



Hampered by hormones?

Addressing the needs of men with
prostate cancer

Campaign Report

June 2009

Summary

Prostate cancer is the most common cancer diagnosed in men in the UK, with 35,000 men diagnosed every year and one man dying from prostate cancer every hour. However, despite the incidence and impact of this condition men with prostate cancer have consistently reported worse experiences of NHS care than patients with other common cancers.⁽ⁱ⁾

Unfortunately, new research undertaken by The Prostate Cancer Charity on the experiences of men receiving hormone therapy, a common treatment for prostate cancer, suggests that this legacy continues - with many men missing out on vital information and support to help them live with the impact of prostate cancer and this treatment on their lives.

Feedback from the men who took part in this research makes for uncomfortable reading:

- Fatigue impacted on the lives of over 70 per cent of those who took part in the Charity's survey (affecting their ability to work, conduct household chores and pursue hobbies) and 1 in 4 men who experienced this side effect found the impact it had on their lives difficult to cope with.
- 1 in 4 survey respondents said that hormone therapy affected their ability to work.
- 8 out of 10 said that they experienced erectile dysfunction as a result of their treatment – with a quarter of these men reporting that they found it difficult to cope with the impact this had on their lives.

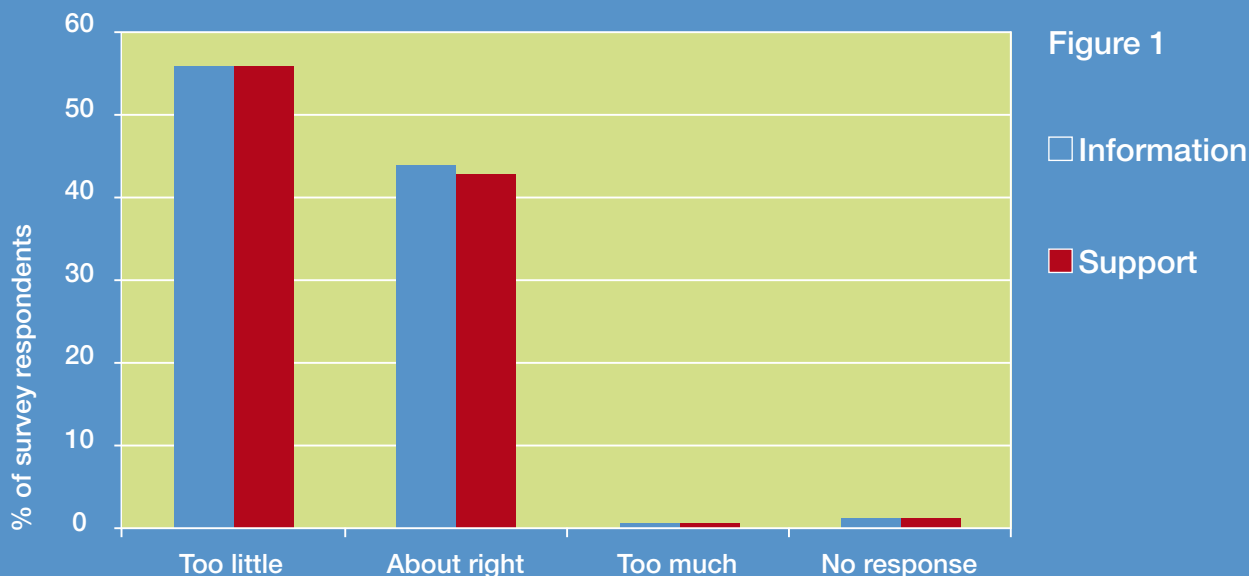
- 1 in every 2 men reported serious issues related to their mental wellbeing, for example, feelings of depression, loss of confidence and cognitive problems.

Despite these experiences, over half of the men who responded to the survey said that they received '**too little**' information before they began hormone therapy and '**too little**' support whilst they were on the treatment. Many did not receive verbal or written information on the potential side effects of hormone therapy before they began treatment – nor were they asked by the healthcare professionals involved in their care about their experiences of side effects, or their support needs.

The Prostate Cancer Charity believes that the failure to provide information and to talk to men about the effects of this treatment means that too many are left unaware that there are practical medical interventions and support services available that could help them better manage and cope with the impact of the treatment. This is unacceptable.

The Charity's research also found evidence of serious issues related to the information and support needs of the partners of men who receive hormone therapy. When surveyed, significant numbers reported that they found the side effects experienced by the partner undergoing hormone therapy difficult to cope with, but nearly two-thirds said that they had not received appropriate support from healthcare professionals to help them cope with the impact of these side effects on their lives.

