governmental organisation PC support programs

The Australian Government invests and provides significant monetary support for Australian men diagnosed with, affected by and/or who have received treatment for PC. The Cancer Council Australia undertakes and funds research into PC prevention, detection and treatment.<sup>8</sup> The Cancer Council Helpline is a free, confidential telephone information and support service run by Cancer Councils in each state and territory.

Through both the Australian Government and Cancer Council Australia, significant funding was given to the Prostate Cancer Foundation of Australia (PCFA) to provide national evidence-based information,

resources and psychosocial support for men and their families affected by PC ([www.pfca.org.au/support](http://www.pfca.org.au/support)).<sup>9</sup> The PCFA regularly promotes and implements various PC awareness and advocacy campaigns and education programs, such as specialist nurse programs, counselling services and MatesCONNECT<sup>10</sup> peer-to-peer support programs to improve PC care access and remove barriers to engagement, especially for those living in rural areas. The Continence Foundation of Australia promotes healthy bladder health in men with PC<sup>11</sup> and assists eligible men who develop urinary incontinence following PC treatments through the Continence Aids Payment Scheme (CAPS) program with the Australian Government to meet some of the cost of their continence products.<sup>12</sup> Similarly, non-governmental organisations such as the Men's Shed (<https://mensshed.org>), PROSTMATE ([www.prostmate.org.au](http://www.prostmate.org.au))

and Mensline (<https://mensline.org.au>) offer various physical, online and/or telephone personalised support and rehabilitation program systems that can be readily accessed by patients and their partners.

Individual states also provide unique services as part of the PC awareness and/or survivorship programs such as the Australian Cancer Survivorship Centre by the Victorian Government ([www.mycareplan.org.au](http://www.mycareplan.org.au)) and ManUp Australia (<https://manupaustalia.org.au>), which is predominantly for Queensland and New South Wales patients, to share knowledge, exchange experiences and create a better care plan for men living with PC. On the international level, True North, a global cancer program funded by Movember (<https://truenorth.movember.com/en-au>) delivers various online tools and educational resources, as well as research funds to improve care and support for men living with and beyond a diagnosis of PC.

### Pharmaceutical-driven PC support programs

Over the past decade, various pharmaceutical companies responsible for manufacturing or marketing ADT have recognised the adverse impact of ADT on patients and, in turn, have initiated and sponsored various patient support programs for patients receiving ADT in Australia. The current PC support programs provided by these ADT companies are delivered through either a web-based platform or a mixed-mode delivery via an external company (Table 1). Interested patients can also access various educational materials provided by these pharmaceutical companies regarding dietary recommendations, instructional exercise programs and clinical resources on various PC topics (Table 1). Several pharmaceutical companies provide structured exercise programs run by physiotherapists (AstraZeneca and Mundipharma; Table 1)

**Table 1. Summary of various patient support prostate cancer programs by the Australian Government, non-governmental organisations and pharmaceutical companies**

Organisation or company	Educational materials	Exercise program	Nurse support program	Sexual health counselling	Financial support	Website
Cancer Council Australia <sup>8</sup>	✓				✓	<a href="http://www.cancer.org.au/cancer-information/types-of-cancer/prostate-cancer">www.cancer.org.au/cancer-information/types-of-cancer/prostate-cancer</a>
Prostate Cancer Foundation of Australia <sup>9</sup>	✓		✓			<a href="http://www.pfca.org.au/support">www.pfca.org.au/support</a>
Continence Foundation of Australia <sup>11</sup>	✓				✓	<a href="http://www.continence.org.au/who-can-help">www.continence.org.au/who-can-help</a>
Men's Shed						<a href="https://mensshed.org">https://mensshed.org</a>
PROSTMATE						<a href="http://www.prostmate.org.au">www.prostmate.org.au</a>
Mensline						<a href="https://mensline.org.au">https://mensline.org.au</a>
ManUp Australia						<a href="https://manupaustalia.org.au">https://manupaustalia.org.au</a>
True North by Movember						<a href="https://truenorth.movember.com/en-au">https://truenorth.movember.com/en-au</a>
AstraZeneca	✓	✓	✓			<a href="https://z-extra.com.au">https://z-extra.com.au</a>
Abbvie	✓	✓	✓			<a href="http://www.themanplan.com.au">www.themanplan.com.au</a>
MundiPharma	✓	✓	✓	✓		<a href="https://eliplus.com.au/main/prescriber">https://eliplus.com.au/main/prescriber</a>
Ferring	✓	✓				<a href="http://www.feelplus.com.au">www.feelplus.com.au</a>
Astellas	✓	✓			✓	<a href="http://www.canceraid.com">www.canceraid.com</a>
Janssen	✓				✓	<a href="http://www.janssenpro.com.au">www.janssenpro.com.au</a>
Bayer	✓				✓	<a href="http://www.nubeqahcp.com">www.nubeqahcp.com</a>

or through physical education materials (Abbvie, Ferring Pharmaceuticals and Osara Health; Table 1).

