

A Psychosocial Care Model For Men With Prostate Cancer:

An Essential Element of the Prostate Cancer Survivorship Essentials Framework

Guide for Health Care Professionals



Endorsed by:







Our Vision, Mission and Values

Prostate Cancer Foundation of Australia (PCFA) is a community organisation and the peak national body for prostate cancer in Australia. We are dedicated to reducing the impact of prostate cancer on Australian men, their partners and families, recognising the diversity of the Australian community.

We do this by:

- Promoting and funding world leading, innovative research into prostate cancer
- Implementing awareness campaigns and education programs for the Australian community, health professionals and Government
- Supporting men and their families affected by prostate cancer, through evidence-based information and resources, support groups and Prostate Cancer Specialist Nurses

PCFA receives Government funding for specific projects and relies on the generosity of individuals, the community and partnerships to carry out our essential work.

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An Essential Element of the Prostate Cancer Survivorship Essentials Framework

Guide for Health Care Professionals

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Foreword

This monograph is a *Psychosocial Care Model for Men with Prostate Cancer* to guide health care professionals in delivering one of the critical **Evidence-based Survivorship Interventions** found within the *Prostate Cancer Survivorship Essentials Framework*¹ (Figure 1).

An expert clinical and community group developed the *Prostate Cancer Survivorship Essentials Framework*¹ to provide guidance to health professionals, health care and cancer control organisations, government and consumers about the essential domains for prostate cancer survivorship care. The framework has been endorsed by Cancer Council Australia, the Urological Society of Australia and New Zealand, the Royal Australian and New Zealand College of Radiologists, the Medical Oncology Group of Australia, the Australian and New Zealand Urogenital and Prostate Cancer Trials Group, the Prostate Cancer Foundation of New Zealand, Cancer Voices Australia, Healthy Male (Andrology Australia), Exercise and Sports Science Australia, St Vincent's Hospital Sydney and Universities involved in prostate cancer survivorship research^a. The framework outlines six survivorship essentials: **Personal Agency, Shared Management, Care Coordination, Health Promotion and Advocacy, Vigilance, and Evidence-based Survivorship Interventions**. The *Prostate Cancer Survivorship Essentials Framework*¹ is unique in that it places men firmly at the centre as active agents in their survivorship care (Appendix 1).

Although psychosocial care is now well accepted as integral to oncology care, to date, maintaining **Vigilance** by screening for distress, and referral to **Evidence-based Survivorship Interventions** to address psychosocial needs, has not yet been systematically implemented in prostate cancer care. To address this gap the Prostate Cancer

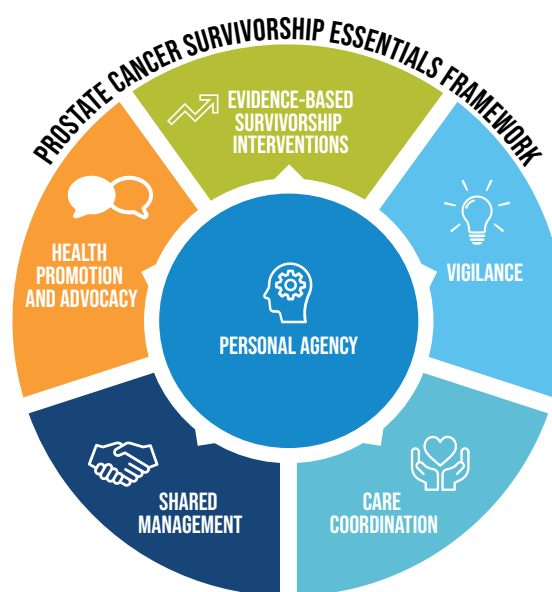


FIGURE 1: *Prostate Cancer Survivorship Essentials Framework*¹

Foundation of Australia developed the *Position Statement on Screening for Distress and Psychosocial Care for Men with Prostate Cancer* that has been endorsed by the Urological Society of Australia and New Zealand, the Australian and New Zealand Urogenital and Prostate Cancer Trials Group, the Australia and New Zealand Urological Nurses Society, the Royal Australian and New Zealand College of Radiologists, the Medical Oncology Group of Australia and the European Association of Urology Nurses and Australian Universities currently working in prostate cancer survivorship research^b. The recommendations within this statement are listed here and the statement in its entirety is included in Appendix 2.

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^b University of Technology Sydney, University of Southern Queensland, Edith Cowan University, Griffith University, Deakin University



Position Statement Recommendations

1. After the diagnosis of prostate cancer and regularly through treatment and surveillance men who have been diagnosed with prostate cancer should be screened for distress and their psychological and quality of life concerns should be explored
2. Men who have high levels of distress should be further evaluated for anxiety and/or depression and evidence of suicidality
3. Men who have high distress or need for support should be referred to evidence-based intervention matched to their individual needs and preferences for support
4. Research is needed to develop effective methods to identify partners of men with prostate cancer with high distress or who are at risk of high distress as well as effective interventions for partners and for couples where the man has a diagnosis of prostate cancer
5. Investment in prostate cancer survivorship research is a national health priority

To support this position statement we have worked with experts in prostate cancer care to produce this monograph, a *Psychosocial Care Model for Men with Prostate Cancer*. The purpose is to guide health care professionals to an optimal approach in delivering psychosocial care for men affected by prostate cancer. The proposed approach is multi-disciplinary including psycho-oncology, health psychology, nursing, sociology, exercise physiology, urology; and is evidence-based and underpinned by best practice where clear evidence is not available.

It is envisaged that health care professionals' delivery of a *Psychosocial Care Model for Men with Prostate Cancer* be framed by the broader *Prostate Cancer Survivorship Essentials Framework*¹. Ensuring an optimal approach to delivering psychosocial care for men affected by prostate cancer is a key way for health care professionals to address the survivorship needs of these men now and into the future.

Professor Jeff Dunn AO

Chief of Mission and Head of Research
Prostate Cancer Foundation of Australia

Prostate Cancer Survivorship Essentials Framework

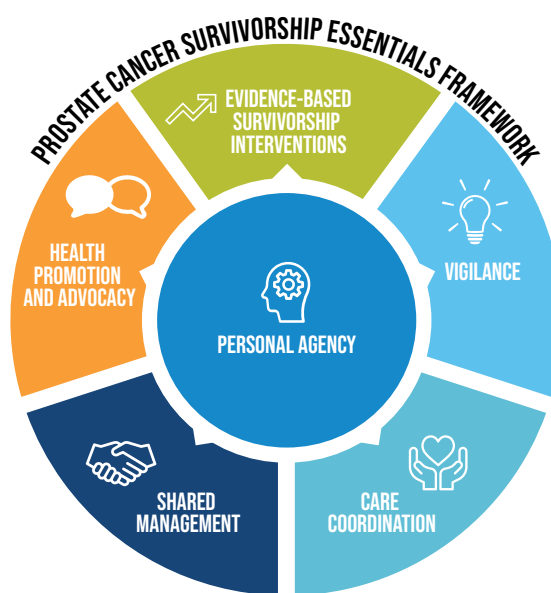
Prostate cancer is the most prevalent male cancer in the world, excluding non-melanoma skin cancer.

In Australia, there are now over 230,000 men living with a diagnosis of prostate cancer. Prostate cancer survivorship care encompasses the health and well-being of men from the point of diagnosis and is essential to cancer care. Survivorship care recognises the physical, psychosocial, spiritual and economic impacts of cancer, which can be long-lasting, and addresses these so that the patient can achieve optimal quality of life. The *Prostate Cancer Survivorship Essentials Framework*¹ places the man and his family at the centre of care.

In 2020, a multi-disciplinary expert panel from clinical and community groups was brought together to better understand the nature of prostate cancer survivorship in the Australian context. After a three-round policy Delphi process, the panel reached a consensus view that the experience remains a challenging one, and must be addressed through integrated quality care. A significant program of work undertaken over the last 15 years to improve prostate cancer survivorship care preceded the Delphi study²⁻²⁴. The cumulative conclusion of this work was the need for a prostate cancer specific essentials framework, a policy Delphi²⁵ was chosen as the optimal method to achieve this goal.

The expert panel identified six key descriptors for men's current prostate cancer survivorship experience: dealing with side-effects; challenging; medically focused; uncoordinated; unmet needs; and anxious. The panel then developed six essential domains for prostate cancer survivorship care to provide guidance to health professionals, health care and cancer control organisations, government and

consumers on what is required to improve the survivorship experience for men and their families. The *Prostate Cancer Survivorship Essentials Framework*¹ has since been endorsed by leading national and international groups involved in prostate cancer survivorship care: the Urological Society of Australia and New Zealand, the Royal Australian and New Zealand College of Radiologists, the Medical Oncology Group of Australia, the Australian and New Zealand Urogenital and Prostate Cancer Trials Group, the Prostate Cancer Foundation of New Zealand, Cancer Council Australia, Cancer Voices Australia, Healthy Male (Andrology Australia), Exercise and Sports Science Australia, St Vincent's Hospital Sydney, University of Technology Sydney, Australian Catholic University, University of Southern Queensland, Edith Cowan University, Griffith University, and the University of British Columbia.





Personal Agency where patients are self-aware in assessing their needs, seeking assistance when required, and building resilience to manage their own health where possible¹.

Personal Agency is important to a patient's ability to understand risk factors and take steps to promote personal well-being, as such, a focus on Personal Agency is central to improving survivorship outcomes. Health professionals, family members and wider social support networks play a role in building Personal Agency and supporting patients to achieve objectives¹.

What can I do? Recognise your patients as active agents in their survivorship care. In partnership, assist patients in building their personal resilience, in managing their own health and with mastery in navigating the health care system. Providing information across the spectrum of survivorship care tailored to the health literacy levels of individual patients will help increase your patients' knowledge base and enable Personal Agency. Seek professional development opportunities to continue to build your skills in supporting the Personal Agency of your patients.



Shared Management between patients and health care professionals to improve outcomes and ensure quality survivorship care with shared and informed decision making about all aspects of care¹.

Once a diagnosis of prostate cancer has been made, Shared Management between patients and health care professionals is required to improve outcomes and ensure quality survivorship care. Developing models of Shared Management to facilitate informed decision making around testing and treatment as well as addressing physical and psychosocial effects, comorbidities, advanced cancer symptoms, and palliative care is a priority. Shared Management extends to respecting a patient's wishes to engage in decision making around care to the extent they prefer. Once shared and informed management decisions are made by patients and health care professionals, these decisions should be supported by effective Care Coordination, with primary care providers and Prostate Cancer Specialist Nurses playing a central role as navigators¹.