How men who have received hormone therapy rate the information and support they received



Together, these findings highlight serious short-comings in how well the information and support needs of men living with the effects of hormone therapy - and their partners - are understood and provided for. They also suggest that existing guidance from the National Institute for Health and Clinical Excellence (NICE) in England and Wales and NHS Quality Improvement Scotland (NHS QIS), on the standards of care that should be in place for men with prostate cancer, have not been implemented.

The Prostate Cancer Charity's campaign, 'Hampered by Hormones?', aims to highlight the needs of men on hormone therapy and their partners and to ensure that they receive the high standard of care and support they deserve and are entitled to. This includes access to appropriate information, the assessment of side effects and associated support needs and the provision of appropriate interventions and support to men (and their partners) to help them cope with and manage these side effects.

Through this campaign, the Charity is calling for the urgent full implementation of current guidelines on the care of men with prostate cancer to address the unacceptable gaps in care.

The Prostate Cancer Charity has also set out a number of recommendations within this report to improve the information, support and care provided by the NHS to men receiving hormone therapy (and their partners). The Charity is calling on Government Health Departments across the UK, the National Cancer Survivorship Initiative in England and the Scottish Cancer Taskforce to review its research findings and take action in accordance with the Charity's recommendations.

In this report, the Charity sets out its key research findings and detailed recommendations for the improved care of men with prostate cancer.



John Neate
Chief Executive

Summary of recommendations

- All men considering hormone therapy for prostate cancer should be informed about the potential side effects of the treatment by a healthcare professional.
- All men receiving hormone therapy should be given verbal and written information about how they can manage the side effects of the treatment and where to go to receive support for these effects.
- All men receiving hormone therapy should be regularly assessed by a healthcare professional for the side effects of the treatment and associated support needs.
- Appropriate medical interventions and support services that can help men manage the side effects of hormone therapy should be available to men across the UK.
- Further research should be conducted into the impact of hormone therapy on the lives of men (and their partners) who receive the treatment and interventions to help them cope with, or manage these side effects.
- The National Cancer Survivorship Initiative in England and the Living with Cancer Group of the Scottish Cancer Taskforce, should review the Campaign research findings and recommendations and consider the action they can take to improve the support and information provided to men receiving hormone therapy.
- NHS Quality Improvement Scotland should develop Standards for Cancer Services for prostate cancer to ensure men receiving hormone therapy receive high quality care.
- The partners of men receiving hormone therapy should be informed about the side effects of the treatment and signposted to support services, by healthcare professionals involved in their partners' care.
- National guidance related to the effective treatment and care of men with prostate cancer must be fully implemented.

The Charity's full recommendations are provided in Part VII of this report.

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Background

What is hormone therapy?

Hormone therapy is a common treatment for prostate cancer that can be used to treat all stages of the disease – including localised (where the cancer is contained within the prostate gland), locally advanced (where the cancer has spread to the area just outside the gland) and advanced disease (where the cancer has spread to other parts of the body).

How does it treat prostate cancer?

Hormone therapy for prostate cancer works by stopping testosterone reaching the prostate cancer cells. Testosterone can cause cancer cells within the prostate gland or prostate cancer cells that have spread outside the prostate gland to grow faster. If testosterone is taken away, the cancer cells shrink, wherever they are in the body.

Hormone therapy is used in men with localised or locally advanced prostate cancer to shrink the tumour and make it easier to treat with other interventions, such as radiotherapy. Most men who receive hormone therapy for localised or locally advanced prostate cancer will usually receive the treatment for between a few months, up to a few years.⁽¹⁾

Hormone therapy is the principal treatment for men with advanced prostate cancer. It is used in men with advanced disease to stop

the cancer from growing, which can extend survival time and relieve symptoms caused by the disease.⁽²⁾ Hormone therapy is also one of the best ways to treat pain caused by disease that has spread outside the prostate gland.⁽³⁾

In men with advanced disease (unlike in men with localised or locally advanced disease), hormone therapy is used to control the cancer until such time that the disease becomes resistant to the treatment. It can be used to control the cancer for many years, so men with advanced disease may receive the treatment for much longer periods of time than men with localised or locally advanced disease.

How many men with prostate cancer receive hormone therapy in the UK?

Every year in the UK, 35,000 men are diagnosed with prostate cancer. The Prostate Cancer Charity estimates that each year in the UK around 9,000 newly diagnosed men will receive hormone therapy.⁽⁴⁾ However, this figure does not take into account the men who are already diagnosed with prostate cancer but, because their cancer progresses, or their first treatment is unsuccessful, go on to receive hormone therapy each year. The figure also fails to include the number of men in the UK who have been receiving hormone therapy for several years.

