

# Prostate Cancer UK

## Best Practice

## Pathway

### Support pathway

# Support pathway overview

This overview is to provide a take away guide that ensures men living with prostate cancer get the support they need.

<p><b>The support men with prostate cancer need</b></p> <p><b>What does good supportive care look like?</b>          More men are living with prostate cancer and therefore more are living with a variety of physical and psychological side effects. Good supportive care is vital and includes interventions such as Holistic Needs Assessments (HNA) and care planning, a stratified approach to follow-up, tailored rehabilitation programmes incorporating self-management. Psychological support is important and peer support should be offered. Specialist nurses and high quality patient information play a key role in the support pathway.</p>
<p><b>Managing side effects</b>          Treatment options associated with prostate cancer, regardless of its stage, will carry significant physical, sexual and emotional side-effects, which may be life-long and impact on day to day living. In turn, this can cause a reduction in quality of life. Men and their families must therefore be supported in being able to cope and live with these side effects and symptoms. Best practice includes access to information, decision making support, multi-disciplinary support and options for self-management of symptoms including making diet and lifestyle changes.</p>
<p><b>Specific support needs</b></p> <p><b>Sexual problems</b>          Prostate cancer treatments commonly cause erectile dysfunction, infertility, psychosexual dysfunction and specific issues such as and climacturia (leaking urine on orgasm). A recent consensus recommends early ED rehabilitation and treatments include a medical approach, conservative management alongside access to psychosexual support and couples therapy.</p>
<p><b>Urinary dysfunction</b>          Up to 97% of men treated for prostate cancer report lower urinary tract symptoms (LUTS). Detailed assessment is important as nature of the problems can vary and include incontinence, radiation cystitis and urinary retention. Management approaches include non-surgical interventions such as pelvic floor muscle exercises, bladder retraining, external collection devices for men who leak urine, lifestyle changes as well as pharmacological treatment and in some cases different surgical options.</p>
<p><b>Pelvic radiotherapy side effects</b>          Radiotherapy to the pelvis to treat prostate cancer also damages normal tissues in that region causing acute and chronic side effects including: skin/hair changes, urinary dysfunction, sexual dysfunction and fatigue, gastrointestinal (GI) problems, lymphoedema, hip /bone problems and second cancer. GI problems require basic assessment, basic advice and treatment and in some cases further referral to specialists for investigation and specific treatment. Some dietary modifications may be helpful.</p>
<p><b>Fatigue</b>          Up to 74% of men with prostate cancer report fatigue. It can have a debilitating effect on every day life and is linked with psychological dysfunction. Management through exercise, dietary changes and psychological support may help. Prostate Cancer UK provide a telephone based support service for men dealing with fatigue that helps reduce overall fatigue levels.</p>
<p><b>Support for men dealing with the side effects of hormone therapy</b>          Hormone therapy decreases testosterone levels, and has an extensive side-effect profile, the main ones being hot flushes, changes to sexual function, fatigue, weight gain, strength and muscle loss, breast swelling and tenderness, osteoporosis, mood changes, risk of heart disease, stroke and diabetes. Intermittent hormone therapy may play a role in management of these side effects.</p>

Generally, physical activity and psychosocial support are important for men on hormone therapy, as is specific treatment for each side effect.

**Bone health**

Osteoporosis is common in older men and may also develop or worsen as a result of hormone therapy. Fracture risk assessment is important and treatment includes medication such as bisphosphonates, lifestyle changes and offering support to maintain quality of life. Bone metastases are common in men with castrate resistant prostate cancer and treatment includes radiotherapy (EBRT or radioisotopes), less commonly surgery. Men may use analgesics as well as self-management strategies to deal with pain.

**Support for men with advanced metastatic prostate cancer**

30 % of men with advanced metastatic prostate cancer may live for five years, these men are also living with symptoms of the spread of the disease, as well as consequences of previous or current treatment. These include lymphoedema, anaemia, hypercalcaemia, eating problems, lowed GI problems and obstructive uropathy. These need appropriately tailored management, as well as referral to palliative care team to address psychosocial issues associated with coping with advanced stage disease.

**Support for men at the end of life**

As well as effective management of symptoms and access to palliative care services, following national guidance/models men with prostate cancer may have specific support and information needs. These include information to enable practical and emotional preparation and planning plus support for psychological issues for them and their loved ones (extending into the bereavement phase).

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# Prostate Cancer UK Best Practice Pathway

## Stage 3: Support pathway

Prostate cancer survival is improving and has tripled in the last 40 years in the UK.<sup>1</sup> In the 1970s, a quarter of men diagnosed with prostate cancer survived their disease beyond ten years, now it's more than 8 in 10.<sup>1</sup>

More men are living with and after prostate cancer, which means that more men are living with a variety of supportive care needs. These needs may be caused by the physical and psychological side effects of their treatment, as well as the broader impact of the diagnosis on the emotional, practical and social aspects of their lives.<sup>2-5</sup> Additionally, 60% of men with prostate cancer are living with other health conditions.<sup>6</sup> As well as assessing health status prior to starting treatment,<sup>7,8</sup> using approaches to care planning that focus on the entire well-being of a man with prostate cancer should help address these multi-factorial needs (see Holistic Needs Assessment below).<sup>8</sup>

Better support for people after cancer treatment can improve quality of life, and promotes behaviours that may prevent recurrence or complications resulting from the unmanaged consequences of treatments.<sup>7,9</sup>

Good support can also equip people and their families with self-management skills. For example self-management interventions have been assessed in survivors and found to improve urinary symptoms with positive results.<sup>10</sup> Interventions focused on coping skills, diet and exercise can improve quality of life for men with prostate cancer.<sup>11-13</sup>

### What does good supportive care look like?

The National Cancer Survivorship Initiative was created in order to 'better understand the needs of those living with cancer and develop models of care that meet their needs.'<sup>14</sup> This involved a key cultural shift in the approach to care and support for people affected by cancer with a 'greater focus on recovery, health and well-being after cancer treatment.'<sup>15,16</sup>

Support for men with prostate cancer should cover the key generic recommendations that came out of the NCSI. These have been translated by Macmillan Cancer Support into a set of essential interventions known as '[The Recovery Package](#)'<sup>9</sup> including:

- **Holistic Needs Assessment (HNA) and care planning.** An HNA is a simple questionnaire completed by a person affected by cancer covering physical, practical, emotional and spiritual needs. This then informs the development of a care and support plan, which is undertaken with their nurse or key worker. Evidence has shown that individual Holistic Needs Assessment (HNA) and effective care and support planning can contribute to better identification of an individual's needs and concerns. It also enables early intervention and diagnosis of side effects or consequences of treatment.<sup>17</sup> Every man with prostate cancer referred back to community services should have their HNA reviewed on a regular basis.
- A **Treatment Summary (TS)** is a document (or record) completed by secondary care

professionals, usually the multi-disciplinary team (MDT) at the end of, or after, a significant phase of a patient's cancer treatment. It describes the treatment, potential side effects, and signs and symptoms of recurrence. It is designed to be shared with the person after finishing or during ongoing cancer treatment and to inform the GP and other primary care professionals of actions that need to be taken and who to contact with any questions or concerns. The patient also receives a copy to improve their understanding of treatment effects and to know if there is anything to look out for during and after their recovery.

- **Health and wellbeing events** are designed to help people affected by cancer, their family and friends get the support they need during and after treatment. They provide information and support on finance, employment, diet, exercise and ways to manage side effects. Evidence has shown that patients who attended an event have increased knowledge, confidence and reassurance.<sup>15</sup> Health and Wellbeing Events can help provide better patient outcomes and reduce unplanned admissions to hospital.<sup>15</sup>
- A **Cancer care review (CCR)** is a discussion between a patient and their GP or practice nurse about their cancer journey. It helps the person affected by cancer to understand what information and support is available to them in their local area, talk about their cancer experience and enable supported self-management. The Quality and Outcomes Framework (QOF) requires all general practitioners (GPs) to carry out a CCR with a patient within six months of receiving notification of a diagnosis.<sup>15</sup>

### **Stratified follow-up pathways**

More tailored after-care has the potential to reduce costs through better management of side-effects, improved patient satisfaction and by supporting people to live well.<sup>9</sup> Throughout the course of their disease, there should be mechanisms in place to ensure that men with prostate cancer and their primary care providers have access to appropriate specialist services.<sup>18</sup>

Stratification should be related to stage of disease. Men at low risk of prostate cancer recurrence and physical and psychosocial late effects should be encouraged towards supported self-management, those at medium risk should receive planned coordinated care and those at high risk should receive complex care from specialist services. This must include a system for rapid re-entry to the specialist cancer service as required.<sup>9</sup> NHS Improvement (2013) produced the document [Stratified Pathways of Care: How to Guide](#) which has more information.

#### **Follow-up in the community**

After at least 2 years, NICE guidance advises that for men with a stable PSA who have had no significant treatment complications, follow-up can be offered outside of a hospital setting by telephone or secure electronic communications (unless they are taking part in a clinical trial that requires formal clinic-based follow-up). Direct access to the urological cancer MDT should be offered..

**For men with localised disease**, the definition of biochemical relapse differs depending upon the treatment received.<sup>18</sup> Therefore the urology cancer MDT should provide letters to community services that set out individual PSA parameters for referral back to specialist care.

**For all men with prostate cancer**, it's recommended that locally commissioned follow-up services should include the following as a minimum,<sup>9</sup> (in addition to what is in the Recovery Package):

- Potential markers of recurrence/ secondary cancers and information on what to do in these circumstances.



- Key contact point for rapid re-entry if recurrence markers are experienced or if serious side effects become apparent.

The following is a well evidenced example that could be adopted:

Prostate Cancer UK has worked with The Christie in Manchester to establish a role for Clinical Nurse Specialists working between primary and specialist care. Men on routine follow-up after prostate cancer treatment are moved into community based prostate cancer follow-up clinics. These are run by a nurse specialist with expert clinical skills, experience in managing this group of men, and who is competent at assessing and dealing with symptoms of late effects. Positive outcome data and patient satisfaction demonstrated the safety of transferring care out of the hospital earlier, and cost savings are anticipated.

## **Rehabilitation**

Men should have access to adequate and appropriate rehabilitation to support their individual needs throughout the whole cancer pathway.<sup>19</sup>

Support should also be tailored to the specific needs of men with prostate cancer such as fatigue, erectile dysfunction, urinary continence, psychological issues and other more generic side effects of cancer,<sup>9,20</sup> all of which are covered in more detail in this best practice pathway.

Self-management and support programmes can be tailored to men with similar needs, for example they can be focused on a specific side effect such as urinary dysfunction.<sup>14</sup> However, it is also important to consider that needs vary in terms of the treatment men have received, their economic status, social support and ethnicity. These factors should also be taken into account explicitly in developing, targeting and evaluating programmes.<sup>14</sup>

Case study: [Creating an effective prostate cancer survivorship programme](#)

Case study: [Supported self-management for prostate cancer patients](#)

## **Access to specialist nurses**

Men should have access to a specialist nurse or dedicated urology key worker, as this has a significant influence on outcomes for men with prostate cancer<sup>15</sup> and has a positive impact on patient experience and outcomes.<sup>22</sup>

Nursing support can improve key areas of care, for example support for sexual dysfunction, psychological care, provision of information, and the management of symptoms and long-term side effects.<sup>17</sup>

## **Access to information**

All men with prostate cancer should be given information and advice on the likelihood of experiencing potential consequences of treatment or late effects and the management of these.<sup>19</sup> This includes information highlighting “red flag” symptoms that need urgent care, such as metastatic spinal cord compression (MSCC).

Having access to high quality information can improve health and wellbeing and contributes to clinical effectiveness and safety as well as improving patient experience.<sup>23</sup> This is as a core part of patient care and should be personalised and delivered as standard. Information should be accompanied by appropriate support structures to ensure it can be used effectively.<sup>24</sup>

Prostate Cancer UK produce award-winning information for men with prostate cancer and their families. Our information is [certified by the Information Standard](#) as being accurate, impartial, balanced, evidence-based, accessible and well-written. All our information is available to [read online](#) and to [order free of charge](#) for patients.

Men can also be referred to the interactive '[How to manage' guides](#) that provide information on managing the side effects of prostate cancer and its treatment. The guides give men the tools to help men take control. They can watch films of real life stories, read tips from those who have been through similar experiences and learn new ways to manage their symptoms and side effects.

## ***Psychosocial support***

A diagnosis of cancer inevitably has psychological consequences<sup>25</sup> and the psychosocial burden of prostate cancer is well documented.<sup>4,26</sup> A meta-analysis found that the pre-treatment prevalence of depression and anxiety across studies was 17.3% and 27.0% respectively and post-treatment was 18.4% and 18.5%.<sup>26</sup>

Under NICE guidance, men with prostate cancer and their carers should have their psychological well-being assessed at key points in the patient pathway<sup>27</sup> (e.g. as part of the Holistic Needs Assessment). All staff directly responsible for patient care should offer men general emotional support based on skilled communication, effective provision of information, courtesy and respect.<sup>28</sup> Men and their carers found to have significant levels of psychological distress should be offered prompt referral to services able to provide specialist psychological care.<sup>28</sup>

Men with prostate cancer who have depression should be offered medication and psychological treatment.<sup>9</sup> Specifically, it's currently recommended that NHS England should consider piloting, through new or existing vanguard sites, the commissioning of integrated evidence-based depression care that includes screening and treatment systems.<sup>9</sup> For example, a recent large randomised trial tested a systematic collaborative care model, "Depression Care for People with Cancer" (DCPC), which is a team-delivered system of care in which a psychiatrist supervises specially trained cancer nurses who see the patient and work in collaboration with primary care to deliver and monitor treatment. DCPC substantially reduced depression and improved quality of life when compared with usual care.<sup>27</sup>

Other possible relevant psychosocial interventions for men with prostate cancer and their partners include group cognitive-behavioural and psychoeducational interventions. A systematic review concluded that these were helpful in promoting better psychological adjustment and quality of life (QOL) for men with prostate cancer and that coping skills training for couples improved QOL for partners.<sup>29</sup>

Men with prostate cancer should have access to peer support. Men have reported that peer support helps by providing a source of useful information and advice about their cancer; helping them understand their condition, 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.<sup>30</sup> Men with prostate cancer have described a preference for having access to peer support as close as possible to the time of diagnosis.<sup>31</sup> Many hospitals now offer access to peer support groups during and after therapy has been completed, additionally men can be referred to Prostate Cancer UK's [one-to-one support service](#) if appropriate.

