Prostate Cancer Foundation of Australia

NHMRC Centre of Research Excellence
PROSTATE CANCER SURVIVORSHIP

A PSYCHOSOCIAL CARE MODEL FOR MEN WITH PROSTATE CANCER

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Endorsed by

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OUR VISION, MISSION AND VALUES

Prostate Cancer Foundation of Australia 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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A PSYCHOSOCIAL CARE MODEL FOR MEN WITH PROSTATE CANCER

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FOREWORD

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 pain[1]. Several countries have developed clinical practice guidelines and standards to guide such care in adults with cancer[2-6]. However, to date screening for distress and referral to evidence-based psychosocial care has not yet been systematically implemented in prostate cancer care.

To address this gap the Prostate Cancer Foundation of Australia has developed a *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[a]. The recommendations within this statement are listed in the box and the statement in its entirety is included in Appendix 1.

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

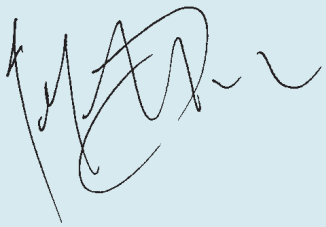
a University of Technology Sydney, University of Southern Queensland, Edith Cowan University, Griffith University, Deakin University

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 of the monograph is to guide health 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.

A Psychosocial Care Model for Men with Prostate Cancer summarises research about men's psychological responses to prostate cancer; the importance of screening for distress; the influence of life course and masculinities on men's experiences of prostate cancer and their help-seeking behaviours; and current evidence about interventions to improve mental well-being in men with prostate cancer. A separate monograph discusses the needs and concerns of gay and bisexual men with prostate cancer[7]. While this resource focusses 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 apply *A Psychosocial Care Model for Men with Prostate Cancer* as a practical guide to developing a care plan for men with prostate cancer in their setting that utilises local services and links to other services in the acute and community sectors.

Holistic and evidence-based psychosocial care for men with prostate cancer is a national and global health priority. We invite you to join us ensuring men and their families receive the care they deserve.



Professor Jeff Dunn AO
Chief Executive Officer
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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 distress[8-10] and many have high unmet psychological support needs[11-13].

The prevalence estimates of psychological distress experienced by prostate cancer survivors vary due to differences in approaches to sampling and measurement[14]. However, studies report that 11-27% of prostate cancer survivors experience some form of psychological distress[8-10]. The prevalence of psychological distress remains relatively high across the treatment spectrum[8].

Specifically, 13-18% of prostate cancer survivors experience depression[8,10,15]. 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 insomnia[16].

Compared with men in the general population, men with prostate cancer may be twice as likely to experience depression[17]. Anxiety is experienced by 14-27% of prostate cancer survivors[8,10,17,18] and is present across the prostate cancer trajectory[18]. Compared with men in the general population, men with prostate cancer are three times more likely to experience anxiety[17]. 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 symptoms[19]. Factors that increase the likelihood a man will experience high distress levels include: younger age[15,18-21]; lower education and income[10,20,21]; comorbidities[10,21]; un-partnered status[21]; receiving adjuvant radiotherapy[19]; and having locally advanced or metastatic prostate cancer[21]. Poor sexual, urinary, and bowel function are associated with cancer-specific distress[21]. Active surveillance (AS) patients experience higher anxiety compared with patients who are treated radically, with divorce a predictor of anxiety for AS patients[17]. 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 concern[18].

Compared with men in the general population, men with prostate cancer have a 70% higher risk of suicide[22]. The risk of suicide is highest within the first year after diagnosis[22-25], in particular in the first 6 months, and increases with severity of clinical stage at diagnosis[16,23,26]. 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 disease[23]. Suicidal ideation has also been found to be experienced by 12% of prostate cancer survivors and is significantly associated with hormonal symptoms[27]. Prostate cancer survivors are at increased risk of suicide when they have non-localised disease[22]; are residents in major cities[22]; are unmarried and/or single[22]; aged 75 years or older[25]; when definitive treatment has been recommended but not received[24]; and when treated with hormonal therapy[25]. Suicidal ideation has been found to be associated with employment status and poor physical health (pain and disability status)[27].