At present, there is no way of accurately knowing how many men in the UK are currently receiving hormone therapy for prostate cancer because Cancer Registries and the National Cancer Intelligence Network do not collect routine data on the number of men whose disease progresses from its stage at diagnosis.

The side effects of hormone therapy

Hormone therapy can be administered in a number of ways:

- through an operation, called an orchidectomy, to remove the testicles where testosterone is produced;
- through the injection of a drug, called an LHRH agonist, that works by stopping the brain from telling the testicles to produce testosterone;
- by taking anti-androgen or oestrogen tablets to block the effects of testosterone. Anti-androgen tablets can be used either on their own or together with an orchidectomy or LHRH agonists.

These different forms of hormone therapy each have associated side effects. For example, surgery (orchidectomy) and LHRH agonists (such as Zoladex or Goselerin) are more commonly associated with erectile dysfunction and hot flushes, whilst anti-androgens (such as Casodex or Bicalutamide) are associated with an increased risk of developing breast swelling.

The side effects of hormone therapy can be divided into three broad categories: physical side effects; effects on sexuality; and effects on mental well-being.

Physical side effects

Studies have found that the most common physical side effects associated with hormone therapy are hot flushes, breast swelling (gynaecomastia) and tiredness or fatigue. It is estimated that between 55 and 80 per cent of men taking hormone therapy will experience hot flushes.⁽⁵⁾ In addition, around half of men taking an anti-androgen will get some breast swelling.⁽⁶⁾ Whilst fatigue is known to be a common side effect, it is hard to quantify because it has not been studied in detail.⁽⁵⁾

Other physical side effects that men may experience are breast tenderness,⁽⁶⁾ weight gain, muscle loss⁽⁷⁾ and osteoporosis (bone thinning).⁽⁸⁾ Some studies have found that men receiving hormone therapy may have an increased risk of developing diabetes and heart disease.⁽⁹⁾⁽¹⁰⁾

Sexual side effects

Erectile dysfunction (impotence) and loss of libido (sexual desire) are also common side effects of hormone therapy.⁽¹¹⁾⁽¹²⁾⁽¹³⁾ One study estimated that 70 per cent of men taking LHRH agonists, or who have had an orchidectomy, will have a problem getting or keeping an erection strong enough for sexual intercourse.⁽¹⁴⁾ Another study found that around half of men who were receiving these types of hormone therapy, lost their interest in sex, or sexual desire.⁽¹⁵⁾

Effects on mental well-being

Hormone therapy can also have an impact on a man's mental well-being. Studies have found that hormone therapy can affect a man's cognitive function, causing problems such as a reduced ability to concentrate, memory problems or problems with decision-making.⁽¹⁶⁾ Men can also experience moodiness and short temper, crying with minimal provocation, and feeling depressed and anxious.⁽¹⁷⁾

While men on hormone therapy may experience depressive symptoms and anxiety,⁽⁵⁾ it is not clear whether hormone therapy causes depression.⁽¹⁸⁾⁽¹⁹⁾

Some men find that the physical changes to their bodies, such as putting on weight, or changes to their sexual function, can make them feel very different about their bodies and cause a sense of loss.⁽¹⁸⁾ Hormone therapy can evoke emotions that are “strongly linked to femininity,”⁽¹⁸⁾ which may impact on a man’s sense of masculinity.

What impact do the side effects of hormone therapy have on men and their partners?

Men have varying reactions to hormone therapy and will experience different side effects. Some men will experience many side effects, whilst others will only experience a few. Whilst most of the side effects associated with hormone therapy are not life threatening, they can substantially affect a man's quality of life.

Research methodology

In order to gain a better understanding of the impact of hormone therapy, we invited men with experience of prostate cancer and hormone therapy to respond to a survey and take part in four focus groups (two in Scotland and two in England). The Charity also surveyed 100 partners of men who had received hormone therapy.

The hormone therapy survey for men

The hormone therapy survey for men asked respondents to identify which side effects they experienced and to provide feedback about the impact of the treatment on their lifestyle, ability to work, daily routine, relationships and mental well-being. The Charity also explored levels of awareness about side effects prior to treatment and the information and support they received from healthcare professionals to help them cope with, or manage, the effects they experienced during treatment.

Overall, 332 men from across the UK responded to the survey: England (79%), Scotland (8%), Wales (5%) and Northern Ireland (0.6%).*

The majority of participants were aged between 55 and 79 years (88%). However, we also had a number of younger (3%) and older respondents (6%).*

* Not all respondents to the survey answered this question because it was optional.