“I greatly benefitted from speaking to the volunteers. It was helpful to hear their personal experience as it was directly related to my situation. I feel better informed about what to expect, because they have actually been through the treatments themselves and know what it’s like.”

Experience of man accessing the Prostate Cancer UK [one-to-one support service](#)

## 3.1 Managing side effects

Treatment options associated with prostate cancer, regardless of its stage, will carry significant physical, sexual and emotional side-effects, which may be life-long and impact on day to day living. In turn, this can cause a reduction in quality of life.<sup>32</sup> Men and their families must therefore be supported in being able to cope and live with these side effects and symptoms.

This may involve measures to 'treat' the side effects and symptoms, but should also involve information and advice on how to 'manage' them and make adjustments to lifestyle. It may also involve psychosocial support such as counselling, or financial support.<sup>33</sup> Men should be informed of the health and social services available to them and encouraged to access them as suits their individual needs.

The side effects of each treatment modality are described in the **Treatment pathway**. In this section common side effects are covered in more detail in the context of recommended support and management strategies.

All men will experience side effects differently, and prevalence rates vary depending on treatment type, age and the previous health and well-being of the individual.<sup>34</sup> However, some key statistics from PCUK’s 2012 survey of men receiving treatment for prostate cancer are:\*

- **68% of men reported urinary incontinence.**<sup>35</sup> This has a major negative effect on quality of life in terms of mental and physical health, and social interactions.<sup>32,36–41</sup> Often, it can be associated with long term conditions like skin irritation and skin breakdown, urinary tract infection, falls, and increased hospital stays.<sup>28</sup>
- **67% of men reported fatigue.**<sup>35</sup> All treatment types caused fatigue, albeit to different extents. Men who received combined radiotherapy and hormone therapy treatments were most at risk of chronic fatigue.<sup>42</sup>
- **76% of men reported erectile dysfunction.**<sup>35</sup> More than half of these men said their erectile dysfunction had a negative impact on how they felt about themselves, citing depression, sadness, inadequacy, low self-esteem and loss of masculinity. 47% said that erectile dysfunction had negatively affected their relationship.<sup>43</sup>

### Side-effects specific to advanced prostate cancer

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\* Breakdown of treatments received in this survey is as follows: active surveillance 10%, brachytherapy 24 %, chemotherapy 21%, cryotherapy 1%, HIFU 4 %, hormone therapy 26%, Other 4 %, radiotherapy 43 %, surgery 35 %, watchful waiting 10 %.

Men whose disease is not curative have specific side effects from treatments, symptoms of advancing disease and different psychosocial support needs relating to disease progression that need to be addressed. Therefore these are covered in a specific section of the support pathway. Information highlighting “red flag” symptoms of metastatic spinal cord compression (MSCC) should be made available to all men.

## General side effect management principles

### *Information and decision making support*

NICE recommends that men with prostate cancer and their partners or carers should be well informed about the effects of prostate cancer and the varying impacts that treatment options can have on their sexual function, physical appearance, continence and other aspects of masculinity.<sup>18</sup> Information should also cover how best to manage these side effects, including those that might appear after some months/years.<sup>9</sup>

### *A holistic approach*

Side effects or late adverse effects of treatment can manifest systemically and have a major influence on the patient’s quality of life (QoL).<sup>44</sup>

Therefore holistic care should consider physical, mental and social issues – for example relationships, work/vocation, as these all have a bearing on perception of quality of life.<sup>46</sup> Psychosocial care and needs of carers and partners should also be considered as part of clinical care.<sup>47</sup>

### *Multi-disciplinary care*

Holistic care requires the intervention of a multi-disciplinary team.<sup>44</sup> Men with prostate cancer should receive care from a multi-disciplinary team (MDT). Collaboration between MDT members (see table below) is central to the treatment and support, with ongoing support from the wider team to manage pain and the adverse effects of therapy.

Urological surgeons	Oncology and urology nurse specialists
Clinical and medical oncologists	Palliative care specialist
MDT co-ordinator and secretarial support	Histopathologists
Radiologists	

This should be implemented in line with the stratified pathways of care described in the introduction to this document.

Refer to MDT Guidance for Managing Prostate Cancer (British Uro-oncology Group (BUG) in partnership with the British Association of Urological Surgeons (BAUS) Section of Oncology).

### *Self-management*

As described in the introduction, some men with prostate cancer can be encouraged to self-manage side effects and symptoms. Promoting self-management can help to reduce the burden on the health service, allows direct professional intervention to be focused on those in most need, and for men who are able to self-manage, it helps to promote a sense of wellbeing and control as they transition into this survivorship phase.<sup>33</sup> It is important to note that self-management doesn’t mean a lack of care; just a different, more personalised means of support, tailored to individual need.<sup>30</sup>

Effective self-management still requires the patient to have access to relevant information and self-management programmes.

## **Physical activity**

Advice on diet, exercise and lifestyle should inform part of a side effects management approach.

In general there is growing evidence to support the role of physical activity during and after cancer treatment, amongst other things to help with management of some of the side effects of prostate cancer treatment<sup>48-52</sup> and help with feelings of anxiety or depression.<sup>53</sup>

For cancer survivors generally:<sup>54</sup>

Physical activity improves, or prevents the decline of, physical function without increasing fatigue

- physical activity helps recover physical function after cancer treatment
- physical activity can reduce the risk of cancer recurrence and mortality for some cancers and can reduce the risk of developing other long term conditions.

Men should aim to be physically active at least two to three times a week<sup>55</sup> and be advised to start gently for short periods of time, such as 10 to 15 minutes, before gradually increasing the amount as they become fitter. If possible, they should aim to build up to 30 minutes of moderate exercise three to five days a week.<sup>56</sup>

- Following an exercise programme such as walking 10,000 steps a day can be useful. Further information is available via [NHS Choices website](#) and [Walking for Health](#) offers men a way to find local walking schemes
- Gentle resistance exercise, such as lifting light weights or using elastic resistance bands, are particularly good for men on hormonal therapy and at risk of bone thinning.<sup>55,57</sup> Men on hormonal therapy and/or with bone metastases should check with their specialist team before doing high-impact exercises such as running or contact sports.

## **Diet and lifestyle**

Dietary and lifestyle advice should form part of effective side effect management as staying a healthy weight can help manage or reduce some of the side effects of treatments, such as urinary problems after surgery.<sup>49,55,58</sup> Men of a healthy weight are more likely to find medical treatments for ED effective<sup>59</sup> and some dietary modifications may help with gastro-intestinal side effects such as diarrhoea.<sup>60-62</sup>

Men should be supported in smoking cessation as smoking may increase the risk of prostate cancer spreading<sup>63</sup> and recurring after surgery or radiotherapy.<sup>63,64</sup> Smoking cessation can also help with reduction of treatment side effects, such as urinary problems after radiotherapy<sup>65</sup> and decreases the risk of osteoporosis.<sup>66</sup>

Men can be referred to Prostate Cancer UK's information on diet and physical activity.

## 3.2 Sexual problems

Psychosexual concerns are the most significant problem encountered by survivors of prostate cancer.<sup>65</sup>

Seventy-eight per cent of men with treatment-induced erectile dysfunction, told us they found - or continue to find - it 'difficult' or 'very difficult' to deal with. More than half of these men said their erectile dysfunction had a negative impact on how they felt about themselves, citing depression, sadness, inadequacy, low self-esteem and loss of masculinity. Forty-seven per cent said that erectile dysfunction had negatively affected their relationship.<sup>43</sup>

The National Institute for Health and Care Excellence (NICE) recommends that men and their partners are given the opportunity to discuss psychosexual problems before and after treatment.<sup>18</sup> Yet it may be difficult for men to raise sexuality-related issues with health professionals due to embarrassment, stigma and feelings about masculinity.<sup>2,67</sup> Additionally, the loss of sexual function may only become important years after treatment when the threat to survival passes, at which point men may feel that they have lost the opportunity to seek support.<sup>67-69</sup>

Equally, clinicians may feel that there are barriers to opening up discussion of sexual concerns with their patients, such as issues to do with sensitivity, complexity and constraints of time and expertise.<sup>70</sup> It's important to develop some effective ways to raise these issues with patients, as clinicians who are responsive to patients' sexual health needs by delivering medical information or by acknowledging patients' concerns, may help alleviate the burden of sexual side effects.<sup>71</sup> It is also vital that health professionals ask specific questions about sexual orientation and sexual practice in order to empower all patients, including men who have sex with men and transgender women, to make fully informed decisions about their treatment and how to manage sexual dysfunction.<sup>72</sup>

As well as having access to high quality information about sexual side effects before and after treatment,<sup>73,74</sup> men and their partners should have access to additional psychological therapy<sup>75</sup> and peer support. For example, support groups allow men the space to be more open about their psychosexual concerns.<sup>76,77</sup>

Management of patients should take a tailored individual psychosexual approach.<sup>78-80</sup> Consultation should include a discussion of the expectations and needs of both the patient and his sexual partner, if available.<sup>59,81</sup> It should also review both the patient's and partner's understanding of sexual problems, and provide a selection of treatment options.<sup>81</sup> Patient and partner education is an essential part of management.<sup>59,81</sup>

### Assessing sexual problems

As it may take time for sexual problems to manifest and for men to place importance on them, assessment of psychosexual needs should take place throughout the follow-up period, and not only at the time of initial treatment. GPs could play an important ongoing role in assessing wider psychosexual needs and signposting where to get help when needed.<sup>67</sup>

The assessment should include:

- Initial assessment of the patient and their partner's sexual function,<sup>82</sup> including full sexual, medical, psychiatric and surgical histories.<sup>83</sup>
- Exploring comorbidities, concurrent medication and lifestyle habits.<sup>82</sup>

- Validated questionnaires, particularly the **International Index of Erectile Function (IIEF)**<sup>84</sup> or the validated shorter version of the **SHIM (Sexual Health Inventory for Men)**(or IIEF-5) may be helpful.<sup>83</sup> The erection hardness score (EHS) can also be helpful in discussing erections.<sup>83</sup>
- A physical examination and laboratory testing, which will depend on the individual patient (for example serum lipids, fasting plasma glucose, and HbA1C, PSA and testosterone levels).<sup>83</sup>
- Assessment of psychological factors (sexual self-esteem/confidence), relationship issues and any social factors that could impact on sexuality or that are affected by sexual dysfunction.<sup>59</sup> It is also important to consider the potentially varied needs of men who have sex with men, transgender women and single men.<sup>72</sup> [See [online learning module on sex, relationships and prostate cancer for further resources](#)]

## Erectile dysfunction

Erectile dysfunction (ED) is defined as the persistent inability to attain and maintain an erection sufficient to permit satisfactory sexual performance.<sup>81</sup>

Erectile function depends on intact vascular and nervous supply to the penis, normal anatomy, normal hormonal response and psychological factors. Disruption to any of these systems can result in ED.<sup>81,85</sup>

ED is common in the general population with rates ranging from 10-52% depending on the study (rates rising with age).<sup>81</sup> As well as prostate cancer and its treatment, there may be a variety of other factors that increase men's risk of ED, including vasculogenic, central/peripheral neurogenic, anatomical/structural, drug-induced, psychogenic, trauma or hormonal causes. (See the [European Association of Urology Guidelines on Male Sexual Dysfunction](#) for a detailed list). Older men may be more at risk of ED, as other ED related health problems such as hypertension and type two diabetes increase with age, as do lower urinary tract symptoms (with or without prostate cancer).<sup>86</sup>

Advanced prostate cancer can cause ED through infiltration of the neurovascular bundles which supply the penis. ED can also be a side effect of treatments for prostate cancer.<sup>81</sup>

Prostate cancer treatments that cause ED:

### Radical prostatectomy

- ED is a result of damage to the neurovascular bundles which supply the penis during surgery.<sup>81</sup> Erectile dysfunction used to occur in nearly all patients, but this can be avoided by using nerve-sparing techniques in early-stage disease. Impotence after RP: 29-100%.<sup>49</sup>
- ED is less likely if the man has had nerve sparing surgery, although it can often take up to 2-3 years for some spontaneous erectile function to return, most men will need to have treatment in order to regain function.<sup>87</sup>
- Erectile function is also more likely to be retained in younger men who did not have erectile problems before surgery.<sup>88</sup>

### External beam radiotherapy (EBRT) and brachytherapy

- ED is due to damage to the corpus cavernosa and the nerves and blood vessels that supply the penis.<sup>86</sup> In EBRT and low dose rate brachytherapy, ED develops in about 40% of the patients after 3-5 years.<sup>49,89</sup> However, the frequency of erectile dysfunction is significantly increased with HDR brachytherapy (86% vs. 34%).<sup>49,89</sup>
- The impact is not immediate, and occurs more slowly than after radical prostatectomy.<sup>81</sup>



### **Hormone therapy**

- ED affects up to 85% of men receiving hormone therapy through inducing a hypogonadic state, and can contribute to reduced libido as well as ED.<sup>81,82</sup>
- The effect can be delayed, or progressive over a number of years.<sup>81</sup>
- Hormone therapy has a particularly detrimental effect on erectile function when combined with radiotherapy and post-treatment potency may be worse than with radiotherapy alone.<sup>90</sup>

### **Other treatments**

There have been fewer studies looking at side effects of treatments such as cryotherapy and high-intensity focused ultrasound (HIFU). But both can cause ED.<sup>81</sup> For cryotherapy, ED is reported to occur in about 80% of patients,<sup>45,89</sup> whereas for HIFU, ostoperative impotence occurs in 55-70% of patients.<sup>45,89</sup>

## **Treating ED**

Men whose prostate cancer treatment may cause erectile dysfunction should have early access to specialist erectile dysfunction services for assessment and treatment. A UK-wide consensus published in the International Journal of Clinical Practice in 2014 recommends early ED rehabilitation as it can improve blood flow to the penis and reduce cavernous tissue damage, thereby preventing penile atrophy.<sup>59</sup> This may help improve long term erectile function and an earlier return of assisted or unassisted erections sufficient for intercourse - in both men after surgery and in men who have had radiotherapy and/or hormone therapy.<sup>59</sup>