Although psychosexual dysfunction is common following PC treatment, only one ADT company provides psychosexual counselling and an intimacy program to assist the patient and his partner.<sup>10</sup> The provision of a nurse injection service by many pharmaceutical companies is commendable, especially during the COVID-19 pandemic with disrupted healthcare service and improved patient access in rural areas (Table 1).<sup>13</sup> Unique web-enabled platforms, apps and community forums for technology-savvy patients have been designed to facilitate the delivery of the message and assist patients to understand and review their treatment plans (Table 1). Some pharmaceutical companies offer a financial subsidy scheme and compassionate access to alleviate some of the cost of their treatments for patients who cannot afford or are not eligible for the Pharmaceutical Benefits Scheme (PBS) or clinical trials (eg Janssen and Bayer; Table 1).

### Relevance of these PC support programs to GPs

PC survivors experience adverse impacts in physical, psychosocial and social domains, with many short-term and long-term unmet needs.<sup>13</sup> These PC support programs provide necessary assistance to patients in terms of information provision, decision support, clinical care management and referral to specialised services (eg continence advice, sexual health counselling and psychological support) where required. However, caution should be exercised, especially when many of these programs are not provided with adequate medical supervision and do not track the clinical response or positive benefits intended for men with PC.

Many PC patients experienced uncertainty, lack of information and poor communication with their medical team about the nature of diagnostic tests, the extent of treatment side effects and the likely progression of the disease.<sup>14,15</sup> Some of the uncertainty experienced by men reflected inherent problems in PC management, such as the uncertainty around disease progression.<sup>16</sup> These survivorship care interventions are relevant to men at all stages of disease and treatment plans. These sources of information

and the availability of various support programs empower patients to feel more in control of their disease and allow them to decide the timing for forthcoming interventions. These PC support groups afforded many patients the opportunities to interact with healthcare providers and other PC survivors. However, the provision of these PC support programs must be carefully managed in terms of their content and the timing of delivery to ensure ongoing commitment and high compliance rates.

Many of these PC support programs lack specific information on the exact number of patients who have subscribed, the actual compliance rate, as well as the perceived versus actual benefits of these programs. Some of the (perceived) barriers to the uptake of these support programs include awareness of programs, willingness to seek out and disclose information, embarrassment, preference for self-reliance and mental health literacy.<sup>17,18</sup> Strategies are required to enable a greater focus on addressing barriers associated with referral to, and uptake of, specific services such as psychological support and sexual counselling based on individual needs.<sup>18</sup> Moreover, survivorship interventions require care coordination strategies that underpin the intervention to manage the multiple service providers required to meet the needs of men, including maintaining a single point of contact and the use of shared assessment and care planning tools. Specific data relating to many of these PC support programs are not available due to privacy clauses and the potential 'competitive' nature of these programs. It would be useful, if full access is granted, to evaluate the validity, efficacy and cost-effectiveness of these programs. More consolidated and coordinated efforts by all stakeholders are desirable to enable risk stratification, tailoring of services to individual needs and optimisation rather than duplication of existing service capacity.

### Conclusion

Presently, there are numerous PC support programs including physical, psychological and sexual rehabilitation interventions for patients in Australia. More concerted efforts and smarter investment in PC survivorship programs are necessary to engage, educate and improve the lives of men living with PC in a more effective manner.

### Key points

- ADT use in men with PC is associated with adverse effects such as physical, cardiometabolic and psychosexual dysfunctions.
- The Australian Government, non-governmental organisations and pharmaceutical companies responsible for marketing ADT have initiated and sponsored various strategic support programs for patients with PC.
- Strategies are required to enable a greater focus on addressing barriers associated with referral to, and uptake of, specific services, such as psychological support and sexual counselling, based on individual needs.
- These PC support programs provide useful assistance, including educational materials, decision support, clinical care management and referral to specialised services.
- More concerted efforts and smarter investment in PC survivorship programs are necessary to engage, educate and improve the lives of men living with PC.

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