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 processing[28-30]. Mood changes such as depressed mood, decreased energy and vigour, and increased irritability have also been reported in men treated with ADT[28]. Compared with other treatments, men treated with ADT also report diminished sexual function, hormonal function, and vitality[31].

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 approaches[31].

Research over a significant period of time demonstrates that men with prostate cancer continue to have unmet supportive care needs[11,12]. 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 issues[13]. 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 interventions[31]. Sexual dysfunction has been found to be of particular concern for men younger than 55 years compared with men aged 75 years and older[31]. Clinical care for patients with advanced prostate cancer is an emerging area of research[32]. Men with advanced prostate cancer report difficulties with access to informational support about the disease and treatment[33,34]. 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 experience[33]. The specific needs of gay and bisexual men with prostate cancer are discussed elsewhere[7].

High early distress is a predictor of later ongoing high distress[16]. Hence, detecting raised distress early on is a priority.

SCREENING FOR DISTRESS IN MEN WITH PROSTATE CANCER

It is now well accepted that screening for psychological distress is a key component of good cancer care[1,35]. 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 crisis[36].

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 settings[37]. 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 settings[38-46], and more recently in prostate cancer populations[47].

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 $\geq$4 was suggested as optimal soon after diagnosis and for longer term assessments $\geq$3 was supported[47]. See Appendix 2 for the prostate cancer-specific version of the Distress Thermometer based on the associated validation data[47]. 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 men[21]. Screening for distress must be accompanied by a process of evaluation if a patient scores $\geq$4 followed by referral to appropriate evidence-based psychosocial care services in order to be effective in meeting support needs[14,48].

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)[49]. 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 referral[50] to the man's general practitioner, community mental health service or the local hospital's emergency department is required[51]. 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 themselves[52]. 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 months[53]. 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 anxiety[54]. 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 cancer[55]. 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 partners[55]. The optimal approach for detecting distress in partners remains unclear and there is a need for more comprehensive screening measures which incorporate partner-specific issues[55].

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 uncertainty[56]. Male partners of men with prostate cancer will have different experiences and concerns and this is an area of ongoing research[7]. 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)[57]. 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.

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
- 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 acceptable for men with prostate cancer and effective in improving survivorship outcomes[14,56,58]. 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[56,58]. Elements of effective interventions include combinations of educational, cognitive-behavioural, decision support, relaxation training, communication skills training, tailored supportive care, and peer support[14,56,58]. There is a lack of research on interventions addressing the key domains of surveillance and cancer care coordination, further work in this area is required[58].

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 unit[56].

Mental health: Specifically, a combined web-based psycho-educational intervention and moderated peer forum[59], and a Qigong intervention[60], 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 intervention[20]. A group nurse-led psycho-educational intervention consisting of four group consultations and one individual consultation[61], and a ten-week web-based group cognitive-behavioural stress management intervention[62] reduced depression.

Another group cognitive-behavioural stress management intervention improved emotional well-being[63]. An eight-week tele-health education intervention improved depression, negative affect, stress, and spiritual well-being for prostate cancer survivors[64]. 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 knowledge[65]. 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 anxiety[66].

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 seminar[67-69].

Fatigue: A twelve-week trial of Qigong[60] and an eight-week telephone delivered health education intervention[64] 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 confidence[70]. 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 intervention[71]. Prostate cancer nurse-delivered and peer-delivered telephone counselling interventions for men who had prostatectomy increased their use of medical treatments for erectile dysfunction[72].

Decision making: A web-based tailored decision support program for newly diagnosed men with localised prostate cancer reduced uncertainty for treatment decision making[73]. A decision aid in the form of a patient booklet was found to decrease decisional conflict[74], and a decision navigation intervention reduced regret and increased decisional self-efficacy[75]. Confidence in treatment choice was increased for patients involved in an online interactive education intervention to enhance treatment decision making[76].

Effective mechanisms for intervention delivery and sources of support include face-to-face and remote communication with therapists, nurses, and peer support[14]. 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 experience[77]. Peer support is also an acceptable support method for men[56,77]. 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-blame[78]. 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 effects[14]. 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[14,58,77]. 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[56,58,77].