This may involve first-line treatment with combination therapy, usually daily low dose PDE5-I tablets and vacuum erection device (VED).<sup>59,82</sup> If initial treatment fails, offer alprostadil pellets, injections or topical alprostadil, with penile implants indicated as a third-line treatment.<sup>82</sup>

In general, treatment options depend on the causes of sexual problems; for example, slightly different pathways are recommended for men who have ED related to hormone therapy or radiotherapy and for men who are recovering after radical prostatectomy. This may vary again depending on whether they've had nerve sparing surgery or not.<sup>59</sup>

Read more:

- [Treating erectile dysfunction after radical radiotherapy and androgen deprivation therapy \(ADT\) for prostate cancer. A quick guide for health professionals: supporting men with erectile dysfunction](#)
- [Treating erectile dysfunction after surgery for pelvic cancers A quick guide for health professionals: supporting men with erectile dysfunction](#)

### **Medical treatments**

- PDE5-1 Tablets (sildenafil, tadalafil, vardenafil and avanafil)
- Vacuum erection device (VED)
- Pellets (transurethral alprostadil)
- Penile injections (ICI)
- Topical cream (transdermal alprostadil)

### **Conservative management**

- Fitness is central to erectile function,<sup>91</sup> and men of a healthy weight are more likely to find



medical treatments for ED effective. So exercise programmes and lifestyle changes should also be offered and supported.<sup>59</sup>

- [Pelvic floor muscle exercises](#) offer a no cost, non-invasive option that may help give men a sense of control over their symptoms.<sup>92</sup> But there is no published evidence of benefit when used alone as an ED management strategy.<sup>59,82</sup>

## Psychosexual issues

Psychosexual concerns are the most significant problem encountered by survivors of prostate cancer.<sup>93</sup> Psychosexual concerns may not develop straight away<sup>94</sup> and may persist for a number of years,<sup>95</sup> even after men have returned to their baseline level of sexual function.<sup>96</sup> Such concerns involve psychological, emotional and physical factors<sup>97</sup> and include issues such as:

- Dissatisfaction with sexual intercourse.<sup>98,99</sup>
- Decreased libido<sup>100</sup> and sexual desire.<sup>101,102</sup>
- Changes to a man's sense of masculinity, identity, self-esteem and his quality of life.<sup>44,46,59,103</sup>
- Impact on relationships.<sup>81,85</sup>

Changes in sexual function for the patient can also affect their partner and intimate relationships.<sup>72</sup> Partners should be involved in any assessment, treatment planning for sexual problems and couples therapy or counselling.<sup>72</sup> In addition, partners may report increased levels of anxiety, depression and relationship dissatisfaction and may need further support.<sup>104–106</sup>

In particular, the psychosexual impact of hormone therapy on a man and his intimate partner can be profound and complex, for some it can mean an end to their sex life.<sup>107</sup> However, psychosexual effects may be mitigated when the man and his partner are well-informed about the effects of treatment before it begins and given access to psychosexual counselling.<sup>108</sup>

Watch [men's personal stories](#) of sex after prostate cancer.

## Psychosexual therapy/counselling

Psychosexual counselling and couples therapy may be beneficial.<sup>75,109–111</sup> They are important in improving outcomes of sexual rehabilitation programmes, improving acceptance of, and adherence to, treatments, reducing feelings of a lack of sexual spontaneity and dissatisfaction, and dealing with a fear of needles. They can help when other treatment strategies are unsuccessful and assist couples to overcome distress and strengthen their relationship.<sup>59,82</sup>

NICE recommend that **all** men with prostate cancer and their partners or carers are given the opportunity to talk to a healthcare professional experienced in dealing with psychosexual issues at any stage of the illness and its treatment. All Trusts in England have sexual function services and specialist continence services available, and most have psychological support services,<sup>112</sup> but NICE acknowledge concerns about current variable access to psychosexual counselling and recommend a particular focus on referring men being treated with long term androgen suppression and their partners for psychosexual counselling.

## Fertility

All the management options for prostate cancer (except active surveillance) harm men's fertility.<sup>113</sup> Brachytherapy may be less harmful than EBRT and surgery.<sup>113</sup> Health professionals should cover

infertility when discussing the pros and cons of various prostate cancer therapies with patients.<sup>113</sup> It should be recognised that the prospect of infertility can be psychologically and socially damaging but that such an outcome can, to some extent, be mitigated by sperm storage prior to treatment.<sup>114</sup>

## Climacturia

After surgery, 3% to 19% of men may leak a small amount of urine on orgasm (climacturia or orgasm associated incontinence).<sup>115</sup> They should be reassured that, although shocking, urine is germ-free and safe.

If it bothers them they could try:

- urinating before sex
- wearing a condom
- having sex in the shower, on a towel, or keeping towels or tissues nearby.

They could also try urinating before sex, then waiting a few seconds and using their fingertips to press gently behind the scrotum. They might also find moving their fingers forward towards the base of the penis under the scrotum and pressing gently useful. This should push the urine further along the urethra. They can then shake the last few drops out in the normal way.

Pelvic floor muscle exercises may also help.<sup>116</sup>

Refer men to Prostate Cancer UK's [video](#) featuring psychosexual therapist Lorraine Grover talking about practical steps they can take to deal with climacturia.

## Other sexual problems

Prostate cancer treatment can cause other sexual problems such as changes to orgasms, changes to ejaculation, genital / pelvic pain, and changes in penis size.<sup>81,85,87</sup> Men can find more information and support on these in Prostate Cancer UK's [How to manage guides](#).

## Case study – Psychosexual therapy, Prostate Cancer UK and Relate

### The team

Prostate Cancer UK worked with Relate to identify ways in which counselling could support men and their partners to deal with these, or similar, issues in a project funded by The Movember Foundation.

### Our solution

Relate counselling services are appropriate for any family member when life events have a negative impact on relationships. Prostate Cancer UK trained Relate counsellors to deliver prostate cancer specific support and counselling. Relate offered men and their loved ones up to 10 sessions of psychosexual therapy or relationship counselling at their local branch. Men could either be referred to the service by a health professional or self-refer via an easy and accessible referral mechanism.

Counsellors used the Hospital Anxiety and Depression scale to measure improvement and changes in clients using the counselling service. The client answers a set of 14 questions at their first session, and the same 14 at their final session. Statements are then given a score of 1-4 with 4 being a high indicator for either anxiety or depression.

### The results

This service had a significant impact for men and their loved ones:

- 73 per cent reported a reduction in anxiety
- 73 per cent reported a reduction in their depression
- 73 per cent reported improved acceptance of their situation
- 73 per cent reported improved ability to manage expectations
- 80 per cent reported improvements in their relationships after the sessions
- 90 per cent reported improved satisfaction with their sexual function.



I now understand more about myself and how I am in a relationship. I feel more in control of my sexual difficulties and can prioritise what I want in a relationship moving forward.



After the first session I felt more relaxed, and when I went home I went through everything with my wife and later, after further sessions, the family. It made a real difference. I'm still worried, but not as much, I realised I had lots of support around me. I would recommend anyone in my situation to seek some counselling, it helped me and my family.

### Next steps

Following the success of this partnership in Greater Manchester, Prostate Cancer UK funded a further 16 Relate services across England, Wales and Northern Ireland with support from The Movember Foundation. We also developed an online Livechat service with Relate, offering 1:1 support via a web link. The service has delivered over 1,600 counselling sessions to those affected by a prostate cancer diagnosis and has provided Relate with a model for supporting men around cancer in the future.

\* Macmillan paper (conducted by Opinion Leader Research) April 2006 p16. Worried Sick – the Emotional Impact of Cancer.

## 3.3 Urinary dysfunction

Treatment for prostate cancer can cause urinary dysfunction; most commonly this is incontinence. Other symptoms include frequency, urgency, urinary retention and pain all of which affect a man's quality of life during and after treatment.

In the general population moderate-to-severe lower urinary tract symptoms (LUTS) are present in about 30% of men over 50.<sup>117</sup> However, a UK survey undertaken in 2008 and involving 741 men, found that 97% of men treated for prostate cancer reported lower urinary tract symptoms (LUTS) of frequency, nocturia, urgency and dysuria.<sup>2</sup> Over half of these men reported their symptoms as moderate to severe.<sup>2</sup>

Stigma is still associated with urinary dysfunction, especially incontinence.<sup>10</sup> Urinary dysfunction may cause embarrassment, isolation or stress for men, and can have an impact on their independence, work, social and sex lives.<sup>118</sup> Psychological distress may be linked with increased urinary symptoms.<sup>2</sup>

Men with urinary dysfunction should have access to specialist continence services and be offered treatment and care that takes into account their individual needs and preferences.<sup>117</sup> It's important that they are able to make informed decisions about the management of symptoms in partnership with their healthcare professionals.<sup>117</sup>

As well as offering information and support, emotional distress may be decreased by encouraging self-management of urinary symptoms. For example, provision of a self-management intervention based on cognitive and behavioural approaches can reduce urinary symptoms and improve HRQL, enhancing men's ability to cope more effectively with enduring effects of prostate cancer and its treatment.<sup>10</sup>

## Assessment of urinary dysfunction in general

A 2015 integrative review of the non-invasive management of LUTS in men who've had treatment for pelvic cancer aimed at non-specialist clinicians and supported by Macmillan Cancer Support recommends:<sup>119</sup>

- General assessment including self-reported incontinence.
- Use of one of the validated questionnaires, e.g. IPSS, ICIQ-LUTS QoL for QoL; ICIQ UI for incontinence and ICIQ OAB for storage LUTS symptoms to complement self-reported continence.
- Writing a 3–7 day bladder diary
- Considering pad usage
- Dipstick urinalysis for leucocytes and nitrites to rule out infection.
- Dipstick analysis for haematuria.

### **Additional actions could include:**

- Bladder ultrasound for identifying residual and structural issues.
- Flow rate and measurement of urodynamics (usually available through community Continence nurse services).
- Considering and evaluating sexual side effects in tandem, as treatment for urinary problems may impact on sexual function.<sup>120</sup>

As urinary symptoms can develop months to years after treatment, regular assessment of prostate cancer survivors is necessary.<sup>119</sup> For men followed-up in secondary care, assessment should occur at every appointment. For those discharged into the community, this assessment would fall to their GP and/or questions about continence could form part of the Holistic Needs Assessment. These men will need rapid access back to specialist urology services as required.

## Urinary incontinence

Urinary incontinence (UI) is the involuntary leakage or passing of urine. It may range from a few drips, to larger amounts which require the use of an incontinence product.

The prevalence of UI after radical prostatectomy can range from 2% to 60%, albeit at varying times after the operation.<sup>121</sup> Problems tends to improve with time, although, some men are left with incontinence that persists for years afterwards.<sup>121</sup>

Incontinence is less likely after radiotherapy treatment, but the risk is increased in men who've previously had a transurethral resection of the prostate (TURP) for an enlarged prostate.<sup>49,122</sup> Incontinence can be broken down into three groups:

**Urge incontinence** is an overwhelming and sudden desire to pass urine and is caused by an instability in the detrusor muscle. Men may also find that they need to pass urine more frequently with this condition. Urge incontinence can sometimes occur after radiotherapy, as the treatment can

irritate the bladder muscles resulting in decreased bladder capacity. It is more likely to occur after prostatectomy, particularly if the prostate caused some urinary outflow obstruction prior to surgery. The bladder muscle will have been working hard to overcome the resistance due to the blockage, and this may continue post-operatively.

**Stress incontinence** occurs when the urinary sphincter loses its ability to remain contracted. The bladder may leak urine whenever it is strained (for example, by exercise, coughing or sneezing). Stress incontinence is common in men who've had radical prostatectomy as during surgery the urinary sphincter can become damaged.

**Overflow incontinence** is common in men with bladder outflow obstruction. Obstruction can be caused by either malignant or benign enlargement of the prostate or a urethral stricture. This causes the bladder to overfill with urine, and some is forced out into the urethra.

## ***Managing incontinence***

Management options depend on the type of incontinence a man is experiencing as well as patient choice, manual dexterity and performance status<sup>123</sup>.

### **Non-surgical interventions**

First-line management in the 12 months post-treatment for prostate cancer should be non-surgical:

#### **Pelvic floor muscle exercises**

NICE recommends offering supervised pelvic floor muscle training to men with stress urinary incontinence caused by prostatectomy. Their guidance promotes continuing the exercises for at least 3 months before considering other options.<sup>117</sup>

Additionally, there is mixed evidence suggesting that preoperative or immediate postoperative exercises are useful,<sup>10,119,121,124–126</sup> and can improve pelvic floor and urethral instability, reducing post-surgery incontinence.<sup>124</sup> An earlier return to continence was observed if exercises were started early in the post-treatment period and therapist-guided exercises were shown to significantly improve time to return of continence, especially after prostate surgery.<sup>119</sup>

*Other recommendations have been developed through clinical consensus and include:*

Start pre-treatment (ideally 1 month before surgery or within one month of radiotherapy, or catheter removal after surgery).

- Consider using a physiotherapist or at least a DVD with a physiotherapist demonstrating the exercises
- Continue exercises for at least 6 weeks in combination with biofeedback, if possible.

[Information for men who want to know more about pelvic floor muscle exercises.](#)

#### ***External collecting devices***

NICE recommends offering external collecting devices for men who are leaking urine, before considering indwelling catheterization.<sup>117</sup>

#### **Absorbent pads or pants**

These are used as a first-line intervention in clinical practice<sup>119</sup> for absorbing and containing a light – to moderate amount of urine. The type of pad will be determined mostly by personal preference but will also be influenced by the severity and frequency of leakage. Some men prefer to use pads in combination with another product. [More information.](#)

### **Urinary sheaths**

These fit over the penis and are connected to a catheter valve for very light leakage, or a drainage bag for moderate to heavy leakage.<sup>127</sup> They may be a suitable solution for men who want to keep active or go out for prolonged periods of time where a toilet may not be accessible or changing a pad may be difficult or cause embarrassment. They can be difficult to use as they don't always stay on, but correctly fitted sheaths can be helpful.<sup>119</sup> [Further information](#).