There was a fairly even spread of when men had been diagnosed with prostate cancer, from within the last six months to ten years or more ago.

Most men had received hormone therapy for either localised (43%), or locally advanced prostate cancer (33%) but the survey also included a significant number of responses from men who had received the treatment for advanced prostate cancer (22%).*

73 per cent of respondents were currently receiving hormone therapy, whilst 27 per cent had received it in the past. This means that the majority of participants were able to describe a recent experience of the treatment.

In relation to treatment, GPs (53%) and practice nurses (40%) were most commonly cited as the healthcare professional involved in providing hormone therapy, although respondents reported receiving hormone therapy from a combination of primary and secondary care practitioners. This is probably because hormone therapy is usually prescribed by a secondary care practitioner and administered in primary care.

The hormone therapy survey for partners

We received 100 responses to our partner's survey. The majority of partners who responded were aged between 45 and 74 years (86%).

Focus groups

Two focus groups were held in Scotland in February 2009. Four men who had received hormone therapy attended an event in Inverness and nine men attended an event in Glasgow. A further eight men attended two focus groups held in London in March 2009. The focus groups were made up of men with advanced prostate cancer and men with localised and locally advanced disease.

* Not all respondents to the survey answered this question because this question was optional.

Research findings 1: The impact of hormone therapy on men

The hormone therapy survey for men showed that the most common side effects experienced by men were:

- hot flushes (85%)
- erectile dysfunction (83%)

- loss of libido (80%)
- tiredness/fatigue (71%)

Figure 2 shows the incidence of side effects experienced by the survey participants.

The side effects of hormone therapy experienced by respondents to the survey

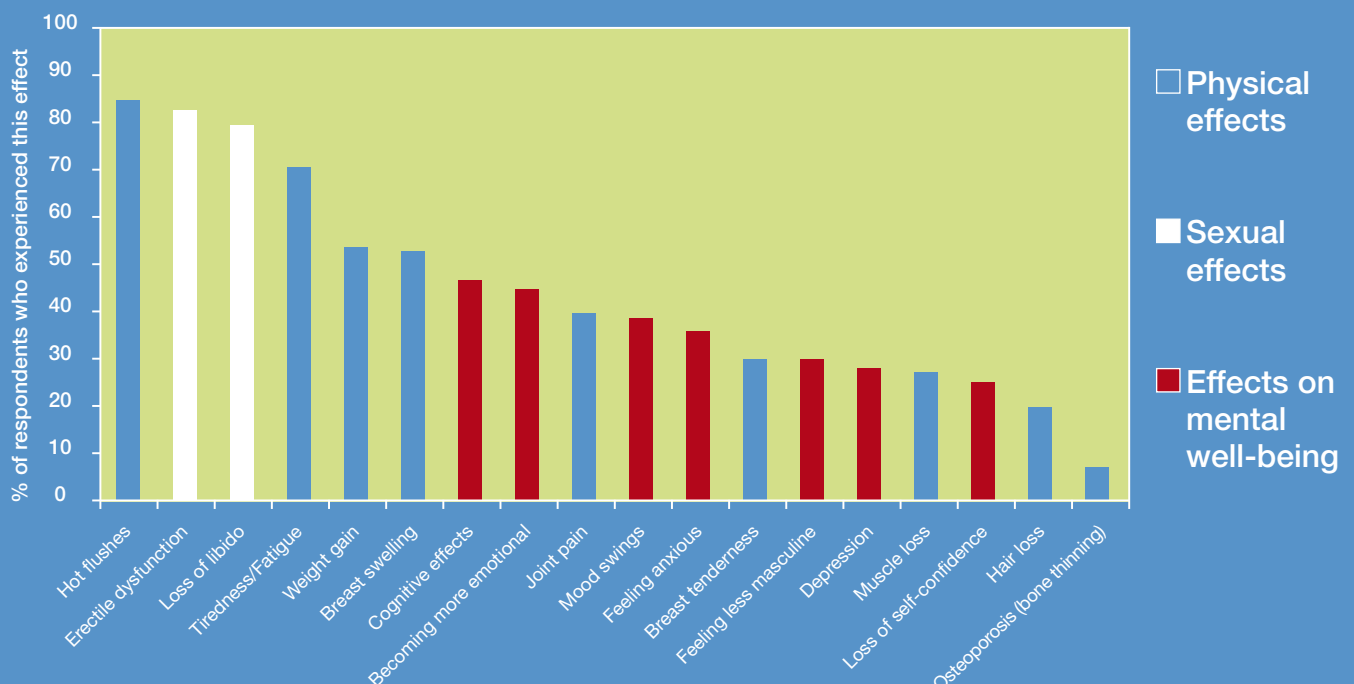


Figure 2

Some of the side effects that can commonly affect men seemed to have a limited impact on their lives. For example, during the focus groups, men described common side effects such as hot flushes (and associated sweating) and breast swelling as “embarrassing” or “bothersome”, but they also said they felt that they could cope with the impact that these side effects had on their life.