What can I do? Use decision aids to assist both you and your patients to come to shared and informed decisions on their survivorship care. Decision aids can help to facilitate patient understanding of treatment options and side-effects, associated financial costs, and assist in the delivery of consistent information. Where required, provide clear explanation to your patients that palliative care not only relates to end-of-life issues but also the prevention and control of symptoms earlier in the survivorship journey. Acknowledge the role family members and carers play in Shared Management for some patients and support their active involvement.



Care Coordination where patients and families arrive at the right place at the right time for the right care once a diagnosis has been made. Men-centred care is central¹.

Care Coordination in consultation with patients and families is critical to survivorship outcomes. Clinical teams, primary care clinicians, nurses and allied health professionals as well as community based health and welfare services should all be active participants in Care Coordination. This requires systems to support the sharing of relevant patient information between health care teams. Specific consideration of access issues to Care Coordination for men living in rural and remote areas and men from culturally and linguistically diverse backgrounds is required¹.

What can I do? Underlying Care Coordination is men-centred care. Maintain a focus on delivering men-centred care when developing plans to meet the needs of individual patients in collaboration with other members of their health care team. This includes approaching care in a men-centred way, acknowledging that men-centred care is deeply contextual and dynamic but includes a consideration of how health care services for men intersect with masculinity and with men's preferences for the design and delivery of prostate cancer survivorship care. See Appendix 3 for an example survivorship essentials care plan. Where required, you should facilitate referral to community based peer support groups (for information on support groups see Other Resources). Information on life course and masculinity, and health literacy, is included in this monograph (see pages 24-25).



Health Promotion and Advocacy through the provision of up-to-date information to increase the community's knowledge of men's health and prostate cancer and support awareness and advocacy¹.

Health Promotion and Advocacy is central to the early detection of prostate cancer and survivorship care after diagnosis and treatment by raising community awareness and maintaining a public focus on men's health. Key to this domain is the provision of up-to-date information to increase the Australian community's knowledge of men's health and prostate cancer. It is important that up-to-date information is evidence-based, provides consistent messaging around prostate cancer, and is tailored taking into account varying levels of health literacy and preferences for different mediums. Information should also be targeted specifically to primary care providers and community workers¹.

Advocacy is required from the non-government sector for the effective promotion of men's health to government and to health service providers and to engaging community support. Advocacy is also required to bring attention to the support needs of survivors and their families, including advocating for programs around peer support and self-management. This involves facilitating public access to up-to-date information, the provision of evidence-based interventions and improving access to survivorship care for all men and their families, including those living in rural and remote areas, LGBTQIA+ people, Indigenous people, and people from culturally and linguistically diverse backgrounds¹.

What can I do? Seek professional development opportunities for training in men's health promotion to continue to develop your skills in working effectively with men. Advocate for the importance of men's health and prostate cancer survivorship issues by raising awareness of the *Prostate Cancer Survivorship Essentials Framework*¹ among your colleagues and wider networks.



Vigilance across the survivorship continuum from diagnosis to end-of-life care with attentive surveillance of physical and psychosocial effects, comorbidities, recurrence and second cancers. This includes psychosocial effects on partners and family members¹.

Vigilance in relation to clinical surveillance of patients is critical to prostate cancer survivorship. Vigilance includes health care professionals taking action on the outcomes of clinical surveillance as required¹.

What can I do? Tailor your level of Vigilance to the changing needs of your patients through screening for physical and psychosocial effects, comorbidities, recurrence and second cancers, early on and then systematically over their survivorship journeys. When required, act on the outcomes of clinical surveillance. Take into account additional sources of information when evaluating patients, including observations from partners and other family members. It is also important to be aware of the potential psychosocial effects of prostate cancer on the partners and family members of your patients, and include them in your routine clinical surveillance where required.



Evidence-based Survivorship Interventions for accessible psychosocial and psychosexual care, exercise and physical activity, nutrition, peer support, financial assistance, and specialist nursing interventions¹.

Accessible Evidence-based Survivorship Interventions are essential in ensuring patients receive the best possible support for their health and well-being. Psychosocial care interventions to maintain intimate relationships that include sexual health support tailored to individual men including those in different age groups and from LGBTQIA+ backgrounds are important¹.

What can I do? High quality evidence now exists for a range of acceptable and effective Evidence-based Survivorship Interventions that improve the survivorship outcomes of men with prostate cancer. A summary of evidence-based psychosocial and psychosexual care, and exercise and physical activity, survivorship interventions is provided in the *Psychosocial Care Model for Men with Prostate Cancer* (see pages 18-23). Where required, you should refer your patients to relevant Evidence-based Survivorship Interventions that are matched to their individual needs and preferences for support.

Delivering a Psychosocial Care Model for Men with Prostate Cancer within the *Prostate Cancer Survivorship Essentials Framework*

The *Prostate Cancer Survivorship Essentials Framework*¹ provides a guide for health care professionals in how to frame their practice around addressing the survivorship needs of men with prostate cancer and their families. Prioritising **Personal Agency** in survivorship care is essential in improving survivorship outcomes. Ensuring an optimal approach to delivering psychosocial care for men affected by prostate cancer through **Vigilance** and referral to **Evidence-based Survivorship Interventions** is an area of survivorship care in particular need of addressing. Developing services to meet the psychosocial needs of men with prostate cancer requires a focus on **Personal Agency, Shared Management** and delivery of men-centred **Care Coordination**. The following sections of this monograph detail a *Psychosocial Care Model for Men with Prostate Cancer*, a guide for what health care professionals can do to address the psychosocial needs of men within the framework.

A Psychosocial Care Model for Men with Prostate Cancer

Maintaining **Vigilance** through routine screening of men for distress, and referral to **Evidence-based Survivorship Interventions** to address psychosocial needs where required, are essential to optimal cancer survivorship care.

Psychosocial care is now well accepted as integral to oncology care. The International Standard of Quality Cancer Care developed by the International Psycho-Oncology Society states that quality cancer care must integrate the psychosocial domain into routine care and that distress should be measured as the 6th Vital Sign after temperature, blood pressure, pulse, respiration and pain⁵. Several countries have developed clinical practice guidelines and standards to guide such care in adults with cancer²⁶⁻³⁰. However, to date, maintaining **Vigilance** through screening for distress and referral to **Evidence-based Survivorship Interventions** for psychosocial care has not been systematically implemented in prostate cancer care.

We have worked with experts in prostate cancer care to produce a *Psychosocial Care Model for Men with Prostate Cancer*. The following sections summarise research about men's psychological responses to prostate cancer; the importance of maintaining **Vigilance** by screening for distress; the influence of life course and masculinities on the **Personal Agency** of men and their help-seeking behaviours; and current evidence about **Evidence-based Survivorship Interventions** to improve mental well-being in men with prostate cancer. Recent resources have been developed discussing the needs and concerns of gay and bisexual men with prostate cancer^{31,32}. While this monograph focuses on men with prostate cancer, it is acknowledged that the partners of men with prostate cancer often experience high

psychological distress and should also be provided with targeted and gender-sensitive supports.

It is envisaged that health care professionals operationalise **Personal Agency, Shared Management** and **Care Coordination** by applying the *Psychosocial Care Model for Men with Prostate Cancer* as a practical guide to developing a care plan in their setting that utilises local services and links to other services in the acute and community sectors. Each aspect of the *Psychosocial Care Model for Men with Prostate Cancer* should be considered within the broader *Prostate Cancer Survivorship Essentials Framework*¹.



Distress and Prostate Cancer

The Psychological Distress Associated with Prostate Cancer

The experience of diagnosis and treatment(s) of prostate cancer is for most men a major life stress. A cancer diagnosis represents a threat to a man's future, not only with regards to survival, but also in terms of physical wellness and bodily integrity; social, family and intimate relationships; lifestyle; and his financial and occupational security. While men often demonstrate great resilience to this experience, a substantive subgroup report high levels of psychological distress³³⁻³⁵ and many have high unmet psychological support needs³⁶⁻³⁸.

The prevalence estimates of psychological distress experienced by prostate cancer survivors vary due to differences in approaches to sampling and measurement¹³. However, studies report that 11-27% of prostate cancer survivors experience some form of psychological distress³³⁻³⁵. The prevalence of psychological distress remains relatively high across the treatment spectrum³³.

Specifically, 13-18% of prostate cancer survivors experience depression^{33,35,39}. Bill-Axelson and colleagues in an eight year longitudinal study reported that although extreme distress was not common in men with localised prostate cancer, 30-40% of men reported ongoing health-related distress, worry, feeling low, and insomnia⁴⁰. Compared with men in the general population, men with prostate cancer may be twice as likely to experience depression⁴¹. Anxiety is experienced by 14-27% of prostate cancer survivors^{33,35,41,42} and is present across the prostate cancer trajectory⁴². Compared with men in the general population, men with prostate cancer are three times more likely to experience anxiety⁴¹. A third of prostate cancer survivors also experience high fear of cancer recurrence which

is associated with high distress levels and increased post-traumatic stress symptoms⁴³. Factors that increase the likelihood a man will experience high distress levels include: younger age^{11,39,42-44}; lower education and income^{11,35,44}; comorbidities^{11,35}; un-partnered status¹¹; receiving adjuvant radiotherapy⁴³; and having locally advanced or metastatic prostate cancer¹¹. Poor sexual, urinary, and bowel function are associated with cancer-specific distress¹¹. Active surveillance (AS) patients experience higher anxiety compared with patients who are treated radically, with divorce a predictor of anxiety for AS patients⁴¹. For men who have undergone radical prostatectomy, anxiety is associated with psychological status, rising PSA levels, and shorter time since initial treatment, and remains a long-term prevalent concern⁴².

Compared with men in the general population, men with prostate cancer have a 70% higher risk of suicide⁴⁵. The risk of suicide is highest within the first year after diagnosis⁴⁵⁻⁴⁸, in particular in the first 6 months, and increases with severity of clinical stage at diagnosis^{40,46,49}. Within the first 6 months following diagnosis, men with metastatic disease have a 10-fold increase in suicide risk compared with a five-fold increase for men with low-risk disease⁴⁶. Suicidal ideation has also been found to be experienced by 12% of prostate cancer survivors and is significantly associated with hormonal symptoms⁵⁰. Prostate cancer survivors are at increased risk of suicide when they have non-localised disease⁴⁵; are residents in major cities⁴⁵; are unmarried and/or single⁴⁵; aged 75 years or older⁴⁸; when definitive treatment has been recommended but not received⁴⁷; and when treated with hormonal therapy⁴⁸. Suicidal ideation has been found to be associated with employment status and poor physical health (pain and disability status)⁵⁰.