### **Penile compression devices**

Also known as or clamps, these devices fit around the penis and compress the urethra in order to prevent leakage. They are **not** recommended by NICE for men with urinary incontinence,<sup>117</sup> as they can be uncomfortable to wear and should not be worn for prolonged periods of time or overnight because they reduce blood flow into the penis.<sup>128</sup> For this reason they may be most suitable for some men in an early stage of treatment (e.g. experiencing stress incontinence to use during exercise)<sup>129</sup>. Good dexterity is required.<sup>119</sup> [More information](#).

### **Catheterisation**

After surgery, men will have a temporary indwelling catheter. Long-term indwelling urethral catheterisation should only be offered to men with lower urinary tract symptoms (LUTS) if medical management has failed and surgery is not appropriate and:

- They are unable to manage intermittent self-catheterisation; or
- They have skin wounds, pressure ulcers or irritation that are being contaminated by urine; or
- They are distressed by bed and clothing changes.

Men on long-term indwelling urethral catheterisation should be given advice about managing it, so that the risk of infection or other complications are reduced.<sup>117</sup> Read Prostate Cancer UK's fact sheet for more information.

### ***Pharmacological management***

NICE recommends drug treatment only after the conservative management options described above have been tried.<sup>117</sup> Drug treatment for urinary incontinence will depend on local prescribing guidance,<sup>119</sup> and should be based on precise symptoms and cause, but may involve alpha blockers, anti-muscarinics (anti-cholinergics), 5-alpha reductase inhibitor or diuretics.<sup>117,119</sup> The 2015 [integrative review](#) described above offers sequencing recommendations and further guidance.

### ***Surgical management for post-prostatectomy incontinence***

Surgical interventions should only be considered after 1 year.<sup>119</sup>

NICE recommend that adjustable compression devices and male slings to manage stress urinary incontinence are offered only as part of a randomised controlled trial.<sup>117</sup>

### **Artificial urinary sphincter (AUS)**

This consists of an inflatable cuff that continuously compresses the urethra and a control pump in the scrotum.<sup>130</sup> When the control pump is squeezed, fluid from the cuff is moved to the reservoir balloon, which means the man can urinate, after which the cuff is automatically refilled.<sup>130</sup> Different cuff sizes are available and are selected before surgery according to urethral diameter.<sup>130</sup>

AUS is an option for men:

- With moderate to severe urinary incontinence.<sup>124</sup>
- Who have not responded to conservative management or drug treatments.<sup>117</sup>

AUS may not be as effective for men who do not have the cognitive ability or dexterity to operate

the pump.<sup>124</sup> Possible complications and side effects include: mechanical dysfunction, urethral constriction by fibrous tissue, erosion and infection.<sup>124,131,132</sup>

### Internal male sling

This involves the insertion of synthetic or organic material that compresses the urethra and supports the urinary sphincter to keep it closed. Slings may be fixed to the pubic bone, retrourethral transobturators or retropubic muscles.<sup>133</sup> The retropubic sling is adjustable and tension can be modified through a superficial suprapubic incision.<sup>133</sup> However, most designs have a similar efficacy.<sup>124,133</sup>

Slings may be a treatment option for men with mild-moderate incontinence.<sup>124,133,134</sup> There is limited evidence, however, that fixed or adjustable improve post-prostatectomy incontinence in patients with mild-to-moderate incontinence.<sup>124</sup> Men who've previously had radiotherapy may not benefit from them.<sup>130,133</sup>

Side effects include: short-term pain, infection and, more rarely, urinary retention.<sup>133,135</sup>

## Radiation cystitis

Both external beam radiotherapy and brachytherapy can irritate parts of the lining of the bladder and the urethra close to the prostate – this is known as radiation cystitis.<sup>136,137</sup> Reported incidence varies from less than 10% to 35% of those who have received external beam pelvic radiotherapy.<sup>137</sup>

Symptoms may include:

- Frequency, urgency or nocturia
- Obstructive symptoms in the form of hesitancy, incomplete emptying or complete outlet obstruction<sup>137</sup>
- Haematuria

Acute Radiation cystitis will usually present itself during or shortly after finishing radiation treatment, and typically improves 6 – 8 weeks following the end of therapy.<sup>138</sup> However, some men will experience problems for several months.<sup>139,140</sup> Late onset radiation cystitis can present months or years after treatment has been completed.<sup>137,141</sup> Symptoms experienced as a result of chronic radiation cystitis can be progressive. Management is symptom related only.<sup>137</sup>

*"My side effects started about seven days after brachytherapy – a weak flow and stinging when peeing. It's now three weeks since my treatment, and the stinging has improved."*

*A personal experience*

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## Management

Depends on grade of cystitis and level of haematuria.<sup>137</sup>

### Lifestyle changes

Drinking cranberry juice or taking cranberry capsule is **not** recommended for prevention of UTIs,<sup>121</sup> however it may help to relieve symptoms of irritation or pain or discomfort on urination.<sup>142,143</sup>

Cranberry products can increase the effect of Warfarin so they may not be suitable for all men.

Other lifestyle changes may be more important e.g. avoiding caffeine, fizzy drinks and alcohol, as

these can irritate the bladder.<sup>119,142,144–146</sup>

### ***Intravesical therapy***

If the symptoms are very severe then intravesical therapy can be considered. Bladder instillations such as sodium hyaluronate have been shown to relieve the symptoms of radiation cystitis with as many as 97% of patients reporting complete relief of pain and dysuria.<sup>1,137</sup> This works by temporarily replenishing the glycosaminoglycan layer which protects the epithelium from becoming irritated.<sup>147</sup> Sodium hyaluronate is instilled into the bladder via a urethral catheter on a weekly basis for a period of between 4 – 12 weeks.

**Other treatment options** include hyperbaric oxygen therapy (although not widely available in the UK) and surgery as a last resort.<sup>137</sup> See further [guidelines](#) for a full management algorithm.

## **Overactive bladder (frequency, urgency and nocturia)**

OAB can be a post-surgery symptom, although it is more common post-radiotherapy (acute radiation cystitis can manifest as OAB),<sup>148</sup> usually resolving after a few months. Less commonly, men may also experience urge incontinence (see above) and leak urine before they reach the toilet.<sup>49,149,150</sup>

Men with overactive bladder symptoms should receive a physiological and anatomical assessment of the urinary tract (flexible cystoscopy).<sup>117</sup> As well as pelvic floor muscle exercises, other treatment options are described below.<sup>145</sup>

### ***Management***

#### ***Bladder retraining***

This involves following a schedule encouraging progressively longer times between urination together with relaxation and distraction for urinary urgency.<sup>119,151</sup> There is limited evidence to show clinical benefit for men who urinate frequently or experience urge incontinence.<sup>151</sup> See Prostate Cancer UK's information for step-by-step guidance.

#### ***Pharmacological management for bladder spasms***

First line drug treatments for OAB<sup>117</sup> include anti-cholinergics or antimuscarinics, such as solifenacin (Vesicare®), tolterodine (Detrusitol XL®), and oxybutynin.<sup>145,152</sup> These can produce side-effects that include a dry mouth, headaches, constipation and dizziness.<sup>124,145</sup> Mirabegron (Betmiga®) tablets are a newer type of drug for treating overactive bladder, and a beta-3-adrenoceptor agonist.<sup>4,153</sup> Side effects include urine infections and an increased heart rate.<sup>153</sup> Mirabegron is recommended as an option for treating the symptoms of overactive bladder only for people in whom antimuscarinic drugs are contraindicated or clinically ineffective, or have unacceptable side effects.<sup>153</sup>

#### ***BOTOX®***

With limited availability in the UK, intravesical botulinum toxin into the wall of the bladder appears to be a safe and effective therapy for refractory OAB symptoms.<sup>153</sup> Side effects and complications include increased risk of urine infection<sup>153</sup> and need for self-catheterisation in a small number of men.<sup>154,155</sup>



## Urinary retention

Radiotherapy and brachytherapy can cause urine retention, particularly in men with a large prostate.<sup>124,149</sup> Swelling of the prostate post-treatment can cause urethral blockage, as well as scarring which can lead to stricture.<sup>139</sup> Additionally surgery, HIFU and cryotherapy may cause urinary retention<sup>138,139,156</sup> and may be acute or chronic:

### Acute urine retention

This is characterised by a sudden and painful inability to urinate,<sup>157,158</sup> it needs immediate treatment with catheterisation.<sup>117</sup>

### Chronic urine retention

This is defined as a non-painful bladder, which remains palpable or percussible after the patient has passed urine. Such patients may be incontinent.<sup>158</sup> The pressure of the urine can slowly stretch and weaken the bladder muscle.<sup>158,159</sup> This can cause urine to be left behind in the bladder after urination, which in turn may lead to infection, bladder stones, haematuria, and kidney damage without treatment.<sup>160</sup>

## Management

Possible treatments include:<sup>117,158</sup>

- Catheterisation (urgently for acute retention)
- Pharmacological management with alpha-blockers or 5-alpha-reductase inhibitors
- Surgery to widen urethra or bladder opening.

*“The pain was really bad and I couldn’t go to the toilet. I was rushed to the hospital and a doctor put a catheter in. It took the pain away instantly.”*

*A personal experience*

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## 3.4 Pelvic radiotherapy side effects

The nature of radiotherapy means that it can affect the normal tissues surrounding cancer cells, thus resulting in side effects in the treated organ, as well as other organs in the pelvic region.<sup>161</sup>

The side effects of radiotherapy may be acute in nature, or chronic - persisting for many years.

The underlying pathology of long-term and late adverse effects is different from that seen in the acute reaction.<sup>162,163</sup> Late-responding tissues, such as vascular and connective tissues, have a slow turnover rate, so even though they sustain radiation damage at the time of treatment, the effects are not expressed until repeated cell division is attempted.<sup>161</sup> For this reason, late radiation tissue injury can take several months to many years to develop and is largely a function of the total radiation dose and fraction size.<sup>138,164–166</sup>

This issue is addressed in a separate section here due to the prevalence of these problems that sometimes go unmanaged. Approximately 50% of the 17,000 patients who receive pelvic radiotherapy every year will experience long-term or 'late' effects, which are collectively described as pelvic radiotherapy disease (PRD).<sup>167</sup> With 20–40% of patients suffering serious side effects that cause medical and psychosocial problems.<sup>167</sup>

The risk of developing long-term and late side effects is increased by older age, diabetes, previous bowel or prostate surgery, and previous bladder, bowel and erectile problems.<sup>168</sup>

Side effects are likely to be more severe, where men are having a combination of treatments, for example brachytherapy and external beam radiotherapy,<sup>18</sup> men having hormone therapy will also be dealing with those side effects as well (see section on hormone therapy).

When men with prostate cancer are diagnosed and treated, they may not have a full understanding of the side effects of treatment, and therefore may not recognise them, especially when occurring years later.<sup>165</sup> They may consult a GP rather than speaking with their specialist team. Equally as a healthcare professional seeing a man months or years later, you may not be aware that he ever received pelvic radiotherapy. As a result, the signs and symptoms of pelvic radiotherapy disease (PRD) may go overlooked and untreated.<sup>165</sup>

A holistic approach to addressing the physical, psychological, social and emotional impact of radiotherapy side effects, is the gold standard management approach.<sup>169</sup>

Men should be offered high quality, relevant information on managing side effects in the right format for them, as well as information on local support groups.<sup>165</sup> This is important so that they can be fully involved in making decisions about their own care.<sup>165</sup>

As part of management of side effects such as gastrointestinal problems men should be given advice to support self-management of symptoms such as information on physical activity, diet and stress management (see below).

### Common side effects

Some of the side effects described below can be both acute and chronic in nature:

### **Acute/temporary side effects**

- Skin and hair changes
- Ejaculation pain
- Changes to semen/dry orgasm

### **Acute/temporary and chronic/late side effects**

- Urinary problems
- Fatigue
- Erectile dysfunction
- Fertility problems
- Gastrointestinal problems

### **Chronic/late side effects**

- Lymphoedema
- Hip and bone problems
- Second cancers

## ***Effects on the skin and hair***

Skin irritation and hair loss are rarer acute side effects, due to improved radiotherapy techniques, but men may still develop:

- red, darker, dry, flaky, itchy skin in treated area;
- darkened, moist, sore skin around back passage and between legs towards the end of treatment-related;
- dreads in skin around scrotum, back passage and groin; and
- temporary loss of pubic hair (no loss of hair on head).

Skin reactions may be worst up to two weeks after radiotherapy but then improve. Clinical oncologists and therapy radiographers will provide advice on skincare during and after treatment.<sup>170</sup>

## ***Urinary problems***

Problems include radiation cystitis, and less commonly men may also experience urge incontinence and leak urine before they reach the toilet.<sup>49,149,171</sup>

Swelling of the prostate and urethral scarring during brachytherapy may also cause urinary retention.<sup>49,172,173</sup> This is rare, but acute urinary retention should be treated as a medical emergency.

Read more about urinary problems in section 3.3.

## ***Fatigue***

The effect of radiation on the body often leaves patients feeling more fatigued than usual, especially towards the end of a treatment course and symptoms may be worse for men also receiving hormone therapy.<sup>32,174</sup>

More information on managing fatigue can be found in section 3.5.

## ***Sexual and fertility problems***

### ***Acute problems***

Immediately after EBRT, men may experience temporary symptoms such as uncomfortable ejaculation, producing less semen and dry orgasm (no ejaculate).<sup>36</sup>

### **Erectile dysfunction**

Retrospective studies suggest that radiotherapy affects erectile function to a lesser degree than surgery.<sup>175,176</sup> External beam radiotherapy may be more likely to cause ED than brachytherapy.<sup>82</sup>

It may be up to two years before erectile dysfunction occurs and problems can get worse over time.<sup>90</sup>

### **Fertility**

As radiotherapy can damage the cells that make semen and cause dry orgasm, it can affect fertility.<sup>32,177</sup> Men may want to consider sperm storage.<sup>114</sup>

There is a very small chance that radiotherapy could affect children conceived during treatment, so contraception is recommended during and for at least a year after radiotherapy if there is a chance of a partner becoming pregnant.<sup>114,178</sup>

More information on managing sexual problems and fertility can be found in section 3.2.