“The weight gain / breast swelling makes me self-conscious about swimming and beach holidays” Anonymous

In the Charity’s survey, 84 per cent of men who experienced hot flushes and 83 per cent of men who experienced breast swelling said that the side effect had not affected their life at all, or had affected it in a way they could cope with.

On the other hand, the Charity’s research found that other side effects can have a significant impact on the daily activities of men, their relationships and their mental well-being.

Impact on daily activities

Hormone therapy and its associated side effects can have a considerable impact on daily activities, such as work, household chores, driving and hobbies. Our survey found that tiredness and fatigue - experienced by 71 per cent of men who responded - was the most common reason for a disruption to daily activities.

In addition, almost a quarter of men who responded to the survey said that the treatment had affected their ability to work. Comments made in the survey and focus groups revealed that tiredness, fatigue and loss of strength (through muscle loss) are the main factors that impact on a man’s ability to work.

“Due to fatigue I have had to give up work and now claim incapacity benefit.” Anonymous

“Loss of strength caused me to be unable to carry on working, as did excess sweating!” Geoffrey

Tiredness and fatigue can also have a significant impact on other aspects of the daily lives of men, because it can limit their ability to drive, carry out household chores, gardening, DIY and pursue hobbies. Men reported being “unhappy” or “frustrated” that they could no longer do these activities.

“The tiredness and fatigue has affected me doing the simplest of manual tasks which leaves me frustrated and distressed.” Anonymous

“I am less able to perform practical jobs around the house, which are now undertaken by my wife who is only 1 year younger than I. My wife now drives me around more than before because of my increasing tiredness. I am unhappy that she should have to do this and feel less supportive.” Anonymous

“Fatigue and tiredness can be a nuisance and has required a change in routine to accommodate ‘rests’.” Harry

Overall, 20 per cent of men who responded to the survey said that tiredness and fatigue had affected their life a great deal, which they found difficult to cope with some, or a lot of the time.** This suggests that men need information and support to help them manage the impact of tiredness and fatigue on their lives.

** Here on in, shortened to ‘affected their lives a great deal, which they found difficult to cope with.’



Impact on relationships

Most of the different treatments for prostate cancer can have a significant impact on a man's sexual function. However, hormone therapy also has an additional impact on sexual desire (libido).

The sexual effects of hormone therapy are very common. Our survey found that 83 per cent of respondents experienced erectile dysfunction as a result of hormone therapy, and 80 per cent experienced loss of libido.

Whilst some respondents experienced erectile dysfunction (34%) and loss of libido (20%) before they began hormone therapy, a significant number reported that erectile dysfunction (31%) and loss of libido (28%) had become worse since they had started the treatment.

Although many men on hormone therapy experience some adverse effects related to their sexual functioning, not all believe that this has a significant impact on their lives. For example, a considerable number of men reported that erectile dysfunction (55%) and loss of libido (52%) had not affected their life at all, or had affected their life in a way they could cope with.

Comments from men who took part in the survey and focus group discussions reveal that part of the reason for this may be that many men accept a decline in their sexual function and desire as a natural part of the ageing process, whilst others feel it is the price they have to pay to prevent their prostate cancer from progressing. Men also commented that the loss of sexual desire they experienced meant that they did not miss their reduced sexual function.



“My wife and I discussed this and came to the conclusion that this was a price to pay for staying well.” Peter

“The virtual complete absence of any physical sex life has been overcome by the wonderful understanding of my wife. We have found other ways of expressing our love for each other.” Anonymous

At the same time, a significant number of men said that the sexual effects of hormone therapy had significantly affected their lives. Around a quarter of men who experienced erectile dysfunction and a quarter of men who experienced a loss of libido after they began hormone therapy, said that the effect had affected their life a great deal, which they found difficult to cope with.

As the following quotes show, for some men, hormone therapy can have a significant effect

on both sexual and emotional relationships which can cause considerable distress.