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

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, musculoskeletal health and quality of life[79]. Exercise medicine has emerged as an important intervention to preserve function and ameliorate and reverse a range of treatment-related adverse effects in men with prostate cancer during and after treatment[80]. In addition, evidence from epidemiological studies have shown that higher levels of physical activity post cancer diagnosis are associated with increased cancer-specific and overall survival including men with prostate cancer[81-83]. 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 harm[84].

Mental health: Increased levels of physical activity and higher physical fitness have been associated with a reduced risk of developing anxiety and depressive symptoms[85-88]. Numerous systematic reviews and meta-analyses have indicated exercise as an effective intervention strategy for the management of clinical depression[89-93].

Meta-analyses have identified that exercise also reduces depressive symptoms amongst cancer patients; however the vast majority of these data arise from investigations involving breast cancer patients[94-97]. Specifically in men with prostate cancer, 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 health as assessed by the SF-36 QOL questionnaire[98]. A significant improvement in social functioning was also observed but neither of these improvements were maintained after a subsequent 6-month home-based exercise program[98]. Systematic reviews specifically to prostate cancer have reported no or limited effects of exercise on depression and anxiety[58,99].

The quality and quantity of the exercise program and level of supervision has been observed to impact the degree of improvement in mental well-being in a dose-response fashion[94,95,100]. Involvement in a group-based exercise program, especially amongst other men with prostate cancer, appears to be another important factor[94,98]. 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 neurotropic factor) and neurogenesis has been suggested to impact mood and cognitive function and thus may contribute to exercise-induced improvement in mental health[101-104].

Quality of life: Numerous studies have shown improvements in quality of life following exercise training[58,105]. For example, in a 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 controls[106]. 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 controls[107].

Fatigue: There is consistent evidence to suggest that exercise is effective at ameliorating cancer related fatigue[108]. 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 treatment[109]. Moreover, it appears that the greatest effects of exercise on fatigue are in those with the greatest levels of fatigue at baseline[109-111].

Sexual health: The effects of exercise on improving sexual and erectile function in men with prostate cancer has been inconsistent[112,113]. Such findings could be attributed to differences in treatments and exercise protocols examined. A systematic review reported no effects of exercise on sexual function[105]. Additional research is required to expand on these preliminary findings.

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 care[107]. Such changes were accompanied by improvements in muscle strength and lean mass[107]. Recently, men with advanced prostate cancer have been reported to preserve physical function following supervised exercise[114].

Bone health: Emerging studies indicate that exercise may attenuate the loss of bone mass in men with prostate cancer undergoing treatment[115-117]. 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 ADT[116]. Results of the trial revealed that impact + resistance exercise attenuated 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[84,118].

KEY POINTS ABOUT EXERCISE MEDICINE

- Exercise medicine is an important intervention to preserve function, ameliorate treatment-related adverse effects and promote wellbeing in men with prostate cancer
- Exercise prescription needs to be personalised for individual men to ensure 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 consider 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.

LIFE COURSE AND MASCULINITIES

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 providers[119]. 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 identities[120]. 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 treatment[121-123].

It has also been proposed that life course is important in considering how masculinity impacts men's health outcomes[124]. 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 belongs[125].

Interventions for men with prostate cancer need to consider life course and masculinity if they are to be acceptable and effective for this patient population[124].

HEALTH LITERACY

In men with prostate cancer, educational level appears to be an important factor in influencing how they respond to psychosocial interventions[20,65,126]; and low literacy has been found to be associated with low knowledge about prostate cancer[127]. This raises a consideration of health literacy when planning and delivering psychological care[128]. Targeting health literacy has been identified as a potentially important factor in addressing the high prevalence of anxiety experienced by men receiving Active Surveillance[17]. For men with newly diagnosed prostate cancer, low health literacy levels are associated with patients being more vulnerable to mental distress[129]. 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 years[130]. In New Zealand, on average, health literacy is also limited[131]. 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 accessible[132]. For men who have low literacy, patient education likely needs to be tailored if it is to be effective[133].

The Health Literacy Questionnaire (HLQ) is a valid and reliable tool for measuring the health literacy of men with prostate cancer[134]. 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 information[135]. 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 life[134]. 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 needed[126]. Seaton and colleagues identify support groups as a potential method to improve access to information and to foster men's health literacy[126].

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 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 value[136]. 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.