### **Gastrointestinal problems**

Regardless of the treatment technique used, radiotherapy for prostate cancer exposes a portion of the lower gastrointestinal (GI) tract to ionizing radiation and consequently carries a risk of GI toxicity.<sup>179</sup> This can cause both acute and chronic problems.

#### **Acute problems**

Radiation toxicity is defined as acute when occurring during radiotherapy or within 3 months.<sup>164</sup> Gastrointestinal symptoms may begin during treatment.<sup>149,180–182</sup> Among the most frequently reported symptoms are:<sup>180,181</sup>

- diarrhoea
- urgency
- rectal bleeding
- faecal incontinence
- tenesmus (cramping rectal pain)
- abdominal cramps
- mucus discharge
- loss of appetite
- nausea.

#### **Chronic**

Nine out of ten patients who received pelvic radiotherapy experience chronic change to their bowel habit, with half reporting a significant change to their quality of life.<sup>183</sup> Despite this, only one-fifth of patients with PRD in the United Kingdom are reviewed by a gastroenterologist.<sup>184</sup>

Problems can develop months or years after treatment and may be similar to the short-term side effects described above.<sup>149</sup> If men had GI problems during treatment, they may be more likely to develop problems later on.<sup>149,185,186</sup>

### **Assessment and management**

Andreyev et al (2013)<sup>187</sup> devised an investigative and management [algorithm](#) to help improve the gastrointestinal symptoms of chronic PRD. Results of a randomised controlled trial showed that the

algorithm-based care improved symptoms in patients with PRD. Additionally, the study indicated that nurse-led care is sufficient for the majority of patients with PRD.<sup>187</sup> Macmillan have produced a quick guide for health professionals that is based on this algorithm covering the management of lower gastrointestinal problems after cancer treatment. Key points include:<sup>188</sup>

**The use of four trigger questions** that should regularly be asked to people who've had pelvic radiotherapy (answering 'yes' will indicate need for basic assessment):

Are you woken up at night to have a bowel movement?

Do you need to rush to the toilet to have a bowel movement?

Do you ever have bowel leakage, soiling or a loss of control over your bowels?

Do you have any bowel symptoms preventing you from living a full life?

**Basic assessment** should involve questions about rectal bleeding (should be investigated at least with flexible sigmoidoscopy), medical history and possibly a bowel/food diary (a template is available from Macmillan).

**Basic advice and treatment** should involve information to support self-management, for example promoting physical activity, reduced alcohol intake, stress management and dietary modification (see more below). Practical advice includes information on accessing public toilets (e.g. RADAR key scheme), bowel training and pelvic floor muscle exercises. Additionally stool bulking agents or anti-diarrhoeal medication should be described depending on symptoms.

**Further investigation and management** are recommended if advice and basic investigations do not help. These should include tests for rectal bleeding, faecal incontinence/leakage and urgency (without diarrhoea), diarrhoea, constipation, abdominal pain and painful bowel movements.

**Referral to gastroenterologist or other specialist is necessary** if symptoms have not improved and if further tests and treatment are needed. Other specialists include oncology and dietitians, depending on symptoms.

**Dietary modification.** There have been benefits demonstrated with dietary modification during pelvic radiotherapy to reduce diarrhoea. Those diets included single interventions or combinations of modified fat, lactose-restriction, fat-restriction and fibre supplementation.<sup>61</sup>

Macmillan's guide to managing lower gastrointestinal problems after cancer treatment recommends that any dietary changes made should be done in a systematic way and should always be for a trial period initially.<sup>188</sup> If symptoms do not improve dramatically, the dietary change may not provide any benefit and may actually restrict the person's nutritional intake. Referral to a dietitian is recommended if long term changes need to be made. Some general advice:<sup>188</sup>

- Excessive fibre is a common cause of GI problems, especially following pelvic radiotherapy. A reduction in fibre for a short time may be beneficial.<sup>60-62</sup>
- Inadequate fibre intake can also exacerbate GI symptoms. Patients should be advised that if they plan to increase the amount of fibre in their diet, they should also increase their fluid intake.
- High fat, caffeine and alcohol intake, artificial sweeteners and carbonated drinks can contribute to bloating, excessive flatulence and diarrhoea.<sup>189,190</sup>
- Patients may develop carbohydrate intolerances including lactose or fructose intolerances. If suspected food intolerance has been confirmed, referral to a dietitian is advised.
- Skipping meals may make bowel habits unpredictable. So, patients may be advised to eat at regular times. If patients are losing weight because of their GI problems,

referral to a dietitian should be considered.

World Cancer Research Fund's booklet [Eat Well during Cancer](#) offers information about healthy ways to modify diet to help cope with the side effects of cancer and treatment.

### **Rectal bleeding**

Bleeding occurs in 50% of patients who receive pelvic radiotherapy as a consequence of radiation induced telangiectasia (small dilated blood vessels- near the surface of the mucous membranes), which usually form on the anterior rectal wall. But it impairs quality of life in fewer than 6%.<sup>165</sup> Telangiectases may heal spontaneously over 5 to 10 years.<sup>165</sup> As above, patients should be assessed at least with flexible sigmoidoscopy.<sup>165</sup>

Treatment options include observation, medical management, endoscopic intervention and even surgical approaches.<sup>191</sup> Management is guided mainly by small randomised trials and single institutional studies.<sup>191</sup> Treatment should be escalated corresponding to the patient's clinical status, keeping in mind the known toxicity of each potential treatment.<sup>191</sup> Treatments with RCT based evidence include sulfracate enemas, 4 week treatment with metronidazole, vitamin A and hyperbaric oxygen therapy.<sup>165</sup>

### **Lymphoedema**

If the lymph nodes have also been treated with radiotherapy, there is a chance of lymphoedema.<sup>192</sup> This usually affects the legs, but it can affect other areas, including the penis or testicles. It can occur months or even years after treatment. **See section 3.8. for management options.**

### **Hip and bone problems**

Radiotherapy can damage the bone cells and the blood supply to the bones near the prostate. This can cause pain, and hip and bone problems later in life.<sup>193</sup> Men who are also having hormone therapy are more at risk of this side effect.<sup>193</sup>

### **Second cancers**

Radiotherapy can damage the cells in the tissues surrounding the prostate. Therefore there is a small increased risk of bladder or bowel cancer.<sup>18,194-196</sup> It would take at least 5 to 10 years after treatment with radiotherapy for a second cancer to appear.<sup>18</sup>

Men should be informed of this increased risk. Men who have symptoms of pelvic radiation disease should be offered full investigations, including flexible sigmoidoscopy to exclude malignancy.

## **Specific support and information needs for men receiving brachytherapy**

Brachytherapy patients should complete a male health questionnaire before implant and prior to every consultation thereafter, covering sexual, bladder and bowel functions. Changes can therefore be monitored and discussed. Men should be given contact details for brachytherapy radiographers or other keyworkers to contact by phone or email for advice.

Men should receive guidance on radiation safety, in particular regarding avoiding close contact with pregnant women, young children and pets.<sup>197</sup> It is recommended that during the first two months

following brachytherapy, children should not sit in close proximity to the patient or on the patient's lap for more than a few minutes a day.<sup>198</sup> Men should also avoid sitting in close proximity to pregnant women for long periods of time.<sup>198</sup>

For men who have received permanent seed implantation the use of a condom for the first five ejaculations is recommended due to the small risk that a seed may be contained within the ejaculate. Condoms should be double wrapped and placed in the dustbin for disposal.<sup>198</sup> Expelled brachytherapy seeds should not be picked up by hand. Should a seed be expelled either through ejaculation or urination it should be picked up with tweezers or a spoon and flushed down the toilet.<sup>198</sup> It is important that the patient knows to inform their oncologist should any of the seeds be expelled as this can impact on the overall dosimetric and in the majority of cases if seeds are expelled through urination, this is likely to happen shortly after implantation.<sup>198</sup>

In the event that the man requires further surgery following seed implantation, he should be made aware that he will need to inform the surgeon and team caring for him as there may be potential for radiation risk.

Men and their caregivers should also be made aware that if the patient passes away within 20 months of their seed implantation, the relevant persons are informed of recent seed implantation ahead of a post-mortem or cremation so that radiation risks can be assessed appropriately.<sup>198</sup>

## 3.5 Fatigue

Fatigue is often under acknowledged in a man's prostate cancer journey.<sup>46</sup> For healthy individuals fatigue may be regarded as a normal response to physical or psychological stress, and is easily overcome with rest and relaxation.<sup>199</sup> However in people with cancer, fatigue has been defined as, "a subjective, unpleasant symptom which incorporates total body feelings ranging from tiredness to exhaustion creating an unrelenting overall condition which interferes with individuals' ability to function to their normal capacity."<sup>2</sup> Thus it is common for prostate cancer related fatigue to be a relentless and distressing symptom before, during and after treatment.<sup>200</sup>

Fatigue is a prevalent symptom in men with prostate cancer and all treatment types may cause fatigue in men at differing levels. A systematic review found that prevalence of any fatigue can be as high as 74% in men with prostate cancer, whilst chronic fatigue prevalence was highest (39 %) when hormone therapy was combined with radiotherapy.<sup>201</sup> Fatigue severity is reported as worse in hormone therapy and treatment combining hormone therapy and radiotherapy.<sup>201</sup>

Through better management of fatigue, men with prostate cancer would be in a better position to lead active lives and engage in hobbies, activities and pastimes.

### The impact of fatigue on physical and emotional wellbeing

The effect of fatigue in men with prostate cancer can be debilitating. Daily life can become severely limited with the symptom impacting on work, routines and activities and resulting in a loss of 'self' for some.<sup>200</sup> The impact on daily life can also have an impact partners' lives and their own sense of 'self'.<sup>202</sup> Perhaps not surprisingly, the negative effects caused by fatigue can lead to co-morbidities that include psychological dysfunctions of depression and anxiety, which can arise in both the man and those around him.<sup>203</sup>

*'Fatigue hits you at random times, you feel as if you are getting your mojo back and its ok for a few days and then all of a sudden you have a really bad day and that was one of the things I found really difficult'\**

### Managing fatigue

Research into the effects of fatigue suggest that exercise, changes in diet, psychosocial support and complementary therapies may help reduce cancer related fatigue in men with prostate cancer.<sup>204</sup> Therefore, regular assessment and teaching self-management techniques are important in the management of fatigue. Encouraging self-monitoring of fatigue levels can be helpful as this highlights the times when a man feels he has the most energy and can help in supporting the planning of activities around fatigue. Some men feel this helps them to regain an element of control in terms of their day-to-day living.

Lots of people find it hard to be more active. Some men may be suffering with incontinence as a result of their treatment and feel worried about exercising. Light to moderate exercise has been shown to improve cancer related fatigue and walking programs are generally safe for most men with



prostate cancer. Some men find that setting small goals helps with managing their fatigue and motivational coaching from their doctor or nurse can be essential in helping them to achieve this.

## Specialist telephone intervention – case study

Working in collaboration with Florence Nightingale School of Nursing and Midwifery, King's College London (KCL), Prostate Cancer UK was awarded a Knowledge Transfer Partnership (KTP) from the Department of Trade and Industry (DTI). KTP projects are designed to help businesses/charities benefit from the expertise in UK universities, colleges and research organisations by helping them to develop new products, services or processes.

Prostate Cancer UK already operated a successful helpline service but lacked the expertise in delivering tailored interventions to help men with prostate cancer manage fatigue. The KTP award allowed us to work in collaboration with Professor Ream and her team at KCL, who are the acknowledged leaders in cancer related fatigue.

The project reviewed the published evidence,<sup>201</sup> and verified that around two-thirds of men with prostate cancer experienced fatigue. Men being treated with hormone therapy and radiotherapy experienced the most severe symptoms, and very few men were offered advice or support to manage their symptoms.

Prostate Cancer UK adapted an intervention developed and tested by KCL which aimed to reduce fatigue in cancer patients during chemotherapy. The development of a trial to test the effectiveness of the intervention was heavily influenced by the findings of the research carried out during the systematic review.<sup>201</sup>

Underpinning the trial intervention was a counselling technique called Motivational Interviewing (MI), which uses behaviour change techniques to improve health and wellbeing. A central concept of MI is the identification, examination, and resolution of ambivalence (feeling two ways about something, both positive and negative) about changing behaviour. Ambivalence is seen as a natural part of the change process. MI is a conversation you have together and is not a one way lecture. It's designed to strengthen your motivation and commitment to changing a behaviour.

***'...It's a combination of things; forcing you to think about it and a bit of encouragement and some ideas really without it being 'do this, do that, do the other'. I was very conscious that I was not being told to do anything'\****

The trial aimed to use nurse-led telephone calls to support and encourage men to make positive changes to their behaviour and lifestyle that could reduce symptoms of fatigue. Examples of such changes could include increasing exercise levels slowly and gradually, increasing social activities, getting back into hobbies, or changing diet.

***'She gave me ideas and, I tried to put them in place and what not and I thought, hey, hang on, this does work'\****

Findings evidenced improved overall fatigue levels, severity, symptoms and management (including social functioning) for men who received the service. These improvements were statistically significant and indicated a sustainable model of service delivery acceptable to men with prostate cancer ensuring they can lead fuller and more active daily lives. As a result, it is now an ongoing

service delivered by Prostate Cancer UK's Specialist Nurses.

Since the successful completion of the pilot study in 2012, the Fatigue support service has been one of the core services provided by the Specialist Nurses. The service continues to be evaluated by measuring fatigue levels on a scale during each call and from telephone interviews after men have completed the programme. Fatigue scores have demonstrated an overall improvement in fatigue levels and evaluation interviews have provided a rich insight into the experience of men taking part in the service.

*'I now have a realistic expectation of what I can achieve and if I work at it and pace myself I do make progress. I have had a recent increase in energy, I anticipate it will drop down again, in which case, I am ready!'*\*

*\*Quotes taken with permission from men from ongoing service evaluation*

### **Resources**

Web-based self-management module for fatigue live on PCUK website.