“Sexual function and desire has been completely wiped out. Unable to make any sexual contact with my wife. Unable to explain the empty feeling.” Peter

“Having a very strong will and resolute determination I overcame erectile dysfunction from both surgery and radiotherapy, but hormonal therapy is entirely different and extremely debilitating.” Anonymous

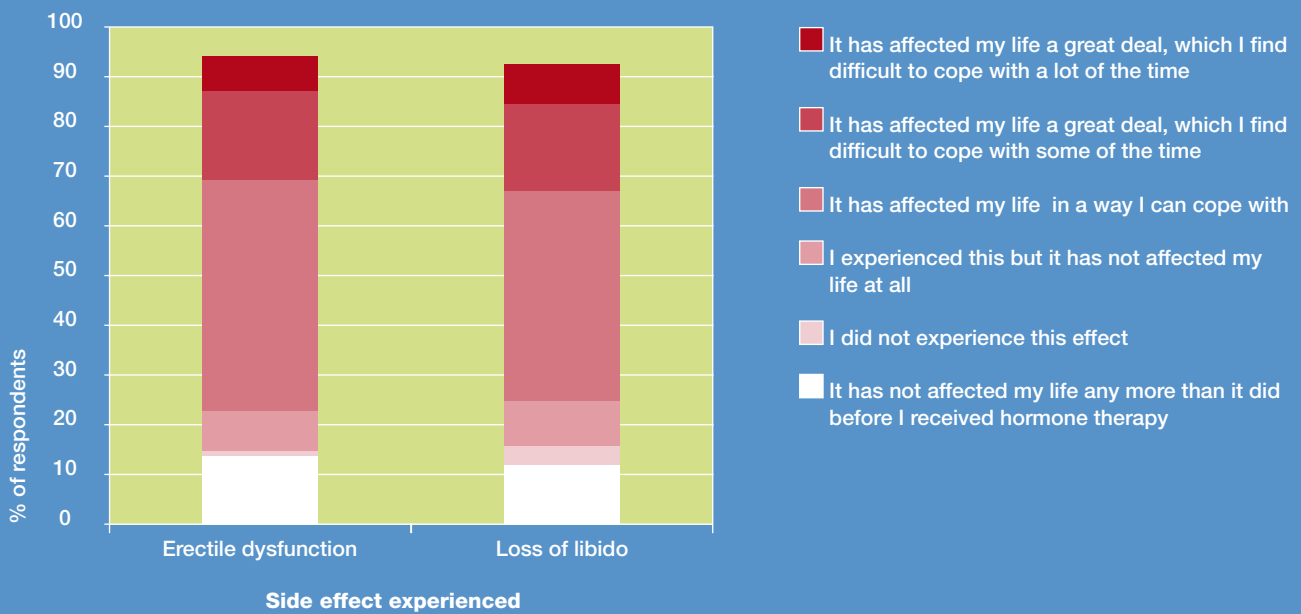
“After living a normal active sexual relationship, the sudden loss of this function has been difficult to accept.” Anthony

“I felt a lesser partner of my marriage.” Anonymous



Figure 3

The impact of erectile dysfunction and loss of libido on all men who responded to the survey



“Being married two months before diagnosis of my prostate cancer – desire was very important to me.” Anonymous

“Hormone therapy is emasculating.” Anonymous

Figure 3 shows the impact that the sexual effects of hormone therapy had on survey respondents.

It is also worth noting that the impact of erectile dysfunction and loss of sexual desire can be difficult for single men who have specific issues and support needs because, for example, they can find it more difficult to start new relationships.

“Being a single person it is now more difficult to meet with members of the opposite sex. I find it embarrassing, especially when it comes to explaining the reason for my loss of libido. I would like to be in a meaningful relationship, which both the loss of sexual function and desire are preventing.” Roland

“As a single person I didn’t think I could ask about treatment as much as I would have if I was in a relationship. As it is, it makes finding an intimate relationship more difficult.” Anonymous

“As a single man I do not have any physical comforts (hugs) or emotional support at hand to compensate.” Anonymous

Impact on mental well-being

Side effects associated with hormone therapy that may impact on mental well-being include: becoming more emotional (for example, crying more easily), mood swings, cognitive effects (such as problems with decision-making and memory loss), feeling less masculine, depressive symptoms and anxiety.

The most common effects that men who responded to the survey said they had experienced on their mental well-being were:

- cognitive effects (47%)
- becoming more emotional (45%)
- mood swings (39%)

Interestingly, the survey showed that most of the effects of hormone therapy on mental well-being tended to have a greater impact on men who experienced them than the impact of the physical and sexual effects.

The mental well-being effects that had the greatest impact on the men who experienced them were depression, a loss of self-confidence and feeling less masculine. For example:

- Just over half of men who reported feeling depressed as a result of hormone therapy said that it had affected their life a great deal, which they found difficult to cope with.
- About one third of men who reported feeling less masculine as a result of the treatment said that it had affected their life a great deal, which they found difficult to cope with.
- One third of men who reported a loss in self-confidence as a result of the treatment said that it had affected their life a great deal, which they found difficult to cope with.