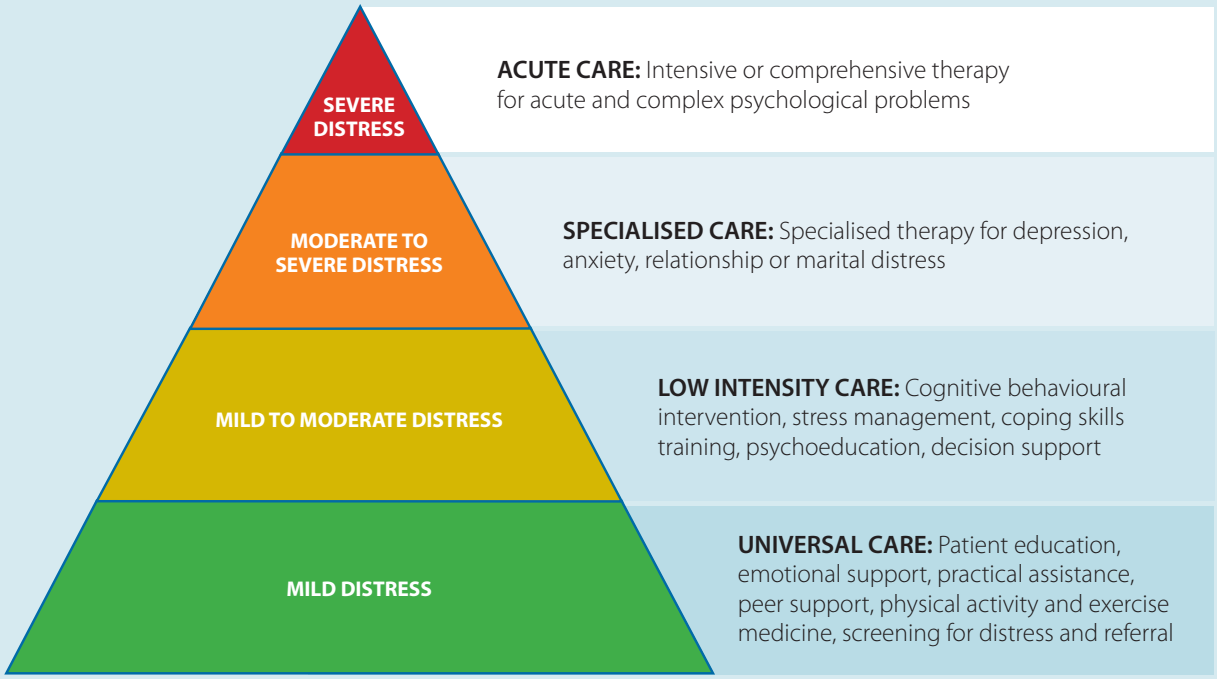
In a tiered approach, as need increases, the depth of care should increase and the area of intervention focus, narrow, and become more specialised[137]. In order for targeted care to be delivered in this way, screening for distress is essential[47].

An example of a care framework that integrates what is currently known about effective interventions for men with prostate cancer with an existing generic cancer and community-based tiered model is presented below in Figure 1.

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.

FIGURE 1. THE TIERED MODEL OF PSYCHOSOCIAL CARE AFTER PROSTATE CANCER
Adapted from the Tiered Model of Care[137]



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.

KEY POINTS TO CONSIDER IN DEVELOPING SERVICES

- Life course and masculinity need to be considered in planning care and developing services for men
- Responsiveness to differing levels of health literacy is needed in order to effectively tailor patient education
- Care should be tailored to the level and type of need expressed by the man with access a key consideration
- A multi-disciplinary approach is needed to provide comprehensive care
- Services across both community and acute settings should be included in a partnership approach

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. **Form 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. **Identify 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. **Examine 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. **Look 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. **Develop 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

Evidence-based and best practice psychosocial care is an essential component of good prostate cancer 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.

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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

To obtain a copy of the Prostate Cancer Distress Screen materials contact the Prostate Cancer Foundation of Australia at Enquiries@pcfa.org.au.

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://www.racgp.org.au/education/gps/gpmhsc/guides/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/index.shtml.

GENERAL

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

Facing the Tiger: A guide for men with prostate cancer and the people who love them. Suzanne K. Chambers. Australian Academic Press, QLD. 2013. ISBN 9781922117052. Also available electronically on Kindle.