## 3.6 Support for men dealing with the side effects of hormone therapy

Hormone therapy decreases testosterone levels, and has an extensive side-effect profile, the main ones being:

- Hot flushes
- Changes to sexual function
- Extreme tiredness (fatigue)
- Weight gain
- Strength and muscle loss
- Breast swelling and tenderness
- Loss of body hair
- Bone thinning
- Mood changes
- Risk of heart disease, stroke and diabetes

Cholesterol, especially LDL cholesterol also tends to rise and muscle tends to get replaced by fat. Most men who are on hormone therapy experience at least some of these effects, but the degree to which any man will be affected by any one drug regimen is impossible to predict

Anti-androgen therapy is less likely to result in sexual dysfunction and/or fatigue.<sup>18</sup> These are oral compounds that are classified according to their chemical structure as:

- steroidal, e.g. cyproterone acetate (CPA), megestrol acetate and medroxyprogesterone acetate;
- non-steroidal or pure, e.g. nilutamide, flutamide and bicalutamide.

Both compete with androgen receptors, but as this is the only function of non-steroidal antiandrogens, they lead to an unchanged or slightly elevated testosterone level. By contrast, steroidal antiandrogens have progestational properties. These agents commonly cause breast enlargement (gynaecomastia).

### **Hormone therapy used in combination**

Hormone therapy can be used as combined androgen blockade (CAB) where an lutenising hormone releasing hormone agent (LHRHa) is given in combination with an anti-androgen to provide an androgen blockade for men with metastatic disease.<sup>18</sup>

Hormone therapy is also combined with radical radiotherapy to treat intermediate and high risk localised and locally advanced tumors that have not yet spread to more distant locations, such as the bones (see section on Radical radiotherapy).

Additionally, The UK STAMPEDE trial<sup>205</sup> demonstrated that the use of docetaxel chemotherapy at the time of initiation of androgen deprivation therapy significantly increased overall survival for men with metastatic or high risk, locally-advanced disease.

However, it's recognised that these combined treatment approaches may result in increased and cumulative adverse events, side effects and reduced quality of life.<sup>18,205-207</sup> Therefore, patients should receive information about this prior to making treatment decisions,<sup>208</sup> and will need

additional support and monitoring.

## Support for men

It is important that men receiving hormone therapy (alone or in combination with other treatments) are regularly monitored, especially in relation to bone health, cardiovascular health, diabetes, anaemia and sexual function. Referrals to relevant specialists should be made as soon as symptoms occur. Additionally, recommendations should be made to ensure a healthy diet, regular exercise and smoking cessation.<sup>49</sup>

Hormone therapy can also affect mood with some research showing increased emotional lability (exaggerated changes in mood in quick succession), and impulsivity.<sup>209</sup> there may be a link between hormone therapy and depression, although results are inconsistent.<sup>210</sup>

In general, living with the side effects of hormone therapy can have an impact on men's quality of life<sup>211,212</sup> and physical and emotional changes can have a profound effect on their sense of identity and masculinity.<sup>103</sup> It's important that men are informed and prepared for these side effects and their impact<sup>213</sup> and have access to psychosexual and psychosocial support in particular.

One model is to provide group patient education and support on side effects:

[Case study: How to stay healthy on hormones – Guy's Hospital](#)

### *Intermittent hormone therapy*

Intermittent hormone therapy is a strategy commonly used for minimising the side effects of hormone therapy. This strategy takes advantage of the fact that it takes a while for testosterone to rise again after LHRH agonists are removed. With intermittent hormone therapy, the LHRH agonist is used for up to twelve months, during which time a low PSA level is maintained. The drug is stopped until the PSA rises to a predetermined level, at which point the drug is restarted. The "drug holidays" in between cycles allow men to return to nearly normal levels of testosterone, potentially enabling improvement in side effects before the next cycle begins again.

NICE guidance recommends that intermittent therapy should be considered for men on long term hormones. Evidence from low quality research shows no difference in overall survival between intermittent and continuous hormone therapy. Intermittent hormone therapy had been associated with improvements in health-related quality of life and reduction in adverse events which could potentially lead to improved patient acceptability. Mixed quality research has shown that this approach may lead to improvement in hot flushes, gynaecomastia, bone health, haematological effects, low libido and erectile dysfunction.<sup>18,214</sup> It may also improve general health-related quality of life.<sup>18</sup> Positive effects on fatigue are less clear.<sup>210</sup> However, NICE recognises that this evidence is of low quality and therefore if men are offered intermittent therapy, they should be informed that there is limited evidence for reduction in side effects and progression-free survival.<sup>18</sup>

NICE recommends that men having intermittent androgen deprivation therapy should:

- have their PSA measured every 3 months **and**
- restart androgen deprivation therapy if PSA is 10 ng/ml or above, or if they are symptomatic

See the Treatment pathway for guidance on treatment approach for intermittent hormone therapy.

## Side effects of hormone therapy

The following are specific side effects associated with hormone therapy:

## Hot flushes

Hot flushes affect men on LHRH agonists or anti-androgens.<sup>49</sup> They're similar in nature to menopausal hot flushes in women, and may last for a few seconds or for severe flushes, a few hours and are also associated with sweating and nausea. Up to eight out of ten men on LHRH agonists (80 per cent) experience hot flushes.<sup>215</sup> Men may experience regular hot flushes for the duration of hormone therapy,<sup>216</sup> others may find they decrease with time or become milder.<sup>217</sup>

### Medical management

NICE recommend medroxyprogesterone (20 mg per day), initially for 10 weeks, to manage troublesome hot flushes caused by long-term androgen suppression and promote evaluating the effect at the end of the treatment period.<sup>18</sup> NICE also suggests that cyproterone acetate (50 mg twice a day for 4 weeks) is considered for treating troublesome hot flushes if medroxyprogesterone is not effective or not tolerated.<sup>18</sup>

### Complementary therapies

NICE recommends informing men that there is **no good-quality evidence** for the use of complementary therapies to treat troublesome hot flushes.<sup>18</sup> If men wish to try unproven herbal remedies such as sage tea, evening primrose oil and red clover, it is important that health professionals are informed and men are made aware that Black cohosh can cause liver damage. Men with a history of liver or kidney disease should be advised to avoid it altogether.<sup>218</sup> Acupuncture has been investigated as a treatment for hot flushes but evidence of its effectiveness is of poor quality and further studies are needed.<sup>219</sup>

### Self-management

There is no strong evidence linking dietary or lifestyle changes to the frequency of hot flushes. However some men may find that making lifestyle changes can help them feel more in control of their symptoms: For example:

- Smoking cessation and maintenance of a health weight.<sup>220</sup>
- Adequate fluid intake, reducing spicy foods, caffeine and alcohol.
- Keeping rooms cool, using cotton bedding and clothes, lukewarm baths and shower.
- Working out potential triggers for hot flushes, using a diary.

There is a small study underway investigating cognitive behavioural therapy (CBT) for the management of hot flushes.<sup>221</sup>

## Sexual dysfunction

See section 3.2 for detailed information on assessing and managing sexual problems.

## Osteoporosis

See section 3.7 for detailed information on osteoporosis.

## Gynaecomastia

Breast swelling and tenderness is the most common side effect of anti-androgens and experienced by most men.<sup>222</sup> Men receiving oestrogen may also experience gynaecomastia. It's a less common effect of LHRH agonists or gonadotrophin releasing hormone antagonists (GnRH) antagonist, orchidectomy or combined hormone therapy.<sup>223</sup>

### Management

For men starting long-term treatment using anti-androgen bicalutamide as a monotherapy (longer than 6 months), it is advised that prophylactic radiotherapy to both breast buds is offered within the first month of treatment. This should be administered as a single fraction of 8 Gy using orthovoltage or electron beam radiotherapy.<sup>18</sup>

If radiotherapy is unsuccessful in preventing gynaecomastia, weekly tamoxifen should be considered.<sup>18</sup>

Surgery may also be used to treat breast swelling by removing painful or swollen areas of the breast. This treatment carries a risk of damage to the nipple and a loss of feeling.<sup>223</sup> It's usually only offered if other treatments have been unsuccessful and symptoms are causing a high degree of stress and pain.<sup>224</sup>

## **Fatigue**

Hormone therapy can cause extreme tiredness.<sup>225</sup> It is important that men are informed that fatigue is a recognised side effect of hormone therapy.<sup>18</sup>

Physical activity is an important way to manage hormone therapy related fatigue.<sup>55,226</sup> In particular, men who are starting or having androgen deprivation therapy should be offered supervised resistance and aerobic exercise at least twice a week for 12 weeks to reduce fatigue and improve quality of life.<sup>18</sup> They should be referred to physiotherapy where appropriate.

See section 3.5 for more guidance on fatigue management.

## **Weight gain / strength and muscle loss**

Men may experience an increase in body weight (particularly around the waist).<sup>227</sup> There may also be a decrease in muscle tissue and an increase in the amount of body fat.<sup>227</sup>

## **Management**

Regular gentle resistance exercise may help to reduce muscle loss and maintain strength.<sup>55,226</sup>

## **Metabolic and cardiovascular effects**

Hormone therapy may cause insulin resistance and a higher prevalence of a metabolic-like syndrome. Symptoms include increased waist circumference, blood pressure and cholesterol.<sup>49</sup> NICE recognises that adverse cardiovascular effects can occur with long term use of hormone therapy.<sup>18</sup> However, evidence is low quality and more research is needed in order to understand the link between these conditions.<sup>18</sup>

The risk-to-benefit ratio of hormone therapy should be considered in patients with a higher risk of cardiovascular complications, especially if it is possible to delay starting treatment.<sup>49</sup>

## **Monitoring and management**

EAU guidance recommends:<sup>49</sup>

- Screening all patients for diabetes.
- Considering a cardiology consultation for men with a history of cardiovascular disease and men older than 65 years when starting hormone therapy.
- Giving advice on lifestyle modification and treating pre-existing conditions, such as diabetes, hyperlipidaemia, and/or hypertension. Lifestyle management may have a preventative effect and includes non-specific measures such as weight loss, increased exercise, improved nutrition and smoking cessation.<sup>44,226</sup>

## **Cognitive effects**

Some studies have suggested that hormone therapy can affect memory and concentration.<sup>228–230</sup> However, it is difficult to ascertain whether these changes are directly related to treatment or other factors such as fatigue, anxiety or normal age-related cognitive decline.<sup>229</sup>

### *Management*

Practical strategies such as list-making as well as combining sufficient rest with physical activity may help. An ongoing randomised trial is evaluating the impact of exercise on reducing the cognitive and psychosocial side effects of ADT.<sup>231</sup>

## 3.7 Bone health

### Osteoporosis

Osteoporosis is a condition characterised by low bone mass and deterioration of bone tissue, with an increase in bone fragility and susceptibility to fracture.<sup>18,232</sup>

Osteoporosis is common in the older men and therefore may be a pre-existing condition in men who are about to start hormonal therapy, which in turn may cause the development or worsening of the condition.<sup>18</sup>

Lutenising hormone releasing hormone (LHRH) agonists, gonadotrophin releasing hormone (GnRH) antagonists and orchidectomy can cause bone thinning, which can occur within 6 to 12 months of beginning treatment. The amount of bone loss may increase the longer a man is receiving hormone deprivation treatment, however anti-androgen and oestrogen tablets are less likely to cause bone thinning.<sup>233,234</sup>

Severe bone thinning can lead to osteoporosis,<sup>230</sup> which can increase fracture risk.<sup>229</sup> Other factors for increased fracture risk include:<sup>235</sup>

- Increasing age (risk increased partly independent of reducing BMD).
- Low body mass (<19 kg/m<sup>2</sup>).
- Parental history of hip fracture.
- Past history of fragility fracture (especially hip, wrist and spine fracture).
- Corticosteroid therapy (current treatment at any dose orally for three months or more).
- Alcohol intake of three or more units per day.
- Smoking.
- Falls and conditions increasing the risk of falls such as visual impairment.

For full list see: <https://patient.info/doctor/osteoporosis-pro>

### Management

#### Monitoring

Fracture risk assessment should be considered in men having hormone therapy and should be undertaken in line with assessments for osteoporosis (NICE clinical guideline 146).

This may involve a dual-energy X-ray absorptiometry [DXA] scan before and during treatment.<sup>236</sup> In particular, for men over 70, bone mineral density should be checked at baseline and, dependent on risk, every 12-24 months.<sup>237</sup>

#### Medication

NICE recommends offering bisphosphonates to men having hormone therapy who have osteoporosis.<sup>18</sup> However, they should **not** be routinely offered to prevent osteoporosis in men having hormone therapy.

Denosumab (Xgeva®) is a new drug for treating bone problems, but it is not yet widely available for men with prostate cancer in the UK. It should only be considered for men having hormone therapy



who have osteoporosis if bisphosphonates are contraindicated or not tolerated.<sup>18</sup>

### *Lifestyle changes*

Men should be advised to make the following lifestyle changes to prevent osteoporosis during their hormonal treatment:

- Ensuring calcium and vitamin D intake is meeting recommended levels.<sup>238–240</sup> If dietary intake is insufficient they should receive supplementation.<sup>241</sup>
- Reducing alcohol intake.<sup>242</sup>
- Stopping smoking.<sup>53</sup>
- Exercising regularly (in particular gentle resistance exercise).<sup>53,243</sup>
- Maintaining a healthy weight.<sup>236</sup>

### *Quality of life and support*

It's possible that quality of life in men with prostate cancer who also have osteoporosis may be adversely affected, as patients with osteoporosis have particular worries around fracture risk, fear of falling as well as symptoms such as pain and fatigue.<sup>232</sup> Knowledge of treatment options and lifestyle changes that could be made may alleviate any anxiety.

Additionally, the [National Osteoporosis Society](#) offer support, information and advice and have a helpline and a list of support groups.