“From being an easy going, well balanced person I now suffer frequent bouts of anger and anxiety. My ‘coping’ mechanism has gone completely.” Anonymous

“Anxiety is heightened.” Anonymous

“I do have concerns about the risk of ‘mood swings’ (or perhaps loss of temper?) when with other people, particularly groups. And how this would be viewed by such groups. This has led to me being very wary of gatherings outside of family (I don’t want to show myself up in front of others).” Anonymous

“I don’t want to socialise as much and my loss of memory is frustrating.” Anonymous



Figure 4

The impact of the effects of hormone therapy on the mental well-being of the men who experienced these effects

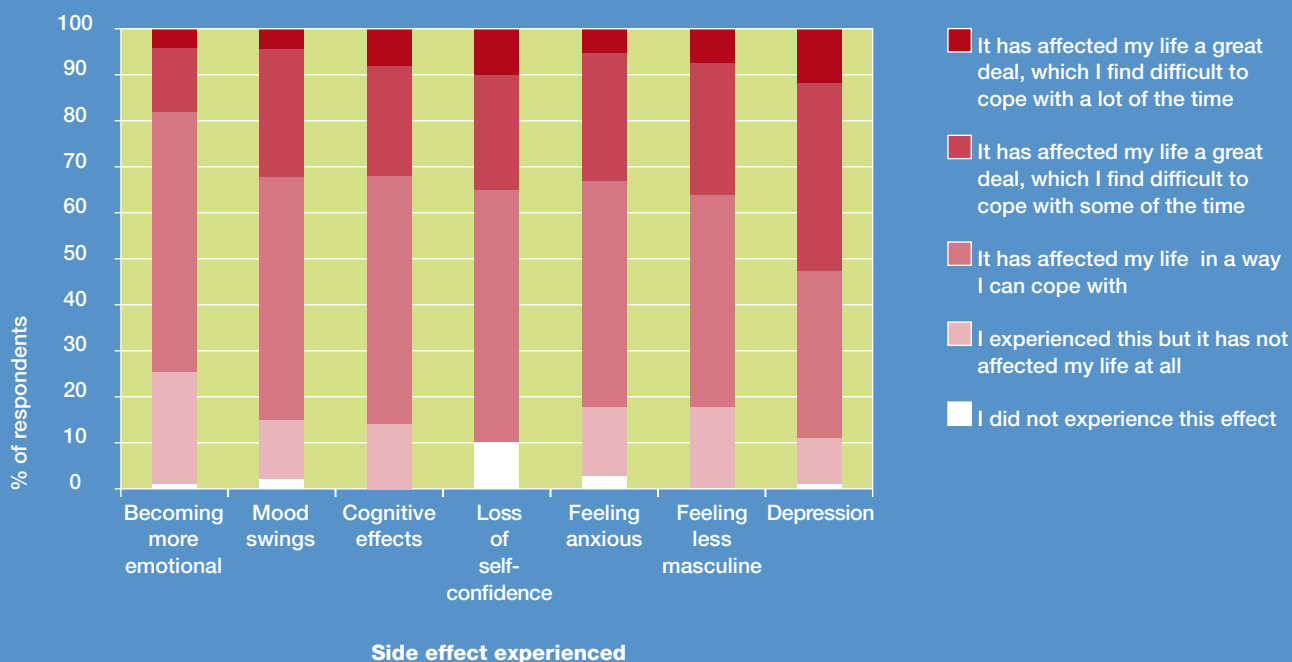


Figure 4 shows the impact the side effects of hormone therapy on mental well-being had on the respondents to the survey who experienced them.

Feedback from men in the survey and the focus groups demonstrated that, problems with decision-making could affect respondents' ability to work, as it made work related decision-making difficult and undermined their confidence.

This may explain why around a third of men who experienced cognitive effects reported that this side effect had affected their life a great deal, which they found difficult to cope with.

“I would find life very difficult coping with some situations compared to before treatment, particularly some work related decisions, e.g. dealing with difficult customers.” Anonymous

“I recall that during the period of hormone therapy the main problem was an inability to make decisions over relatively trivial matters.” Anonymous

“Lack of confidence in decision-making impacts [on] my personal and sometimes professional life (I now have to assess decision-making).” Anonymous

“Major effect again - poor memory, unable to concentrate on tasks. Less able to drive safely – loss of overall confidence in myself.” Anonymous

It is unclear from this research whether hormone therapy is the direct cause of some of the effects on mental well-being, such as loss of self-confidence, anxiety and depression. It is likely that these feelings are caused by a combination of issues, including living with a prostate cancer diagnosis and the psychological effect of the physical and sexual side effects men experience.