Androgen deprivation therapy (ADT) may also affect neurocognitive function and mood in men with prostate cancer. Cognitive effects can include decrements in verbal memory, coding and inhibitory tasks, spatial reasoning and ability, and tasks that require complex information processing⁵¹⁻⁵³. Mood changes such as depressed mood, decreased energy and vigour, and increased irritability have also been reported in men treated with ADT⁵¹. Compared with other treatments, men treated with ADT also report diminished sexual function, hormonal function, and vitality⁵⁴. As such, recent research suggests that when possible, clinicians should minimise ADT use via intermittent ADT and/or reduced neoadjuvant courses, with the aim of preserving testosterone function through other treatment approaches⁵⁴.

Research over a significant period of time demonstrates that men with prostate cancer continue to have unmet supportive care needs^{36,37}. A study of men's help-seeking in the first year after diagnosis found 82% of men reported unmet supportive care needs relating to sexuality, psychological, and health system and information issues³⁸. The largest population based study to date on patient-reported outcomes in the United Kingdom recently found more than 80% of men reported poor or very poor sexual function across all disease stages; with more than half of these men identifying an unmet need for support interventions⁵⁴. Sexual dysfunction has been found to be of particular concern for men younger than 55 years compared with men aged 75 years and older⁵⁴. Clinical care for patients with advanced prostate cancer is an emerging area of research⁵⁵. Men with advanced prostate cancer report difficulties with access to informational support about the disease and treatment^{56,57}. Supportive care services for men with advanced prostate cancer should take into account the influence of life course, in terms of age and expression of masculinities, on their illness experience⁵⁶. The specific needs of gay and bisexual men with prostate cancer are discussed elsewhere⁵⁸.

High early distress is a predictor of later ongoing high distress⁴⁰. Hence, maintaining **Vigilance** in detecting raised distress early on is a priority.

Screening for Distress in Men with Prostate Cancer

It is now well accepted that maintaining **Vigilance** through screening for psychological distress is a key component of good cancer care^{5,59}. Screening for distress allows for the efficient identification of patients who require more in-depth psychological intervention in order to ameliorate current distress and prevent ongoing later distress. Distress has been defined as:

a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis⁶⁰.

The single item Distress Thermometer presents as a scale that does not incur a cost; and is brief and simple to administer and score, making it ideal for use in practice settings⁶¹. The Distress Thermometer asks patients how distressed they feel on an eleven-point scale, ranging from 0 (no distress) to 10 (extreme distress). The scale has been well validated across cancer sites worldwide, in acute and community settings⁶²⁻⁷⁰, and more recently in prostate cancer populations⁶.

Specifically, Chambers and colleagues in a study with three large prostate cancer patient cohorts, including both cross-sectional and prospective cohorts found the Distress Thermometer to be a valid tool to detect cancer-specific distress, anxiety and depression among prostate cancer patients, particularly close to diagnosis. A cut-off of ≥ 4 was suggested as optimal soon after diagnosis and for longer term assessments ≥ 3 was supported⁶. See Appendix 4 for the prostate cancer-specific version of the Distress



Thermometer based on the associated validation data⁶. The problem checklist as part of the Distress Screen helps men and health care providers to identify what type of intervention might best match the key challenges being faced and the drivers of that distress.

Screening for distress should commence early in the prostate cancer experience and be undertaken at regular intervals over the illness trajectory to monitor the man's emotional wellbeing, as the adjustment will not be linear for many men¹¹. Screening for distress must be accompanied by a process of evaluation if a patient scores ≥ 4 followed by referral to appropriate evidence-based psychosocial care services in order to be effective in meeting support needs^{13,71}.

The current evidence for depression and anxiety screening for cancer patients does not preference any one tool as physical symptoms associated with cancer and/or treatment can also be symptoms of depression and anxiety (for example: appetite loss, fatigue, sleep disturbance)⁷². This can make it difficult to determine normal adjustment and distress from psychological symptoms that require treatment. It is therefore recommended that the patient's responses on the Distress Thermometer are cross referenced with a depression and anxiety tool to ensure that cancer related physical symptoms do not influence an overestimation of depression or anxiety. The most commonly used depression screening tools will contain questions about suicide. It is recommended that responses to these specific questions are always reviewed and followed up as soon as the questionnaire is completed. In situations where the man discloses thoughts or plans about suicide, immediate referral⁷³ to the man's general practitioner, community mental health service or the local hospital's emergency department is required⁷⁴. Refer to the Resources Section for resources on suicide.

Distress in Partners

A review of the psychological adjustment of female partners of men with prostate cancer concluded that partners report more distress than do the men themselves⁷⁵. In a study of the partners of men with both localised and metastatic prostate cancer, partners had twice the rate of major depression and generalised anxiety disorders compared with their community counterparts, with distress lessening after six months⁷⁶. An Australian study found that the female partners of men with localised prostate cancer had overall low distress; however women were more anxious than patients with 36% reporting mild to severe anxiety⁷⁷. For these women, the man's psychological distress and his sexual bother were most strongly related to her mental health status with higher social intimacy most strongly associated with physical quality of life. In essence, how a man adjusts to his prostate cancer influences his female partner's outcomes.

Validity of the Distress Thermometer has recently been tested in female partners of men with prostate cancer⁷⁸. The diagnostic accuracy of the Distress Thermometer in female partners was found to be inconsistent such that currently it is not possible to recommend use of the Distress Thermometer in female partners⁷⁸. The optimal approach for detecting distress in partners remains unclear and there is a need for more comprehensive screening measures which incorporate partner-specific issues⁷⁸.

An updated systematic review of psychological interventions for prostate cancer survivors and their partners found insufficient evidence of effective and acceptable interventions for female partners and couples, highlighting that this also remains an area of uncertainty¹⁰. Male partners of men with prostate cancer will have different experiences and concerns and this is an area of ongoing research⁵⁸. The supportive care needs of partners of men living with advanced disease may change accordingly overtime.

Additional areas of concern may contribute to their distress that would be well captured by using the Needs Assessment Tool: Progressive Disease (NAT: PD)⁷⁹. The NAT: PD facilitates communication between primary and specialist care providers about the needs of patients and their caregivers and how to best address them.

Vigilance



Key Points about Distress and Prostate Cancer

The diagnosis of prostate cancer is a distressing experience for most men and their partners and families.

- Up to one in five men with prostate cancer may experience high psychological distress such as anxiety, depression or cancer-specific distress (trauma like symptoms)
- The most common unmet supportive care needs for men with prostate cancer are fears about the cancer returning or spreading, uncertainty about the future, worry about close family, health system and information needs, and support interventions for sexual dysfunction
- Men with prostate cancer have an increased risk of suicide
- Risk factors for higher distress include: younger age at diagnosis; lower education and income; advanced stage disease; comorbidities; un-partnered status; and receiving adjuvant radiotherapy
- In the context of men with advanced disease, in-depth assessment of the spectrum of needs for both patients and partners should be considered
- Maintaining **Vigilance** through screening for distress is effective in detecting increased anxiety, depression and cancer-specific distress in men with prostate cancer with referral to appropriate evidence-based psychosocial care services the next step



Psychosocial Care

Psychosocial Interventions for Men with Prostate Cancer

Multi-modal psychosocial and psychosexual interventions are **Evidence-based Survivorship Interventions** that are acceptable for men with prostate cancer and effective in improving survivorship outcomes^{10,13,14}. Recent research has found that these interventions can reduce decision-related stress, depression and anxiety, and improve mental health, domain-specific, and health-related quality of life^{10,14}. Elements of effective interventions include combinations of educational, cognitive-behavioural, decision support, relaxation training, communication skills training, tailored supportive care, and peer support^{10,13,14}. There is a lack of research on interventions addressing the key domains of surveillance and cancer care coordination, further work in this area is required¹⁴.

A recent systematic review of psychosocial interventions for men with prostate cancer and their partners concluded group cognitive-behavioural and psycho-educational interventions were helpful in promoting psychological adjustment and quality of life for men with prostate cancer, but that the evidence is less clear for their partners and couples as a dyadic unit¹⁰.

Mental health: Specifically, a combined web-based psycho-educational intervention and moderated peer forum⁸⁰, and a Qigong intervention⁸¹, improved psychosocial distress. Cancer-specific distress was reduced, and mental well-being improved, in newly diagnosed young, well-educated men with localised prostate cancer who received a tele-based nurse-delivered five-session psycho-educational intervention⁴⁴. A group nurse-led psycho-educational intervention consisting of four group consultations and one individual

consultation⁸², and a ten-week web-based group cognitive-behavioural stress management intervention⁸³ reduced depression. Another group cognitive-behavioural stress management intervention improved emotional well-being⁸⁴. An eight-week tele-health education intervention improved depression, negative affect, stress, and spiritual well-being for prostate cancer survivors⁸⁵. In this intervention group, men had more favourable depression outcomes if they were older, had lower prostate specific functioning, were in active chemotherapy, had lower social support and cancer knowledge⁸⁶. An eight-session group-based multi-disciplinary tailored behavioural program improved mental well-being, in the short term, for men with biochemical recurrence; with longer term positive effects for prostate cancer-specific anxiety⁸⁷.

Quality of life: In one study, men who attended ten weekly group meetings with cognitive-behavioural stress management and relaxation training experienced a significant improvement in physical and emotional quality of life and benefit finding when compared with men who received a single stress management seminar⁸⁸⁻⁹⁰.

Fatigue: A twelve-week trial of Qigong⁸¹ and an eight-week telephone delivered health education intervention⁸⁵ both improved fatigue.

Sexuality: A web-based psycho-educational intervention, 'My Road Ahead', combined with a moderated peer-support forum for men with localised prostate cancer improved sexual satisfaction through increases in sexual function, masculine self-esteem and sexual confidence⁹¹. Men with localised prostate cancer who had undergone a prostatectomy experienced significant improvements in sexual confidence, sexual intimacy, masculine self-esteem, and satisfaction with orgasm in an eight-week



cognitive-behavioural group intervention⁹². Prostate cancer nurse-delivered and peer-delivered telephone counselling interventions for men who had prostatectomy increased their use of medical treatments for erectile dysfunction⁹³.