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 Kobo and NOOK Book.

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.

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.

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

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.

Prostate Recovery MAP: Men's Action Plan. Craig Allingham. Redsok, Australia. 2013. ISBN 9780987076656.

MINDFULNESS AND MEDITATION

Happy For No Good Reason: A meditators guide. Swami Shankarananda. Motilal Banasidass, India. 2004. ISBN 978-8120820050. Also available electronically on Kindle.

Full Catastrophe Living (Revised Edition): Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness. Jon Kabat-Zinn. Delta Publishing, United Kingdom. 2013. ISBN-13: 978-0345536938. Also available electronically on Kindle.

PROSTATE CANCER RESOURCES

Understanding Prostate Cancer Treatments and Side Effects Series, electronic copies available from the Prostate Cancer Foundation of Australia https://www.prostate.org.au/awareness/further-detailed-information/understanding-prostate-cancer-treatments-and-side-effects/.

The Prostate Cancer Foundation of Australia have developed the following information packs. Hardcopies can be ordered by calling 1800 220 099 or email enquiries@pcfa.org.au:

Localised Prostate Cancer information pack, electronic copies available from the Prostate Cancer Foundation of Australia https://www.prostate.org.au/awareness/for-recently-diagnosed-men-and-their-families/localised-prostate-cancer/.

Advanced Prostate Cancer information pack, electronic copies available from the Prostate Cancer Foundation of Australia https://www.prostate.org.au/awareness/for-recently-diagnosed-men-and-their-families/advanced-prostate-cancer/.

Gay and Bisexual Men information pack, electronic copies available from the Prostate Cancer Foundation of Australia https://www.prostate.org.au/awareness/for-recently-diagnosed-men-and-their-families/gay-and-bisexual-men/.

Partners and Carers information pack, electronic copies available from the Prostate Cancer Foundation of Australia https://www.prostate.org.au/awareness/for-recently-diagnosed-men-and-their-families/partners-and-carers/.

Younger Men information pack, electronic copies available from the Prostate Cancer Foundation of Australia https://www.prostate.org.au/awareness/for-recently-diagnosed-men-and-their-families/younger-men/.

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

To contact a prostate cancer support group in your local area look up the Prostate Cancer Foundation of Australia website (https://www.pcfa.org.au/support/) or call freecall: 1800 220 099. The Prostate Cancer Foundation of Australia is a broad-based community organisation and 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 Helpline 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), open between 9am and 5pm, Monday to Friday, Central Time.

UNITED KINGDOM

The National Federation of Prostate Cancer Support Groups can connect you to a support group 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/.

OTHER USEFUL WEBSITES

http://blog.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.

http://www.pcfa.org.au/

The Prostate Cancer Foundation of Australia is a broad-based community organisation and 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.

https://prostate.org.nz/

The Prostate Cancer Foundation of New Zealand is a community organisation who sees it's role as to helping those recently diagnosed with prostate cancer, and survivors of prostate cancer, to lead productive and full lives through shared counselling and discussions.

https://lionsclubs.org.au/activities/health/prostate-cancer-research-treatment/#scrollSpot2

The Lions Australian Prostate Cancer Website was developed by the education committee of The Australian Prostate Cancer Collaboration (APCC) with funding from the Lions International Clubs of Australia to assist men affected by prostate cancer and their families.

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.

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.

Prostate Cancer Foundation of Australia

NHMRC Centre of Research Excellence
PROSTATE CANCER SURVIVORSHIP

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].

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

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].

Endorsed by

Urological Society of Australia and New Zealand · Australia and New Zealand Urological Nurses Society · The Royal Australian and New Zealand College of Radiologists · Medical Oncology Group of Australia · ANZUP Cancer Trials Group Limited · European Association of Urology Nurses

UTS Centre for Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT) · EMRI Exercise Medicine Research Institute · vario health clinic · ECU Australia's Edith Cowan University · Deakin University · Griffith University Queensland, Australia · Menzies Health Institute Queensland · University of Southern Queensland

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

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)

0 1 2 3 4 5 6 7 8 9 10

No distress **Extreme distress**

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)

_____

Which of these concerns would you like help with?

_____

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.

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