## **Bone metastases**

More than 90% of patients with castrate resistant prostate cancer have bone metastases.<sup>243</sup> These can lead to skeletal-related events such as spinal cord compression, pathologic fracture, and the need for surgery or radiotherapy.<sup>244</sup> Bone metastases are a major cause of death, disability, and decreased quality of life.<sup>245</sup>

Bone metastases can damage or weaken the bone and may cause pain. Pain in the bone and the spine can impact on mobility.<sup>246</sup> Skeletal related events and their treatment in men with metastatic prostate cancer are linked to declines in physical and emotional well-being.<sup>247</sup> Cancer-related pain can affect quality of life, relationships and sleep quality.<sup>248</sup> Equally, low mood and anxiety can exacerbate pain.<sup>249</sup>

Therefore, it's vital that men with bone metastases receive psychosocial support. Palliative care should be integrated into their coordinated care and not restricted to end of life or hospice care.<sup>18</sup>

### *Management*

Alongside first or second-line hormone therapy and other therapies to control the cancer, men with symptomatic bone metastases may benefit from bone targeted therapies such as bisphosphonates, strontium-89 and radium-223 dichloride<sup>18</sup> as well as other pain controlling treatments.

**Bisphosphonates** for pain relief may be considered for men with hormone-relapsed prostate cancer when other treatments (including analgesics and palliative radiotherapy) have failed.<sup>18</sup>

Bisphosphonates may help to control bone thinning (see above), reduce the risk of fracture, reduce the level of calcium in the blood and reduce pain. NICE advise choosing the oral or intravenous administration according to convenience, tolerability and cost. Zoledronic acid (Zometa®) is administered intravenously and is the most common bisphosphonate drug given to men with advanced prostate cancer

**External beam radiotherapy (EBRT)** is an effective way of improving pain from bone metastases<sup>49</sup> and is useful as treatment for spinal cord compression caused by bone metastases in the vertebrae.<sup>18</sup> EBRT helps with pain control<sup>18,250,251</sup> and if pain reoccurs, treatment to the same area may be possible.<sup>252</sup>

**Strontium-89 (Sr-89)** is a beta-emitting radioactive isotope which is given intravenously and is taken up preferentially in bone metastases. In systematic reviews of randomised trials, Sr-89 has been shown to improve pain control and prevent new sites of pain In comparison with standard care.<sup>18</sup>

**Radium-223 (Xofigo)<sup>®</sup>** is an alpha-emitting radioactive isotope, also given intravenously. It is associated with improvement in pain, quality of life, delayed bone fractures and has a survival benefit.<sup>49</sup> It is available in the UK for men with hormone-relapsed prostate cancer with bone metastases, who have not yet received chemotherapy or for whom chemotherapy is not deemed suitable.<sup>253</sup>

**Surgery** is a less common approach but may involve internal fixation with a metal pin/plan to stabilise the area of affected bone and reduce fracture risk.<sup>254</sup> Percutaneous cementoplasty is indicated for patients with painful bone metastases. The aim is to reduce pain and stabilise bones.<sup>254–256</sup> Radiation can be given after surgery to prevent regrowth of cancer in the area.<sup>254</sup>

**Pain medication** - standard analgesia should be prescribed in a step-wise approach in accordance with the World Health Organisation's pain relief ladder.<sup>257,258</sup> Additionally, higher dose steroids can have an anti-inflammatory effect on bone metastases and can reduce pain.<sup>18</sup>

#### **Self-management**

- Small studies have found that transcutaneous electrical nerve stimulation (TENS) could help some people with bone pain,<sup>259,260</sup> although more research is needed.<sup>254</sup>
- Men may wish to try strategies such as relaxation, distraction, hot/cold packs and gentle exercise to help make themselves comfortable.<sup>248</sup>
- Some men may find using complementary therapies such as massage, acupuncture, hypnosis and reflexology helpful, increasing their relaxation and sense of well-being.<sup>261</sup>

Refer to Prostate Cancer UK's information on managing pain for further detail and more strategies. There is more information on metastatic spinal cord compression in the treatment section of this pathway.

## 3.8 Support for men with advanced metastatic prostate cancer

Men with prostate cancer may live for long periods of time even after the development of advanced disease – 30 % of men diagnosed with stage IV disease live for five years,<sup>262</sup> and therefore, face the challenges of living with a chronic illness.<sup>263</sup>

The complications of advanced prostate cancer are most commonly caused by spread to the bones and lymph, urethra, bladder, ureters and rectum.<sup>18</sup> Less commonly metastatic spread is to the lungs and the liver.<sup>18</sup>

Other common symptoms of advanced prostate cancer such as fatigue, sexual dysfunction, urinary problems and issues with bone health are covered in previous sections of this support pathway. Metastatic spinal cord compression is an oncological emergency and is covered in the treatment section of this pathway.

Symptomatic advanced-stage prostate cancer and its treatment can have a negative impact on patient quality of life.<sup>263</sup> Men with advanced prostate cancer report a range of unmet needs in relation to physical, intimacy/sexual, practical, and health system/informational needs; existential concerns; emotional and psychological needs; and patient/clinician communication.<sup>264</sup> A recent UK based study found that men with advanced prostate cancer felt that current care delivery is not providing the holistic person-centred support that they needed, which is why it's important to consider the distinct symptoms associated with this stage, as well as psychosocial issues.<sup>264</sup> Living with advanced prostate cancer can also involve living with fears over disease progression and the end of life.<sup>50</sup>

Consequently patients with advanced prostate cancer can experience significant reductions in health-related quality of life,<sup>51</sup> and can fare worse in terms of psychological distress and adjustment than those at the localised disease stage.<sup>265</sup>

Men with metastatic prostate cancer should be offered tailored information and access to specialist urology and palliative care teams to address their specific needs. This includes:<sup>18</sup>

- The opportunity to discuss any significant changes in their disease status or symptoms as these occur.
- A regular assessment of needs.
- Integration of palliative interventions at any stage into coordinated care, facilitating transitions between care settings as smoothly as possible.
- The discussion of personal preferences for palliative care as early as possible with men with metastatic prostate cancer, their partners and carers.
- Tailoring treatment/care plans accordingly and identifying the preferred place of care.
- Ensuring that palliative care is available when needed and is not limited to the end of life. It should not be restricted to being associated with hospice care.

For more information on supporting the psychological consequences of prostate cancer general see section 3.

For more information on end of life/palliative care see section 3.9.  
Refer patients to Prostate Cancer UK information on advanced prostate cancer.

## Symptoms of advanced prostate cancer:

### *Lymphoedema*

For men with prostate cancer, lymphoedema usually results from lymphatic obstruction caused by metastases to the lymph nodes or treatments such as surgery and radiotherapy.<sup>266</sup> Additionally, obesity is a well-known risk factor for the development of secondary lymphoedema following cancer treatment.<sup>267</sup> Prevalence ranges from 4<sup>268</sup> to 20% among men post-treatment and can occur months or even years after treatment.<sup>264</sup>

### *Symptoms*

Lymphoedema typically manifests as swollen, sometimes disfigured extremities or truncal regions that can be uncomfortable, painful and cause functional impairment.<sup>267</sup> In prostate cancer, lymphoedema most commonly affects the legs as well as the penis or scrotum. Lymphoedema is associated with an increased risk of cellulitis, bacterial and fungal infections.<sup>267</sup>

### *Management and support*

Lymphoedema is a significant health issue, and requires long term management and support.<sup>267,269</sup> Once diagnosed, men should be referred for specialist treatment as soon as possible to prevent further complications such as skin damage, leakage and infection.<sup>270</sup> As pharmacologic agents are of little benefit,<sup>271</sup> the only effective treatment is therapy to induce tumour regression. However, complete decongestive therapy (CDT) has been shown to decrease limb volume and improve overall quality of life.<sup>272</sup> CDT involves the use of manual lymph drainage (MLD), daily bandaging, skin care, exercise, and compression.<sup>272</sup> The Lymphoedema Support Network provides more information on this for health professionals and patients.

Nurses can also play a critical role in supporting patients living with lymphoedema by recommending self-care programs. They can motivate men to wear their prescribed compression garments, perform their lymphatic exercises and self-MLD (a simplified form can be taught to patients and/or their partners/carers).

Therefore referral to a specialist lymphoedema nurse is important, as is providing men with details of the Lymphoedema Support Network, which provides a list of services in the UK and advice about what you can do if specialist care is not available.

Patients with lymphoedema may also experience a wide range of psychological and physical difficulties including poor body image, anxiety, depression, embarrassment, impaired limb movement and physical mobility, and pain.<sup>267,269</sup> Education and information about self-management is a vital part of management,<sup>269</sup> as well as further support - Macmillan Cancer Support and the Lymphoedema Support Network provide more information and can put men in touch with local support groups.

### *Anaemia*

Anaemia may occur where bone marrow is damaged – this may be because of the prostate cancer itself, nutritional decline, haematuria, or by treatment such as hormonal therapy, chemotherapy or radiotherapy.<sup>271,273,274</sup> Symptoms may include fatigue, dyspnea, and tachycardia, these can impact on daily activities.<sup>274</sup>

Approximately 30% of prostate cancer patients with metastases to the bone have anaemia at the time of diagnosis,<sup>274</sup> and anaemia is the most common haematological change encountered in men receiving hormonal therapy, with prevalence varying from 9 to 37 percent.<sup>214</sup> The risk increases for men receiving complete androgen blockade.

### *Diagnosis and treatment*

Anaemia requires investigation to ascertain the cause of the disease (medullar invasion, mainly inflammatory, renal insufficiency, iron deficiency, chronic bleeding) and individualised treatment.<sup>49</sup> Iron supplementation must be systematic if deficiency is observed. More rarely, regular blood transfusion is required if severe anaemia is present,<sup>49</sup> although other treatment methods should be tried first.

The EAU Guidelines recommend that pharmacological treatment with erythropoiesis-stimulating agents might be considered in dedicated cases taking into account the possible increased risk of thrombovascular events.<sup>49</sup>

Macmillan Cancer Support and Cancer Research UK provide more detailed patient information about anaemia.

### *Hypercalcaemia*

In hypercalcaemia, abnormally high concentrations of calcium compounds are found in the bloodstream.<sup>18</sup> This is rare in men with advanced prostate cancer<sup>275</sup> but, should it occur, it is critical to urgently treat men that have symptomatic, moderate or severe hypercalcaemia, (adjusted serum calcium concentration greater than 3.0 mmol/L). They should be admitted to hospital or a hospice immediately if appropriate (preferably involving the person's specialist),<sup>276</sup> for example where they are symptomatic, some men can be treated as outpatients.

Hypercalcaemia can be asymptomatic and can be difficult to differentiate from other symptoms of advanced cancer. Definitive diagnosis is achieved through blood tests to measure serum calcium and albumin concentrations.<sup>276</sup> Symptoms can include:

- Bone pain.
- Fractures associated with underlying bone disorders (fragility fractures in hyperparathyroidism or pathological fractures in malignancy).
- Drowsiness, delirium, coma.
- Fatigue, muscle weakness.
- Impaired concentration and memory.
- Depression.
- Neurological signs (for example upper motor neurone deficits and ataxia).
- Nausea, vomiting, anorexia, weight loss.
- Constipation, abdominal pain.
- Renal colic due to renal stones.
- Polyuria, polydipsia, and dehydration (due to nephrogenic diabetes insipidus).
- Renal impairment (due to nephrocalcinosis).
- Hypertension.
- Shortened QT interval on electrocardiogram (ECG).
- Cardiac arrhythmias (rare).
- Itching, keratitis, conjunctivitis, and corneal calcification

### *Management*

For men with asymptomatic, **mild** hypercalcaemia (adjusted serum calcium concentration

3.0 mmol/L or less), hospital admission may not be necessary, although further specialist advice should be sought. Men should be provided with further information about maintaining sufficient hydration (drinking 3–4 L of fluid per day), provided there are no contraindications (such as severe renal impairment or heart failure). Following a low calcium diet is not necessary, but men should be encouraged to avoid any medicines or vitamin supplements that could exacerbate the hypercalcaemia. Men should also be encouraged to be mobile, where possible and advised to report any further symptoms.

Men with symptomatic hypercalcaemia, or moderate or severe hypercalcaemia should be admitted to a hospital or a hospice and treated with intravenous fluids and bisphosphonates can help treat hypercalcaemia.<sup>18,276</sup> Bisphosphonates effectively lower calcium in the blood and usually start to work in two to four days. Another dose of bisphosphonates can be administered after a week if necessary.<sup>277</sup> Regular blood tests are required to monitor calcium levels.<sup>269</sup>

### **Eating problems**

Advanced prostate cancer may be associated with reduced appetite, weight loss and nausea.<sup>257</sup>

Reduced food intake and metabolic changes can create a negative energy balance and skeletal muscle in cancer patients generally, this may be as a result of the tumour/s or side effects of cancer treatments.<sup>278</sup>

### **Management**

Management is important as malnutrition is associated with increased mortality in elderly cancer patients.<sup>279</sup>

Treatment may include medication:

- Megesterol acetate is usually effective after one to two weeks and can increase food intake and improve well-being.<sup>257</sup>
- Corticosteroids,<sup>280</sup> can have antiemetic and analgesic properties, but are short lived as appetite stimulants and have unpleasant medium-to-long-term side effects.<sup>257</sup>
- Antiemetics for nausea (as well as treating underlying causes such as autonomic failure, gastroparesis, constipation and the use of strong opioids).<sup>257</sup>

Additionally, men can be referred to a dietitian who can recommend appropriate interventions, for example nutrition counselling focusing on the best ways to maintain or increase energy and protein intake with normal food.<sup>278</sup> Oral nutritional supplements may be required in some cases.<sup>278</sup>

Men may be able to self-manage by finding out about dietary changes to minimise symptoms like nausea and maximise energy intake. Macmillan Cancer Support and World Cancer Research Fund have more information on this.

### **Lower gastrointestinal problems**

Bowel problems in advanced prostate cancer can include constipation, diarrhoea, flatulence, faecal urgency and incontinence, pain in the abdomen or rectum and bowel obstruction. These may be late effects of radiotherapy,<sup>149,281</sup> side effects of medication such as morphine and codeine as well as the result of reduced mobility, dietary changes and reduction in fluid intake.

In some rare cases, prostate cancer may spread to the rectum<sup>18,271,282</sup> and is associated with symptoms including constipation, pain, bleeding and, rarely, inability to empty the bowels.<sup>18</sup>

## **Management**

For general management of bowel problems see section 3.4. Additionally, referral to a local continence service is recommended for further support.