Decision making: A web-based tailored decision support program for newly diagnosed men with localised prostate cancer reduced uncertainty for treatment decision making⁹⁴. A decision aid in the form of a patient booklet was found to decrease decisional conflict⁹⁵, and a decision navigation intervention reduced regret and increased decisional self-efficacy⁹⁶. Confidence in treatment choice was increased for patients involved in an online interactive education intervention to enhance treatment decision making⁹⁷.

Effective mechanisms for intervention delivery and sources of support include face-to-face and remote communication with therapists, nurses, and peer support¹³. A systematic review of the experiences of men with prostate cancer found men value the care received from cancer specialist nurses in terms of the approach to communication and their ability to act as advocates across the prostate cancer experience⁹⁸. Peer support is also an acceptable support method for men^{10,98}. Peer support is based on the sharing of personal mutual experience and has been widely developed in Europe, North America, and Australia in the context of prostate cancer. Men with prostate cancer have reported that peer support helps by providing a source of useful information and advice about their cancer; helping them understand their cancer better and to feel less alone and more in control of their life; providing the opportunity to talk about their concerns; and helping reduce feelings of self-blame⁹⁹. Men with prostate cancer have described a

preference for having access to peer support as close as possible to the time of diagnosis.

Long-term survivorship care needs to be responsive and targeted to the clinical, psychosocial, sociodemographic, and cultural circumstances of men with prostate cancer as these factors moderate intervention effects¹³. Care plans should actively take the specific life circumstances of individual patients into account and be tailored to all stages of a patient's prostate cancer experience^{13,14,98}. There is increasing recognition of the need to better understand the needs of patients from minority ethnic backgrounds, socio-economically disadvantaged backgrounds, those living in rural regions, and gay and bisexual men^{10,14,98}.

Evidence-based Survivorship Interventions



Key Points about Psychosocial Care for Men with Prostate Cancer

A range of multi-modal approaches appear to have efficacy for improving psychological outcomes for men with prostate cancer and these include combinations of:

- Psycho-education
- Cognitive-behavioural therapy
- Health education and decision support
- Stress management and relaxation training
- Communication skills training
- Peer support
- Multi-modal (aerobic/resistance) moderate- to high-intensity exercise

Care should be tailored to the specific needs of the individual man when implementing **Evidence-based Survivorship Interventions** to provide psychosocial care.





Exercise Medicine

Exercise Interventions for Men with Prostate Cancer

Men with prostate cancer experience wide-ranging acute and persistent toxicities that have implications for reduced physical function, cardiovascular and metabolic complications, compromised musculoskeletal health and quality of life¹⁰⁰. Exercise medicine has emerged as an important **Evidence-based Survivorship Intervention** to preserve function and ameliorate or reverse a range of treatment-related adverse effects in men with prostate cancer during and after treatment¹⁰¹. In addition, evidence from epidemiological studies has shown that higher levels of physical activity post cancer diagnosis are associated with increased cancer-specific and overall survival including men with prostate cancer¹⁰²⁻¹⁰⁴. Exercise prescription needs to be personalised for individual patients, to ensure greatest benefit (as defined by the patient) in the short and longer term, with low risk of harm²⁰.

Mental health: Physically inactive men with prostate cancer experience higher global distress and anxiety than those who are physically active⁷. In non-prostate cancer populations, exercise has been shown to have a significant antidepressant effect in people with depression,¹⁰⁵ and in those with other chronic conditions¹⁰⁶. Recently, exercise interventions that included specifically resistance-based exercise have been shown to reduce depressive symptoms in adults¹⁰⁷. Specifically, in men with prostate cancer, a recent year-long study reported that various supervised exercise modes (aerobic, resistance and impact loading) were effective in reducing symptoms of psychological

distress in men with prostate cancer undergoing androgen deprivation therapy (ADT)¹⁰⁸. Importantly, men with the highest level of psychological distress improved the most. In addition, a 6-month supervised, group-based, resistance and aerobic exercise intervention involving men previously treated with androgen suppression and radiation led to a significant improvement in mental health¹⁰⁹. In a recent systematic review and meta-analysis on exercise and prostate cancer patient-reported outcomes, exercise mitigated symptoms of depression and anxiety¹¹⁰.

The quality and quantity of the exercise prescription and level of supervision have been observed to impact the degree of improvement in mental well-being in a dose-response fashion¹¹¹⁻¹¹³. Involvement in a group-based exercise program, especially amongst other men with prostate cancer, appears to be another important factor^{109,112,114}. Although further investigation is required, exercise-induced physiological effects such as alterations to hormones (e.g. endorphin and monoamine levels), corticosteroids, pro-inflammatory cytokines, growth factors (including brain-derived neurotrophic factor) and neurogenesis have been suggested to impact mood and cognitive function and thus may contribute to exercise-induced improvement in mental health¹¹⁵⁻¹¹⁸.

Quality of life: Numerous studies have shown improvements in quality of life following exercise training^{14,119}. For example, in a randomised controlled trial (RCT) of 155 men with prostate cancer undertaking or scheduled to receive ADT, resistance exercise led to improvements in health-related quality of life compared to

controls¹²⁰. Galvão and colleagues reported the effects of a 12-week multi-modal (resistance and aerobic exercise) program versus usual care in men undertaking ADT for prostate cancer with several aspects of quality of life including general health enhanced in the exercise group compared to controls⁴. In a recent systematic review and meta-analysis of 18 trials involving 1,112 men with prostate cancer, resistance training exercise programs resulted in significant improvements in quality of life¹¹⁰.

Fatigue: There is consistent evidence to suggest that exercise is effective at ameliorating cancer-related fatigue¹²¹. For example, Taaffe and colleagues reported in a large year-long RCT with 163 prostate cancer patients that different exercise modes undertaken at moderate to high intensity had comparable effects on reducing fatigue during treatment¹². Moreover, it appears that the greatest effects of exercise on fatigue are in those with the greatest levels of fatigue at baseline^{12,122,123}. In a recent systematic review and meta-analysis, resistance training exercise programs resulted in a significant reduction in fatigue in men with prostate cancer¹¹⁰.

Sexual health: The effects of exercise on improving sexual and erectile function in men with prostate cancer has been inconsistent^{124,125}. Such findings could be attributed to differences in treatments and exercise protocols examined. However, a systematic review reported no effects of exercise on sexual function¹¹⁹. Additional research is required to clarify the effect of exercise on sexual health.

Physical function: Numerous studies have shown that exercise improves objective and self-reported physical function in men with prostate cancer. For example, improvements in functional performance (e.g. gait speed), balance and self-reported physical function have been reported in patients undergoing supervised multi-modal exercise compared to usual care⁴. Such changes were accompanied by improvements in muscle strength and lean mass⁴. Recently, men with advanced prostate cancer have been reported to preserve physical function following supervised exercise¹²⁶. In a

recent systematic review and meta-analysis with 21 trials and involving 1,748 men with prostate cancer, exercise improved functional capacity (chair rise, 400-m walk, 6-m fast walk, and stair climb tests), and fitness outcomes (cardiorespiratory and muscle strength)¹²⁷.

Body composition: Several studies have documented alterations in body composition in men receiving prostate cancer treatments (e.g. androgen deprivation). For example, Smith and colleagues reported a 9.4% increase in whole body fat and a 2.7% reduction in whole body lean mass following 48 weeks of therapy¹²⁸. Exercise studies reported gains in lean mass following combined resistance and aerobic training in men with prostate cancer undergoing androgen deprivation¹²⁹. In a recent systematic review and meta-analysis that evaluated the effects of resistance training exercise programs in men with prostate cancer, exercise reduced fat mass by -0.6 kg and increased lean mass by ~0.5 kg¹²⁷.

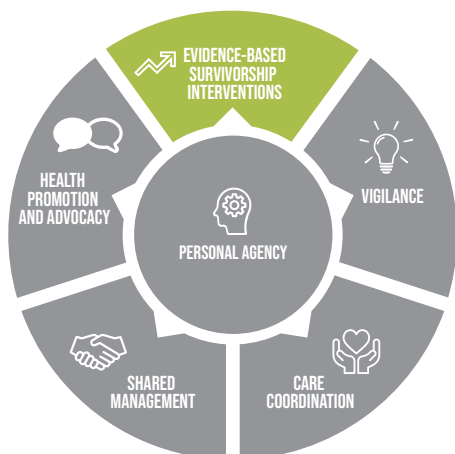
Bone health: Emerging studies indicate that exercise may attenuate the loss of bone mass in men with prostate cancer undergoing treatment¹³⁰⁻¹³². In a year-long trial, Newton and colleagues recently investigated the comparative efficacy of impact loading + resistance training, aerobic + resistance training, and delayed aerobic exercise on bone mineral density in 154 prostate cancer patients undergoing ADT¹³¹. Results of the trial revealed that impact + resistance exercise attenuated the decline in spine and hip bone mineral density compared to aerobic + resistance exercise and delayed aerobic exercise. Exercise specific to preserve bone mass in men with prostate cancer must be targeted and prescribed accordingly^{20,133}.

Evidence-based Survivorship Interventions



Key Points about Exercise Medicine

- Exercise medicine is an important **Evidence-based Survivorship Intervention** to preserve function, ameliorate treatment-related adverse effects and promote wellbeing in men with prostate cancer
- Exercise prescription needs to be personalised to ensure the greatest benefit in the short and longer term with low risk of harm. Specifically, the type, duration, frequency, intensity and total volume of exercise prescription needs to be tailored to the man's needs and priorities



Considerations in Developing Services

In developing services to meet the psychosocial needs of men with prostate cancer it is important to focus on supporting **Personal Agency, Shared Management** and delivery of men-centred **Care Coordination** by considering masculinity, health literacy, and the depth and focus of need through a tiered model of care. Research in this area is emergent, however these three factors speak to acceptability and access that are important for all cancer populations and, in particular, men. It is important to recognise that men and their family members are not passive recipients of support. They assert their **Personal Agency** through actively seeking out the channels and modes of support that suit them best. Ensuring a role for self-direction should therefore be a key element in the design of services.

Life Course and Masculinities

Consideration of life course and masculinities is essential to effectively supporting the **Personal Agency** of men to understand psychosocial risk factors and take steps to promote their psychosocial well-being. Men are typically low users of psychological support services for cancer and are less likely than women to discuss their psychosocial concerns with their health care providers¹³⁴. The lack of engagement with psychosocial support programs after prostate cancer has been described in connection to a conflict with the values that underpin masculine identities¹³⁵. Specifically, traditional masculine values such as being self-reliant; stoic in the face of difficulty; and emotionally restrained, are not conducive to help seeking. This is especially critical in a health context where male gender scripts are compromised by changes to erectile function; bodily function and appearance; and roles and relationships, as a result of the

diagnosis of prostate cancer and the morbidities associated with treatment¹³⁶⁻¹³⁸.

It has also been proposed that life course is important in considering how masculinity impacts men's health outcomes¹³⁹. A life course perspective encompasses the events of life that occur in different life domains across the life span. In this approach individual life courses intersect with the social historical contexts in which the man lives; the life courses of his family and friends; and the dynamics of the social groups in which the man belongs¹⁴⁰.

Evidence-based Survivorship Interventions for men with prostate cancer need to consider life course and masculinity if they are to be acceptable and effective for this patient population¹³⁹.

Health Literacy

In men with prostate cancer, educational level appears to be an important factor in influencing how they respond to psychosocial interventions^{44,86,141}; and low literacy has been found to be associated with low knowledge about prostate cancer¹⁴², underlying its importance to **Health Promotion and Advocacy** efforts. This also raises a consideration of health literacy when planning and delivering psychological care¹⁴³ to support **Personal Agency, Shared Management**, and men-centred **Care Coordination**. Targeting health literacy has been identified as a potentially important factor in addressing the high prevalence of anxiety experienced by men receiving Active Surveillance⁴¹. For men with newly diagnosed prostate cancer, low health literacy levels are associated with patients being more vulnerable to mental distress¹⁴⁴. The ability to effectively access and apply health-related



information and services requires reading, listening, analytical and decision-making skills. The 2006 Adult Literacy and Life Skills Survey found that 59% of Australian adults aged 15-74 years had health literacy levels below an adequate standard; with adequate health literacy negatively associated with age for Australian adults over 50 years¹⁴⁵. In New Zealand, on average, health literacy is also limited¹⁴⁶. Strategies to address low health literacy include: ensuring that communication is clear; focusing on key messages; checking that information has been understood; providing written resources to reinforce verbal discussion; encouraging questions; and ensuring services are easily and clearly accessible¹⁴⁷. For men who have low literacy, patient education likely needs to be tailored if it is to be effective¹⁴⁸.

The Health Literacy Questionnaire (HLQ) is a valid and reliable tool for measuring the health literacy of men with prostate cancer¹⁵. The HLQ is a comprehensive multidimensional measure of health literacy incorporating nine factors including feeling understood and supported by health care providers, having sufficient information to manage health, active health management, social support for health, appraisal of health information, ability to actively engage with health care providers, ability to navigate health care systems, ability to find good health information, and understanding of health information¹⁴⁹. For men with prostate cancer, health literacy skills which facilitate navigating health care systems and engaging health services and providers for support are associated with better mental health-related quality of life¹⁵. A recent study assessing health literacy among Canadian men with prostate cancer using the HLQ found that while they understood the information they had access to, they felt that they did not have all the information they

needed¹⁴¹. Seaton and colleagues identify support groups as a potential method to improve access to information and to foster men's health literacy¹⁴¹.

A Tiered Model of Psychosocial Care after Prostate Cancer

A tiered model of care is underpinned by the understanding that the needs of men and their families after prostate cancer are heterogeneous; vary over time; are influenced by life course, gender, and context; and that care should be individualised to the level of need.

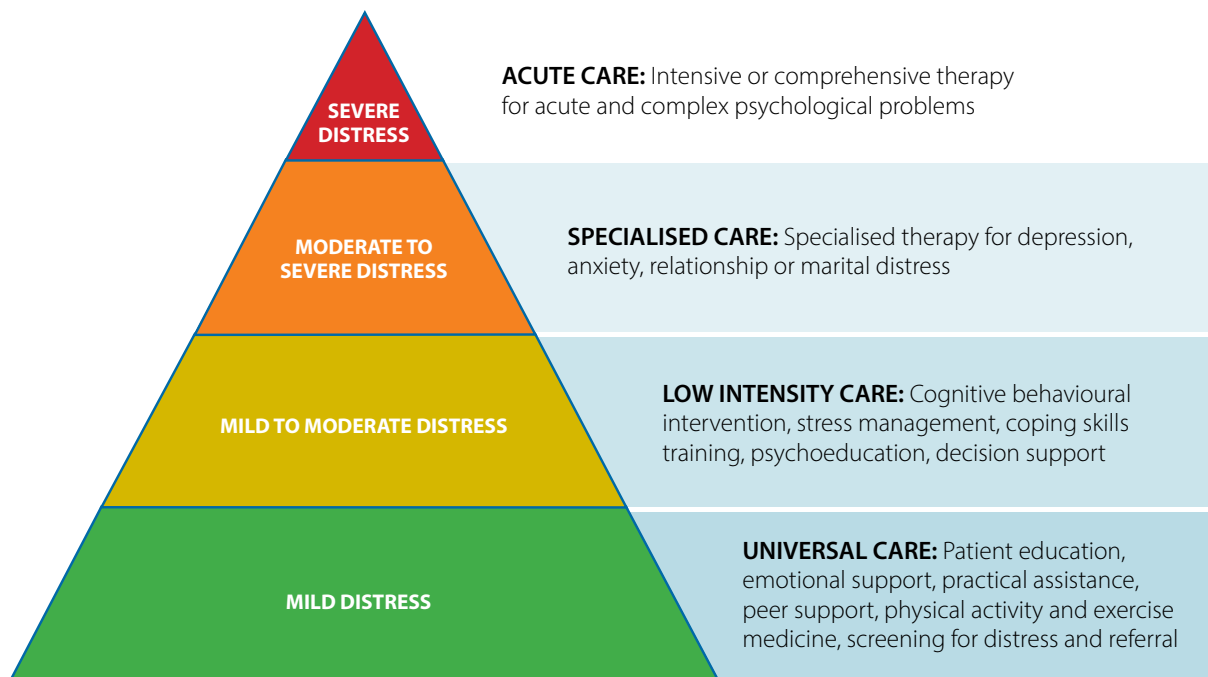
As well, a multi-disciplinary approach through men-centred **Care Coordination** that utilises services in a partnership across both community and acute settings is essential.

Embedded in this tiered model is a low intensity approach where access to services is a guiding value¹⁵⁰. A low intensity approach can be expressed in terms of the delivery method, for example applying remote technology or self-help strategies; or the service provider, for example peer or nurse providers.

In a tiered approach, as need increases, the depth of care should increase and the area of intervention focus, narrow, and become more specialised². In order for targeted care to be delivered in this way, maintaining **Vigilance** in screening for distress is essential⁶.

An example of a care framework that integrates what is currently known about effective **Evidence-based Survivorship Interventions** for men with prostate cancer with an existing generic cancer and community-based tiered model is presented below in Figure 2.

FIGURE 2. The Tiered Model of Psychosocial Care after Prostate Cancer
Adapted from the Tiered Model of Care²



Universal Care

Universal care includes care that, based on current evidence and best practice, should be offered and available to all men with prostate cancer throughout their cancer experience and lays a foundation of care for more in-depth levels of intervention for men with higher need or distress. This care level includes patient health education to promote self-management and effective decision making; support to validate the emotional experience of prostate cancer and allow expression of worries; advice for practical concerns; peer support that may be in a group setting or one-to-one, and face-to-face or remote; physical activity and exercise medicine; and screening for distress and referral. Screening for distress provides a mechanism to support referral to other care levels. Evidence-based telephone-delivered cancer helplines provide accessible support and linkages to community services.

Low Intensity Care

Low intensity care provides additional support for men who are experiencing mild to moderate distress and/or who express need for additional support. This care level includes a suite of standardised interventions that are considered relevant for most men experiencing distress as a result of a prostate cancer diagnosis and includes psycho-education, stress management and coping skills training, decision support, enhancing support networks, and managing treatment side-effects. Interventions are self-guided and can be supplemented with support/guidance from a nurse or other health professionals trained in the delivery of these interventions.



Specialised Care

Specialised care provides a further and more in-depth level of care for men who are experiencing moderate to high distress and/or who express need for additional support beyond that already provided.

Specialised interventions are individualised and based on a comprehensive assessment that guides the therapist in the development of a treatment plan targeting factors relevant to the development and maintenance of that individual's distress. Intervention types include tailored cognitive and behavioural strategies targeting specific negative thoughts and maladaptive ways of coping. Given that relationship distress can be a contributing factor to high distress following prostate cancer (either triggering or maintaining distress) relationship therapy targeting communication strategies and intimacy may be indicated. Specialised therapy or clinical psychology skills along with comprehensive knowledge of prostate specific factors that are likely to impact on distress (e.g. side-effects of treatments) are critical to the delivery of these interventions.



Acute Care

Acute care provides high level multi-disciplinary mental health care for men with severe distress and complex problems.

Men with severe distress may present with depression, anxiety or trauma symptoms that may seriously impact upon their ability to function day to day. Suicidal ideation may be present in men with severe depression. These men require an immediate assessment and intervention with an initial focus on assessment of safety and management of the acute crisis. An urgent psychological or psychiatric review is indicated. Specific treatments should be developed according to the particular needs of the patient that potentially include medication as well as psychological treatments.





Shared
Management



Personal
Agency



Care
Coordination



Vigilance



Evidence-based
Survivorship
Interventions



Health Promotion
and Advocacy

Key Points to Consider in Developing Services

- Life course and masculinity need to be considered for **Evidence-based Survivorship Interventions** to be acceptable and effective, and when planning care and developing services in partnership with men
- Self-direction should be supported as a key element in the design of services
- Responsiveness to differing levels of health literacy should underlie **Health Promotion and Advocacy** efforts, and is needed in order to effectively tailor patient education to support **Personal Agency** and facilitate **Shared Management**
- Care should be tailored to the level and type of need expressed by the man with access and ongoing **Vigilance** in screening for distress key considerations
- A multi-disciplinary approach is needed to provide comprehensive care
- Services across both community and acute settings should be included in a partnership approach to operationalise men-centred **Care Coordination**





Next Steps

In developing a psychosocial care approach within a specific health setting there are a number of steps to consider. A FIELD approach, outlined below, provides steps to follow to help develop a model of care that is connected to your local context.