Treatment for constipation can include dietary/lifestyle measures (such as a high fibre diet, adequate fluid intake and exercise), laxatives, and in cases where constipation or bowel obstruction is caused by prostate cancer, radiotherapy to the bowel may be recommended.<sup>18</sup> Complete obstruction of the lower bowel may require a defunctioning colostomy.<sup>18</sup>

## **Obstructive uropathy**

Prostate cancer may result in unilateral or bilateral obstruction of the ureters resulting in impaired renal function.<sup>18</sup> The development of obstructive uropathy in men with hormone-relapsed prostate cancer is a frequent, potentially fatal, event.<sup>18</sup>

Signs and symptoms of urinary tract obstruction depend largely on the degree, time course, and anatomic level of obstruction:<sup>283</sup>

- Lower urinary tract obstruction can result in urinary urgency, frequency, decreased force of stream, or incomplete bladder emptying.
- Acute upper tract obstruction symptoms may include severe flank pain, nausea, and vomiting.
- Complete obstruction of the urethra, both ureters, or unilateral obstruction of a solitary kidney may result in failure of the kidneys to produce urine.
- Extrinsic compression of the urinary system is more commonly a chronic process with a slow progression to renal insufficiency. Consequently, patients often present with vague symptoms such as back pain, anorexia, lethargy, and/or mental status changes.
- In advanced prostate cancer, urinary tract obstruction may also be relatively asymptomatic, with hydronephrosis being discovered as an incidental finding during a workup for renal insufficiency. In some cases, a urinary tract infection may be the main symptom.

## **Management**

Decompression with external placement of a nephrostomy tube under local anaesthetic or the internal insertion of a double J stent from the bladder to the kidney under general anaesthetic.<sup>18</sup> Medical intervention such as high-dose steroids have also shown promise.<sup>18</sup>

## 3.9 Support for men at the end of life

Some men will die from their prostate cancer but many will die from other diseases whilst they have prostate cancer. NICE recommend identifying when men are close to death and ensuring that symptom relief and generic or specialist palliative care is available to all. The effective management of symptoms at the end of life, in all care settings, is supported by the use of appropriate care pathways and other relevant guidance and models that facilitate the quality of care at the end of life.

- [Gold Standards Framework](#)
- [Care of dying adults in the last days of life](#) (National Institute for Health and Care Excellence, 2015)
- [Improving supportive and palliative care for adults with cancer'](#) (National Institute for Health and Care Excellence, 2004)

### Specific needs:

Men with prostate cancer and their loved ones may want to know how long they have left to live and what to expect at the end of life.<sup>6</sup> Although it may be difficult to give precise timeframes, some idea of where the cancer has spread to and what problems it may cause may mean that men can be better prepared.

Men can be referred to Prostate Cancer UK's information on [what to expect](#).

Additionally, it's important that men with advanced prostate cancer have the opportunity to think about how, and where, they will be cared for at the end of life and can access advice on advanced care planning, practical affairs, making wills and funeral plans. This may enable them to feel more prepared and confident about making decisions,<sup>284-286</sup> ensure they get the support they need<sup>284</sup> and make things easier for their family and friends.<sup>263</sup>

Men can be referred to Prostate Cancer UK's information on [planning ahead](#).

*"I've basically said I'm not going to put my head under the pillow and just let things happen. We've subsequently currently sorted our wills out, our executor knows everything that he needs to know, they've got keys ... it's all ... oh I've got a funeral plan. All of that has been done. And erm, I think because we've done all that, that's helped me to deal with it. Because I know that my wife's going to be ok."*<sup>287</sup>

*Jack, 72, living with advanced prostate cancer*

Psychological needs should also be addressed. Some men may experience anxiety, grief, anger and frustration when given a terminal prognosis.<sup>263</sup> It can be difficult for men to think about death and some may not want to dwell on it or make plans.<sup>6</sup> Men may worry about upsetting their family and friends.<sup>6</sup>

See section on psychological support for care men and their partners should receive. Additionally, all patients with cancer and their carers should have access to different forms of spiritual support, appropriate to their needs.<sup>39 27</sup>



Men can be referred to Prostate Cancer UK's information on [thoughts and feeling for men dying from prostate cancer](#).

Those caring for loved ones at the end of life should also be offered practical and emotional support, which should extend into the bereavement phase.<sup>285</sup>

## Useful resources:

Dying Matters [directory of services](#).

Download or order [End of life: a guide](#) from Marie Curie Cancer Care and Macmillan Cancer Support.

[National Council for Palliative Care](#)

[Cruse bereavement care](#)

## 3.10 List of resources for health professionals to signpost men to

### Physical concerns

#### Exercise and diet

A healthy lifestyle can give men more control over their health and help them improve it. It can also help them to manage the effects of prostate cancer and its treatment. There is also strong evidence that being overweight increases the risk of aggressive or advanced prostate cancer, and may increase the risk of recurrence or progression after treatment.

Read more in our booklet: [Living with and after prostate cancer: A guide to physical, emotional and practical issues](#)

Further information is available in our factsheet: [Diet and physical activity for men with prostate cancer](#).

#### Managing pain

Not all men with prostate cancer have pain. However, when it does occur, the best ways to treat it depend on a number of things including what's causing the pain, general health, how men are feeling emotionally, and what sort of things they do in their daily lives. Pain may be a sign of cancer progression, so it may be important to review cancer treatment.

Read more in our booklet: [Living with and after prostate cancer: A guide to physical, emotional and practical issues](#)

Further information is available in our factsheet: [Managing pain in advanced prostate cancer](#)

### Emotional concerns

Men living with a diagnosis of prostate cancer may experience a range of emotions, some of which are discussed below.

Patients' emotional needs should be considered at all stages of their diagnosis, treatment and ongoing care, and a referral for specialist psychological support made as appropriate. The emotional needs of partners and carers should also routinely be considered and support or respite care offered as appropriate.

#### Worry, fear or anxiety

Living with prostate cancer can be difficult to deal with emotionally as well as physically, and many men will feel anxious and worried at times.

#### Feelings of depression

Men can experience changes in themselves such as feeling down, altered sleep patterns and appetite changes, or becoming angry more easily.

#### Feelings of isolation

Men may feel isolated, especially if their treatment has finished and they're no longer seeing their

doctor or nurse.

### **Difficulty or reluctance to make plans**

It's natural to find it difficult and upsetting to think about the future – particularly if men have advanced prostate cancer. Many men with advanced cancer will have treatment that will control their cancer for many months or years but it can be a worrying time. An open and honest discussion about a man's outlook to help with these worries could be helpful, if the man wishes to have this discussion.

### **Inability to express feelings**

It can be difficult for men to discuss their feelings, but a lot of men find that talking about how they feel can help. Some men get support from talking to their family and friends, but not everyone will want to share their feelings with those close to them and professional support may be more appropriate.

### **Anger or frustration**

Men respond in all kinds of ways to being diagnosed and living with prostate cancer. There is no right way to think and feel.

Read more in our booklet: [Living with and after prostate cancer: A guide to physical, emotional and practical issues](#)

Men can find out more about planning ahead and the support available in our booklet: [Advanced prostate cancer: Managing symptoms and getting support](#) and on our website at [prostatecanceruk.org/plan-ahead](http://prostatecanceruk.org/plan-ahead)

Our Specialist Nurses can answer men's questions and discuss their diagnosis and treatment options on 0800 074 838.

Consider a referral to counselling services or if they need immediate help ring the Samaritans. Support is also available in local cancer support centres.

Men can join one of our local support groups and meet others affected by the disease; more information is available at [prostatecanceruk.org/get-support/support-groups](http://prostatecanceruk.org/get-support/support-groups)

Men can also speak to others living with prostate cancer through our one-to-one support service, more information is available at [prostatecanceruk.org/get-support/one-to-one-support](http://prostatecanceruk.org/get-support/one-to-one-support)

They can also join our online community at [prostatecanceruk.org/online-community](http://prostatecanceruk.org/online-community)

Information and support for mental health issues such as depression or anxiety is available from the charity Mind at [www.mind.org.uk](http://www.mind.org.uk)

Information and support for anyone affected by mental health problems is available from the charity Sane at [www.sane.org.uk](http://www.sane.org.uk)

Men can also find information on how to look after themselves from:

[Macmillan Cancer Support](#)

[Maggie's Centres](#)

[Penny Brohn Cancer Care](#)

## Relationship concerns

### Partners

Men and their partners might need particular support for relationship and sexual issues. Prostate cancer can change the normal pattern of men's lives and affect relationships, friendships and roles within the family.

More information is available in our resources including:

[Living with and after prostate cancer: A guide to physical, emotional and practical issues](#)

[When you're close to a man with prostate cancer: A guide for partners and family](#)

[Prostate cancer and your sex life \(booklet and DVD\)](#)

[Prostate facts for gay and bisexual men](#)

### Support for carers

Relationship changes and sexual issues can cause distress in partners as well as patients, and partners may need particular support for these issues. If a partner or carer is providing ongoing care, respite care might be considered.

More information is available in our resources including:

[When you're close to a man with prostate cancer: A guide for partners and family](#)

[Prostate cancer and your sex life \(booklet and DVD\)](#)

Advanced prostate cancer: Managing symptoms and getting support [and on our website at prostatecanceruk.org/plan-ahead](#)

[Supporting someone who is approaching the end of their life](#)

Macmillan Cancer Support: [Supporting carers of people with cancer: Practical guidance for healthcare professionals](#)

Macmillan Cancer Support: [Looking after someone with cancer](#)

The charity Relate provides relationship counselling and a range of other relationship support services, more information is available at [www.relate.org.uk](http://www.relate.org.uk)

### Children

It can be difficult and upsetting to talk to children or grandchildren about cancer. What they'll need to know and how they will react will depend on their age.

Read more in our booklet: [When you're close to a man with prostate cancer: A guide for partners and family](#)

Macmillan Cancer Support: [Talking to children and teenagers when an adult has cancer](#)

For more information on talking to children about cancer, visit Winston's Wish at [winstonswish.org.uk/](http://winstonswish.org.uk/)

### Other relatives/friends

Friends and family can provide a good support network for men living with prostate cancer. This might be practical support or having someone to talk to about how they feel.

Read more in our booklet [When you're close to a man with prostate cancer: A guide for partners and family](#)

### **Support for single men**

Not all men will have a support network at home and will require access to the emotional and practical support they need.

Read more in our booklet: [Living with and after prostate cancer: A guide to physical, emotional and practical issues](#)

Men can speak to their GP, hospital doctor or nurse. Our Specialist Nurses are available to talk things through on 0800 074 838.

## **Practical concerns**

### **Help at home**

An occupational therapist may be able to advise about practical things that can help make living at home easier. They can suggest changes to the home, or special equipment that can help with everyday tasks. The social services department or a GP can make a referral to an occupational therapist.

Men may also be able to get help from a home care worker. Home care workers include care assistants, who can help with housework and shopping, and personal care assistants, who can help with tasks like getting washed and dressed.

Not all local areas provide or pay for the same services. Men should speak to their GP, nurse or local social services about what practical support is available for them.

### **Financial concerns**

There is support available for men who are struggling with the financial costs of cancer, or if their income has changed.

Read more in our booklet: [When you're close to a man with prostate cancer: A guide for partners and family](#)

More information on sick pay, benefits, costs and financial management is available in our booklet: [Living with and after prostate cancer: A guide to physical, emotional and practical issues](#)

Advanced prostate cancer: Managing symptoms and getting support  
and on our website at [prostatecanceruk.org/plan-ahead](http://prostatecanceruk.org/plan-ahead)

[Macmillan Financial Guidance Service](#) and [Financial Support Tool](#)

[Macmillan Financial Guidance referral checklist](#) – Use this to refer a patient to the Financial Guidance Service. Also includes helpful questions HCPs can use when talking to people about money worries.

### **Work concerns (time off, modifications or returning to work)**

Prostate cancer can affect men's working lives as they may need to take time off for treatments. This includes time for travelling to hospital and, for some men, time to recover.

Read more in our booklet: [When you're close to a man with prostate cancer: A guide for partners and family](#)

More information on support for men in the workplace is available in our booklets: [Living with and after prostate cancer: A guide to physical, emotional and practical issues](#)

Advanced prostate cancer: Managing symptoms and getting support and on our website at [prostatecanceruk.org/plan-ahead](http://prostatecanceruk.org/plan-ahead)

Macmillan Cancer Support: [Work support route guide](#) This booklet is designed to help health professionals talk to people with cancer about work, their options and rights.

Macmillan Cancer Support: [The Work and Cancer Toolkit](#) for HR and Occupational Health Professionals

### **Insurance**

Some men find it harder to get travel insurance because of their prostate cancer.

Our fact sheet, [Travel and prostate cancer](#) , gives tips on buying travel insurance.

[Macmillan](#) provides a comprehensive list of travel insurance providers.

### **Planning for the future**

Men often find that making plans helps them to feel more prepared for what the future may hold, both for themselves and for their loved ones. This may include advance care planning, making a lasting power of attorney, and making a Will and funeral plan.

More information is available in our booklet [Advanced prostate cancer: Managing symptoms and getting support](#) and on our website at [prostatecanceruk.org/plan-ahead](http://prostatecanceruk.org/plan-ahead)

For men approaching their end of life, information on planning for the future and advice on talking about dying is available from Dying Matters at [dyingmatters.org](http://dyingmatters.org)

### **Travelling to hospital appointments**

Men might be able to get help with the costs of travel to and from hospital, and some other medical costs.

More information is available in our booklets: [Living with and after prostate cancer: A guide to physical, emotional and practical issues](#)

More information is available in our booklet [Advanced prostate cancer: Managing symptoms and getting support](#) and on our website at [prostatecanceruk.org/plan-ahead](http://prostatecanceruk.org/plan-ahead)

### **Social concerns**

Some men with prostate cancer may find everyday tasks more difficult. This could be because of side effects, pain, or because they find it harder to move about.

Read more in our booklet: [Living with and after prostate cancer: A guide to physical, emotional and practical issues](#)

More information on extra help in the home, driving and public transport is available in our booklets:

[Living with and after prostate cancer: A guide to physical, emotional and practical issues](#) [Advanced prostate cancer: Managing symptoms and getting support](#)

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