A **FIELD** Approach

1. **F**orm a reference group

It is crucial to involve key stakeholders in your local setting to guide the development of a psychosocial care approach for men with prostate cancer that will be effective in your community or setting. This helps build local support for your approach and also helps ensure you are informed about current local services and experiences. Your stakeholder group should as much as possible be multi-disciplinary and include consumers and key people working in prostate cancer in your setting. It is important to meet regularly with your stakeholder group as you progress in developing your care model.

2. **I**dentify or scope current services

In developing a care model you need to be aware of currently available services within your local setting and those that are available elsewhere on a state and national level. Remember to include both community and acute settings and not-for-profit organisations. Current services provide a platform of care on which you can build.

3. **E**xamine current use of services by men and their families

Examine carefully the current patterns of utilisation of services in your setting by the men with prostate cancer in your community. This will help make sure you have not missed out on any important services that are 'under the radar' and will give you a sense of what types of services men in your community use, and how they may prefer to access psychosocial care.

4. **L**ook for gaps in services

Using the tiered model of care as a reference point look to see where there are gaps in services and then prioritise these for action. Remember to use your stakeholder group for expert advice and to engage their knowledge, skills and enthusiasm!

5. **D**evelop and implement a plan

Draw together a plan for how you can better connect men to current services. This might involve system changes; changes in how you communicate with men in your setting about support; and further development of your approach to providing information and managing referral. Investigate ways to develop new programs to meet gaps or to link into services in other organisations or settings. Have a timeline that includes implementation and evaluation that should then blend into regular quality assurance and re-development of the plan as services evolve and in response to new knowledge and health policies and practices.

Conclusion

Ensuring an optimal approach to delivering evidence-based and best practice psychosocial care is an essential component of good prostate cancer survivorship care. As the population of men living with prostate cancer increases in number and diversity it will become even more critical to develop tailored and targeted care systems to meet the psychosocial needs of these men and those close to them. The *Psychosocial Care Model for Men with Prostate Cancer* provides an approach to meeting these needs that can be applied in the community or acute setting building on current service strengths in a collaborative partnership approach. Framing delivery of this psychosocial care model within the broader *Prostate Cancer Survivorship Essentials Framework*¹ is key to improving the prostate cancer survivorship experience for men and their families.





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Other Resources

Below is a brief list of resources that you may find helpful. For medical or treatment questions the man's treating clinician is the best first point of call for advice personalised to his situation. Details were accurate at time of printing.

Screening for Distress Materials

For a copy of the Prostate Cancer Distress Screen materials contact Prostate Cancer Foundation of Australia (PCFA) at enquiries@pcfa.org.au.

Specialist Nursing Services

PCFA has a dedicated Specialist Nursing Service and Telenursing Service to provide free, confidential nursing and psychological support. The service includes hospital-based and telehealth specialist nurses. Phone 1800 220 099 or email telenurse@pcfa.org.au.

Peer Support Programs

PCFA has Support Groups around Australia, and a national MatesCONNECT peer support program for newly diagnosed men. Email matesconnect@pcfa.org.au, or go to www.pcfa.org.au for more information.

Online Forums

PCFA has an Online Community at <https://facebook.com/groups/pcsgs>. Email enquiries@pcfa.org.au for direct links.

Prostate Cancer Resources

For information booklets on a range of topics, go to <https://www.pcfa.org.au/awareness/general-information/>. Hardcopies can be ordered by calling 1800 220 099 or email enquiries@pcfa.org.au.

General

The Prostate Playbook: Keep It. Healthy. Craig Allingham. Redsox Publications, Australia. 2019. ISBN 978098706670.

Facing the Tiger: A Survivorship Guide for Men with Prostate Cancer and Their Partners 2nd Ed. Suzanne K. Chambers. Australian Academic Press, QLD. 2020. ISBN 9781925644425. Also available electronically on Kindle, GooglePlay, Kobo and NOOK Book.

Gay and Bisexual Men Living with Prostate Cancer: From Diagnosis to Recovery. Edited by Jane Ussher, Janette Perz, and B.R. Simon Rosser. Harrington Park Press, LLC, New York, United States. 2018. ISBN 9781939594259. Also available electronically on GooglePlay, Kobo and NOOK Book.

The Health Professionals Guide to Delivering Psychological Care for Men With Prostate Cancer. Suzanne K. Chambers, Nicole Heneka, and Jeff Dunn. Australian Academic Press, QLD. 2021. ISBN 9781925644555.

Sex and Sexuality

Saving Your Sex Life: A Guide for Men with Prostate Cancer. John P. Mulhall. Hilton Publishing, Bethesda, MD. 2010. ISBN-13: 978-0980064964. Also available electronically on Kindle and NOOK Book.

After Prostate Cancer: A What-comes-next guide to a safe and informed recovery. Arnold Melman MD and Rosemary E. Newnham. Oxford University Press, New York. 2011. ISBN-13: 978-0195399660. Also available electronically on Kindle, GooglePlay, Kobo NOOK Book.

A gay man's guide to prostate cancer. Gerald Perlman and Jack Drescher. Haworth Medical Press, United States. 2005. ISBN 978-1560235521.

<http://www.renewintimacy.org/>
The Center for Intimacy after Cancer Therapy, Inc. is a non-profit organisation dedicated to helping couples renew their intimacy after cancer. Founders and Co-Executive Directors: Ralph and Barbara Alterowitz.



Urinary Problems

Conquering Incontinence: A New and Physical Approach to a Freer Lifestyle Exercise. Peter Dornan. Allen & Unwin, Australia 2003. ISBN 9781741141443. Also available electronically on Kindle, GooglePlay, Kobo and NOOK Book.

Prostate Recovery MAP: Men's Action Plan 3rd Ed. Craig Allingham. Redsok, Australia. 2020. ISBN 9780987076687.

Suicide

Lifeline provides 24/7 crisis support and suicide prevention services in Australia (<https://www.lifeline.org.au/>). Call 13 11 14 for the Lifeline Crisis Hotline.

General Practice Mental Health Standards Collaboration (GPMHSC). *Suicide prevention and first aid: A resource for GPs.* East Melbourne, Vic: RACGP, 2016. Electronic copies available at <https://gpmhsc.org.au/guidelinessection/index/fd093e3b-ceff-4e0d-81c0-b04dfba936d1/suicide-prevention-and-first-aid>.

Suicide prevention. Beyond Blue, Australia. Webpage and resources available at <https://www.beyondblue.org.au/the-facts/suicide-prevention>.

Suicide & self-harm. Black Dog Institute, Australia. Webpage and resources available at <https://www.blackdoginstitute.org.au/clinical-resources/suicide-self-harm>.

Suicide Prevention. National Institute of Mental Health (NIMH), United States. Webpage and resources available at <https://www.nimh.nih.gov/health/topics/suicide-prevention>.

Mindfulness and Meditation

Happy For No Good Reason: A meditator's guide. Swami Shankarananda. Shaktipat Press, Australia. 2013. ISBN-13: 9780975099582. Also available electronically on Kobo and NOOK Book.

Full Catastrophe Living (Revised Edition): Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness. Jon Kabat-Zinn. Bantam Books, United States. 2013. ISBN 9780345536938. Also available electronically on Kindle, GooglePlay, Kobo and NOOK Book.

Complementary Medicine

Promoting Wellness for Prostate Cancer Patients: A guide for men and their families. Fourth Edition. Mark A Moyad. Spry Publishing LLC, United States. 2013. ISBN-13: 978-1938170034.

Wellbeing

What Women (and Their Men) Need to Know About Prostate Cancer. Irena Madjar in collaboration with Gail Tingle. Prostate Survival Alliance Inc., Australia. 2008. ISBN 9780646482965.

Exercise

Exercise and Sports Science Australia (ESSA) - www.essa.org.au provide details of registered exercise professionals with University qualifications who are able to conduct exercise training with people who have had cancer or other chronic illnesses. The ESSA website has a section in their main page on How to Find an Exercise Physiologist: <https://www.essa.org.au/find-aep>.

American College of Sports Medicine (ACSM) - www.acsm.org provides a similar service as does the British Association of Sport and Exercise Sciences, BASES - www.bases.org.uk/ in the United Kingdom.

Cancer Helplines and Support Groups

Australia

Contact the Prostate Cancer Foundation of Australia on 1800 220 099 or via www.pcfa.org.au. The Prostate Cancer Foundation of Australia is the peak national body for prostate cancer in Australia dedicated to reducing the impact of prostate cancer on Australian men, their partners, families and the wider community.

Cancer Council 13 11 20 is a free, confidential telephone information and support service run by Cancer Councils in each state and territory in Australia. Specially trained staff are available to answer questions about cancer and provide support. Call 13 11 20 (local call cost from anywhere in Australia but mobile calls charged at mobile rates), open between 9am and 5pm, Monday to Friday, however some states have extended hours.

New Zealand

To contact a prostate cancer support group in your local area look up the Prostate Cancer Foundation of New Zealand website (<http://prostate.org.nz/support-groups/>) or call 0800 477 678. The Prostate Cancer Foundation of New Zealand aims to help those recently diagnosed with prostate cancer, and survivors of prostate cancer, to lead productive and full lives through shared counselling and discussions.

The Cancer Society of New Zealand has a free Cancer Information Helpline, 0800 CANCER (226 237), which supplies booklets, information sheets and other information resources which can also be downloaded directly from their website <http://www.cancernz.org.nz/>.

North America

Us TOO International Prostate Cancer Education and Support Network is a non-profit, grassroots organisation that provides support for prostate cancer patients, survivors, their spouses and partners and families. More details can be found on their website <http://www.ustoo.org/>. They have a toll free line to link for patients and concerned others to resources regarding diagnosis, treatment options and support systems and phone support from a prostate cancer survivor. Call 1-800-80-UsTOO (1-800-808-7866).

<http://malecare.org/>

Malecare develops practical, life-enhancing men's health programs and has a focus on gay and bisexual men's survivorship. Malecare runs a series of workshops and Prostate Cancer Support groups throughout the United States in areas of newly diagnosed cancer support groups, advanced prostate cancer, men diagnosed under age 50 and gay cancer survivor support.

Canada

Prostate Cancer Canada has amalgamated with the Canadian Cancer Society; the organisation connects men to support groups and provides a range of information on prostate cancer related topics. The web address for this organisation is <https://www.prostatecancer.ca/>.

United Kingdom

The National Federation of Prostate Cancer Support Groups connects men to support groups through their free Helpline on 0800 035 5302 or via <https://www.tackleprostate.org/find-a-support-group-near-you.php>. The web address for this group is <https://www.tackleprostate.org/>.

Prostate Cancer UK provides a free hotline and live website chat run by specialist nurses, which can be accessed by calling 0800 074 8383 or via the website <https://prostatecanceruk.org/>. The organisation also provides a range of support options including local and online support groups (<https://prostatecanceruk.org/get-support>).

Prostate Scotland is a charity set up to provide information, advice and help on prostate cancer (<https://www.prostatescotland.org.uk/>). They also connect men to support groups (<https://www.prostatescotland.org.uk/help-and-support-for-you/support-groups>).

Europe

Europa Uomo (Italian for Europe man) is an advocacy movement representing 27 prostate patients' groups in countries across Europe (<https://www.europa-uomo.org/>). The list of member organisations can be found on their website <https://www.europa-uomo.org/members/member-organisations/>.

Other Useful Websites

<http://prostatenet.com/page/>

The Prostate Net is an international organisation that uses a matrix of informational techniques (web site, 800#, email and personal team counsellors, public forums, newsletters and community disease interventions) to address disease risk awareness and early disease detection.



APPENDIX 1. PROSTATE CANCER SURVIVORSHIP ESSENTIALS FRAMEWORK

PROSTATE CANCER SURVIVORSHIP ESSENTIALS FRAMEWORK



Prostate cancer is the most prevalent male cancer in the world, excluding non-melanoma skin cancer.

In Australia, there are now over 230,000 men living with a diagnosis of prostate cancer. Prostate cancer survivorship care encompasses the health and wellbeing of men from the point of diagnosis and is essential to cancer care. Survivorship care recognises the physical, psychosocial, spiritual and economic impacts of cancer, which can be long-lasting, and addresses these so that the patient can achieve optimal quality of life. The Prostate Cancer Survivorship Essentials Framework places the man and his family at the centre of care.



Personal Agency where patients are self-aware in assessing their needs, seeking assistance when required, and building resilience to manage their own health where possible.



Evidence-based Survivorship Interventions for accessible psychosocial and psychosexual care, exercise and physical activity, nutrition, peer support, financial assistance, and specialist nursing interventions.



Health Promotion and Advocacy through the provision of up-to-date information to increase the community's knowledge of men's health and prostate cancer and support awareness and advocacy.



Shared Management between patients and health professionals to improve outcomes and ensure quality survivorship care with shared and informed decision making about all aspects of care.



Care Coordination where patients and families arrive at the right place at the right time for the right care once a diagnosis has been made. Men-centred care is central.



Vigilance across the survivorship continuum from diagnosis to end-of-life care with attentive surveillance of physical and psychosocial effects, comorbidities, recurrence and second cancers. This includes psychosocial effects on partners and family members.

ENDORISING ORGANISATIONS



Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT)



THE UNIVERSITY OF BRITISH COLUMBIA



UNIVERSITY OF SOUTHERN QUEENSLAND AUSTRALIA



The Royal Australian and New Zealand College of Radiologists



Dunn J, Green A, Ralph N, Newton R, Kneebone A, Frydenberg M, Chambers SK. Prostate Cancer Survivorship Essentials Framework: Guidelines for Practitioners (2020). *British Journal of Urology International*. <https://doi.org/10.1111/bju.15159>.

APPENDIX 2. POSITION STATEMENT ON SCREENING FOR DISTRESS AND PSYCHOSOCIAL CARE FOR MEN WITH PROSTATE CANCER



POSITION STATEMENT ON SCREENING FOR DISTRESS AND PSYCHOSOCIAL CARE FOR MEN WITH PROSTATE CANCER

SEPTEMBER 2019

Every year 1.3 million men worldwide are diagnosed with prostate cancer ⁽¹⁾. Australia has one of the highest incidence rates internationally with 1 in every 7 Australian men likely to be diagnosed during their lifetime. While survival rates for prostate cancer are high (over 95% of men survive to at least five years) there are over 200,000 Australian men currently living with a previous diagnosis. With a growing and aging population this prevalent pool of survivors will continue to grow ⁽²⁾.

The diagnosis of prostate cancer is a major life stress that for many men is followed by challenging treatment-related symptoms and heightened psychological distress. Before and after prostate cancer treatment up to one in four men experience anxiety and up to one in five report depression ⁽³⁾. Heightened distress occurs across all

treatment approaches, however distress levels are greater for men who have locally advanced or metastatic disease. Although psychological distress is higher closer to diagnosis, distress can persist over the longer term. Younger age, socio-economic disadvantage, and a greater symptom burden increase men's risk of higher distress ^(4, 5).

Men have an increased risk of suicide after prostate cancer by comparison with controls ⁽⁶⁻⁸⁾ with the first six to twelve months after diagnosis a period of heightened suicide risk ^(9, 10). Men who have locally advanced or metastatic disease and/or are single/divorced/widowed are at greater risk. Suicidal ideation has been reported by approximately 12% of men with prostate cancer and may persist for many years ⁽¹¹⁾; and one third may experience high fear of cancer recurrence ⁽¹²⁾.

Recognition and treatment of the negative psychological consequences of cancer is central to survivorship care ⁽¹³⁾. Brief distress screening in people with cancer is an accepted standard in oncology care ⁽¹⁴⁾ and has been well validated in men with prostate cancer ⁽¹⁵⁾. Effective psychosocial oncology interventions for men with prostate cancer have been identified ⁽¹⁶⁾.

Multi-modal psychosocial and psychosexual care for men with prostate cancer is acceptable and effective for improving decision-related distress, mental health, domain-specific, and health-related QOL ^(16, 17, 18). Combinations of educational, cognitive behavioural, communication, and peer support have been most commonly applied and found effective; followed by decision support and relaxation. Face-to-face and remote technologies, with therapist, nurse or peer supports provide a range of mechanisms and sources for support.

The partners of men with prostate cancer may also experience high psychological distress. To date the optimal method of screening for distress in these partners has not been identified ⁽¹⁹⁾ nor is there good quality evidence to direct effective psychosocial interventions for partners and couples ⁽¹⁶⁾. There are gaps in knowledge in the survivorship domains of surveillance and care coordination for men with prostate cancer, both of which are influencers of men's psychological and quality of life outcomes ⁽¹⁷⁾.

RECOMMENDATIONS

1. After the diagnosis of prostate cancer and regularly through treatment and surveillance men who have been diagnosed with prostate cancer should be screened for distress and their psychological and quality of life concerns should be explored
2. Men who have high levels of distress should be further evaluated for anxiety and/or depression and evidence of suicidality
3. Men who have high distress or need for support should be referred to evidence-based intervention matched to their individual needs and preferences for support
4. Research is needed to develop effective methods to identify partners of men with prostate cancer with high distress or who are at risk of high distress as well as effective interventions for partners and for couples where the man has a diagnosis of prostate cancer
5. Investment in prostate cancer survivorship research is a national health priority

Endorsed by





**Prostate Cancer
Foundation of Australia**



NHMRC Centre of Research Excellence
**PROSTATE CANCER
SURVIVORSHIP**

This Position Statement is supported by the monograph *A Psychosocial Care Model for Men with Prostate Cancer* that includes a Prostate Cancer Distress Screen and Problem Checklist ⁽¹⁵⁾. For more information go to www.pcfa.org.au.

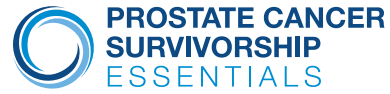
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Prostate Cancer Foundation of Australia (PCFA) and the NHMRC Centre for Research Excellence in Prostate Cancer Survivorship (NHMRC CRE-PCS) developed this material and information based on the best available evidence. However, PCFA and NHMRC CRE-PCS cannot guarantee and does not warrant or represent that the information is accurate, current or complete. PCFA and NHMRC CRE-PCS assumes no legal liability or responsibility for any injury, loss, damage, cost or expense incurred by use of, reliance on, or interpretation of the information.

My Personal Plan



A Survivorship Plan is a summary of information about your diagnosis, treatment and ongoing care. You can take this with you to any future health care appointments so that any care providers involved in your current and future care have a clear picture of your diagnosis and treatment. Ask a member of your Prostate Cancer healthcare team to assist you in completing your Survivorship Plan and ensure you keep this up to date.

My Details

Name	Care Plan Start Date
<input type="text"/>	<input type="text"/>
Treating Specialist	Treating Hospital/Centre
<input type="text"/>	<input type="text"/>
Prostate Cancer Specialist Nurse	General Practitioner
<input type="text"/>	<input type="text"/>
My Diagnosis	Date of Diagnosis
<input type="text"/>	<input type="text"/>

My Treatment Plan

Complete any areas that apply to you.

Surgery

Surgery date:

Treating Hospital /Centre:

Procedure:

Complications:

Comments:

Radiation Therapy

Start date:

Treating Hospital:

Site (e.g. prostate, hip):

Number of Treatments:

Side Effects:

Comments:

Hormone Therapy

Start date:

Treating Hospital /Centre:

Therapy Type:

Treatment Term:

Side Effects:

Comments:

Brachytherapy

Start date:

Treating Hospital:

LDR or HDR:

Side Effects:

Comments:



Chemotherapy / Targeted Therapy

Start date:

Treating Hospital /Centre:

Therapy Type:

Number of Treatments:

Side Effects:

Comments:

Active Surveillance

Start date:

Treating Hospital /Centre:

Next PSA test:

Next scan:

Next biopsy:

Comments:

Medications

If not stated already please list any medications you are currently taking that are related to Prostate Cancer treatment or symptoms:

Follow Up Appointments

Please list any follow up appointments you have scheduled:

Date	Specialist	Tests required	Comments
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Additional Information

Please note any additional information that is relevant to your diagnosis or treatment e.g., PSA levels, Active Surveillance Plan, etc.



My Wellbeing Plan

For most men having prostate cancer leads to some changes in wellbeing. The type of changes and how long they persist will depend on the types of treatments you receive and your overall health. There are evidence-based interventions that you can use to help self-manage or minimise these effects and your doctor or nurse can advise you about this. This plan includes a list of some possible effects and who can help. Any person who has had a cancer diagnosis is considered to be a survivor. Survivorship care means having a plan to look after your wellbeing now and for any changes that might happen in the future. It's all about you!

There are six areas to consider:

1. Personal agency



Personal agency means taking control about what help you need, and seeking support to manage your own health where you can. This does not mean going it alone, it means finding out who is there to help, what you can do yourself and what others can offer, and being an active part of the team.

What can I do?

- ✓ Set survivorship goals that most matter to you. In thinking of the months and years ahead, what are the health and wellbeing goals that you would like to work towards. These might be goals around physical activity or mental wellbeing, you may also have goals around urinary control or other physical symptoms. Strengthening your intimate relationship or perhaps looking to develop one might be on your list. Once you have your goals clear then identify the information and other support you might need to achieve these goals. Set targets that are achievable and put an action plan in place with a timeline. Be prepared to be flexible and problem solve as you go along. This approach will help you to feel more in control of your care.

2. Shared management



Shared management means being an equal partner in your health care, sharing decision making with your health care team and sharing how you will tackle challenges as they arise. This includes informed decision making around testing and treatment, understanding and managing the physical and psychological effects of treatment and of the disease.

What can I do?

- ✓ Let your health care team know how involved you want to be in decisions about your care, and who else you want to be involved, such as your partner or other family or friends. Question lists can help guide the conversation with your doctor, nurse or other health professional and ensure you ask about the things that matter most to you. Plan in advance what questions you need answered, perhaps with the support of a partner or a close friend.
- ✓ Make sure your General Practitioner is connected into your care so that they are well prepared to support you.



3. Vigilance

Your health care provider will manage surveillance from diagnosis and through life, and this includes physical issues such as the control of the cancer and management of physical side effects but also other illnesses that can occur as we age. This also includes checking on your emotional and social wellbeing.

What can I do?

- ✓ Ask your doctor about your check-up schedule going forward and keep a record of this using this care plan.
- ✓ Communicate your concerns and how you are going physically and emotionally to your health care team.
- ✓ Your psychological wellbeing is just as important as your physical health. Use the scale and problem list below to gauge your level of stress.

A quick way to gauge your level of stress is to ask yourself how distressed have you felt over the past week on a scale of 0 (no distress), to 10 (extreme distress)? If you are 4 or over on this scale then your doctor or nurse needs to know so they can work with you on what support you might need. If you are 4 or over on this scale then your doctor or nurse needs to know so they can work with you on what support you might need.

Click or check the number to score how distressed you have felt in the last week:

Check the items on the list below to get a sense of what might be most strongly influencing how you are feeling:

No distress
0 <input type="radio"/>
1 <input type="radio"/>
2 <input type="radio"/>
3 <input type="radio"/>
4 <input type="radio"/>
5 <input type="radio"/>
6 <input type="radio"/>
7 <input type="radio"/>
8 <input type="radio"/>
9 <input type="radio"/>
10 <input type="radio"/>
Extreme distress

Practical problems

Work

Financial/insurance

Family problems

Partner

Emotional problems

Depression

Uncertainty about the future

Nervousness

Sadness

Worry

Loss of interest in usual activities

Treatment problems

Understanding treatments

Making a decision

Information about my illness

Physical problems

Pain

Fatigue

Sexual

Urinary

Bowel

Hot flushes

Weight gain

Weight loss

Loss of muscle mass

Memory/concentration

Sleep

Other problems (please list)

Talk to your doctor or nurse about the problem that is concerning you the most to find out what services are available to you and how you can access them.

4. Evidence-based survivorship interventions



Your time and energy are valuable. Being evidence-based is about directing your time, energy and resources to strategies that have strong evidence to support their effectiveness. There is excellent evidence for the benefits of exercise medicine. For overall wellness good nutritional habits are important. Psychological support helps manage mood changes and the stress and anxiety associated with cancer. Sexual health support tailored to individual men in different age groups and with different sexual orientations and relationships is also an area where good evidence exists about what works.

What can I do?

- ✓ Check with your doctor or nurse or organisations such as the Prostate Cancer Foundation of Australia about what services are available for you.
- ✓ Talk to other men who have had prostate cancer to see what they have found helpful and accessible, support groups can help here.
- ✓ Ask your General Practitioner to help with Medicare support for service through a Chronic Disease Management Plan for allied health services, or the Better Access to Mental Health for psychology.

Your referrals

The following is a list of services that may assist you in your Prostate Cancer recovery journey. Please tick any services that you have engaged with. If you are interested in any of these services, ask your treating team or GP for a referral.

	Referred	On-going treatment	No longer required
Psychology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sexual counselling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychiatry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain or palliative care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Continence support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Genetic counselling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dietician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Occupational therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fertility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Prostate nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Smoking cessation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input style="width: 100%; height: 20px;" type="text"/>		

5. Care coordination



Care Coordination is about your health care team working together to get you the best care possible in a 'right place at the right time' approach.

What can I do?

- ✓ Ask your doctor or nurse who is the lead person coordinating your care and how you can contact them if you need to. Also ask who is keeping your General Practitioner in the loop. If you move to a different treatment approach you might need to ask this again.

6. Health promotion and advocacy



Having accurate and up to date information about prostate cancer is important for you, your family and your community.

What can I do?

- ✓ Be informed and active in seeking information about your cancer and your health care from credible and reliable sources.
- ✓ Share what you know about prostate cancer with people who matter to you, your partner and family and close networks.
- ✓ Reach out to local support prostate cancer support groups in your area.



Supplementary health services

Services such as allied health professionals can assist with your recovery from Prostate Cancer symptoms and treatment, as well as benefiting your overall health and wellbeing. In order to access these services, speak to your GP or your treating team at the hospital. Your doctors can provide you with a referral to public or private services that may benefit you. Services include:

- **Exercise Physiology** provides tailored clinical exercise interventions to manage symptoms associated with prostate cancer treatment and improve functional performance. Interventions also include health and physical activity information, and support for lifestyle modifications and behavioural change. You can find out more about exercise physiology at: <https://exerciseright.com.au/what-is-an-accredited-exercise-physiologist/>
- **Dietetics** provides personalised nutrition advice and support including eating plans, advice on supplements and nutritional counselling. You can find out more about dietetics at: <https://dietitiansaustralia.org.au/what-dietitians-do/>
- **Psychology** services provide support and treatment for anxiety, depression and distress, and other psychological concerns related to cancer. You can find out more about psychology at: <https://www.psychology.org.au/for-the-public/about-psychology>
- **Physiotherapy** helps strengthen the body, improve mobility and manage pain after prostate cancer treatment using movement and exercise, manual therapy, education and advice. You can find out more about physiotherapy at: <https://choose.physio/what-is-physio>
- **Occupational therapy** provides support if you are having difficulty with everyday tasks and helps you maintain, regain or improve your independence. You can find out more about occupational therapy at: <https://otaus.com.au/about/about-ot>
- **Social work** offers counselling services, therapeutic interventions, and information and resources for patients, families and carers to support decision making and access services and support. You can find out more about social work at: <https://www.aasw.asn.au/information-for-the-community/information-for-the-community>

Other Helpful Services

- **Prostate Cancer Foundation of Australia (PCFA)** is the peak national body for prostate cancer in Australia and supports men and their families affected by prostate cancer through evidence-based information and resources, support groups and Prostate Cancer Specialist Nurses: <https://www.prostate.org.au/>
- **Prostate Cancer Specialist Telenursing Service:** This service, provided by the Prostate Cancer Foundation of Australia (PCFA), connects you to a Prostate Cancer Specialist Nurse who can help you with evidence-based information, practical and emotional support, and can link you with local support networks: <https://www.prostate.org.au/support/prostate-cancer-specialist-telenursing-service/>

To access this service you can:

- ✓ Phone: 1800 22 00 99
- ✓ Email: telenurse@pcfa.org.au
- ✓ Submit an online form: <https://www.prostate.org.au/telenursing-request-form/>

If you have a *hearing or speech impairment*, call the [National Relay Service](#) on 1800 555 677 and ask to be transferred to PCFA's Telenursing Service at 1800 22 00 99. If *English is not your main language* and you need an interpreter, call [TIS National](#) on 131 450 and ask to be transferred to PCFA's Telenursing Service at 1800 22 00 99.

Dunn J, Green A, Ralph N, Newton R, Kneebone A, Frydenberg M, Chambers SK. Prostate Cancer Survivorship Essentials Framework: Guidelines for Practitioners. BJUI. 2020; <https://doi.org/10.1111/bju.15159>.

Chambers SK. Facing the Tiger: A Survivorship Guide for Men with Prostate Cancer and their Partners. Brisbane, Australia: Australian Academic Press; 2020.

APPENDIX 4. PROSTATE CANCER DISTRESS SCREEN



**Prostate Cancer
Foundation of Australia**

U.R Number _____

Surname _____

Given Name(s) _____

Date of Birth _____

AFFIX PATIENT LABEL HERE

PROSTATE CANCER DISTRESS SCREEN

The experience of prostate cancer is for many men a difficult time. I would like to ask you a few brief questions to check how you have been feeling and ask about your main concerns. Thinking about how you have been feeling over the past week including today, how distressed do you feel on a scale of '0', no distress to '10', extreme distress? (circle)



This is a list of problems that some men with prostate cancer experience. Do any of these problems apply to you? (Read the list below, tick if yes)

Practical Problems

- Work
- Financial/Insurance

Family Problems

- Partner

Emotional Problems

- Depression
- Uncertainty about the future
- Nervousness
- Sadness
- Worry
- Loss of interest in usual activities

Treatment Problems

- Understanding treatments
- Making a decision
- Information about my illness

Physical Problems

- Pain
- Fatigue
- Sexual
- Urinary
- Bowel
- Hot Flushes
- Weight Gain
- Weight Loss
- Loss of Muscle Mass
- Memory/Concentration
- Sleep

Other Problems (please list)

Which of these are the **most important concerns** for you right now? (Please list)

For men with a rating of ≥ 4 consider further assessment and referral to appropriate support services.

Person completing form: _____ **Date:** ___ / ___ / ___
Name & designation: _____
Action taken: _____

Adapted from National Comprehensive Cancer Network (NCCN) Guidelines Version 2.2103 Distress management – Distress Thermometer and Problem Checklist http://www.nccn.org/professionals/physician_gls/pdf/distress.pdf
Chambers SK et al. (2014) The Validity of the Distress Thermometer in Prostate Cancer Populations. *Psycho-Oncology*, 23(2):195-203.
Prostate Cancer Foundation of Australia (PCFA) developed this material and information based on the best available evidence. However, PCFA cannot guarantee and does not warrant or represent that the information is accurate, current or complete. PCFA assumes no legal liability or responsibility for any injury, loss, damage, cost or expense incurred by use of, reliance on, or interpretation of the information.