Nevertheless, our research shows that men on hormone therapy do feel that the treatment has had a significant impact on their mental well-being. Because of this, it is essential that these men have their psychological needs assessed so that they receive the support they need to cope with these effects.

Impact on men with advanced prostate cancer

Our survey found that the side effects of hormone therapy can have a greater impact on men with advanced cancer than men with earlier stages of the disease. This could be because hormone therapy is the only first-line treatment available for men with advanced cancer and is usually a lifelong treatment.

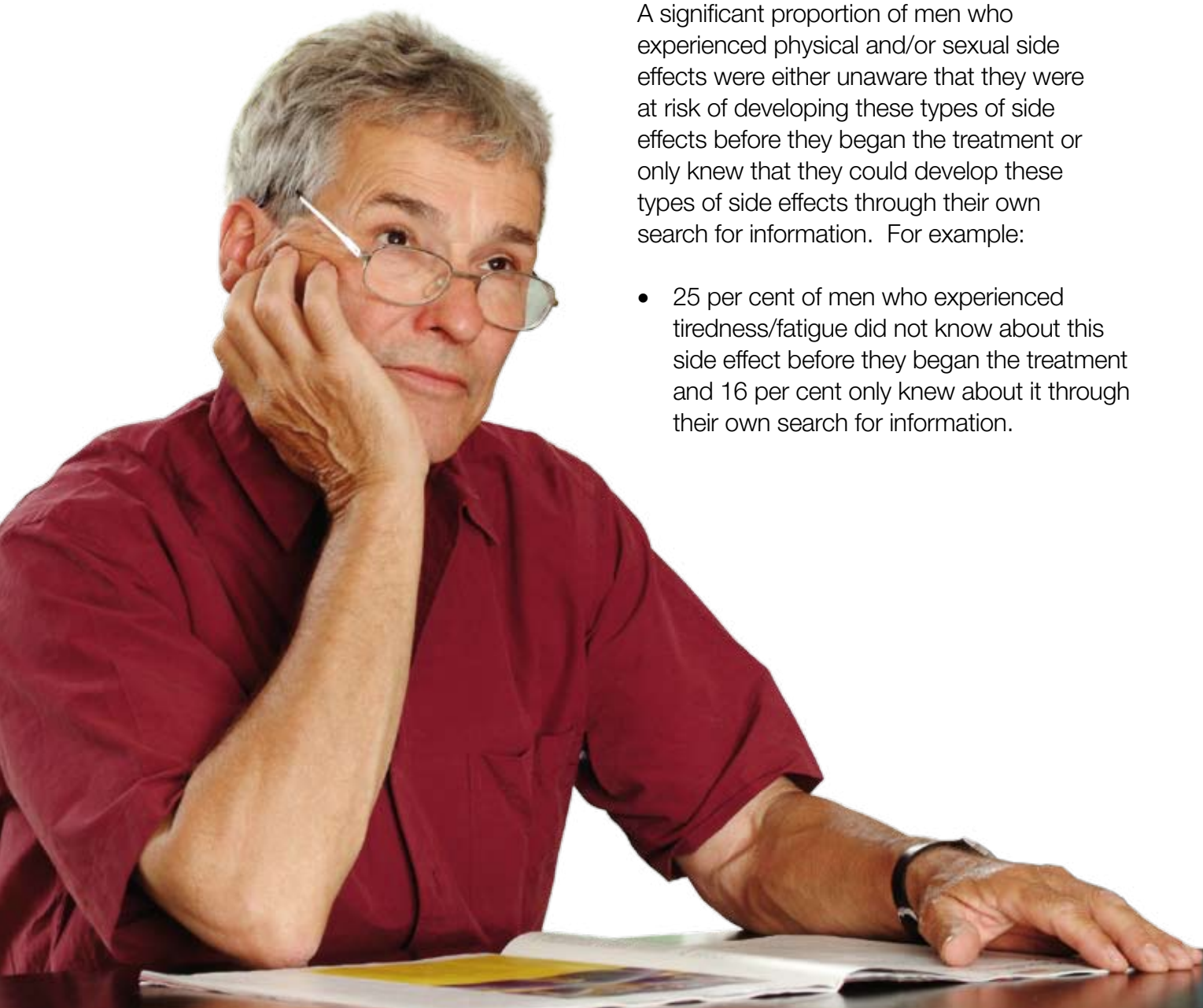
In contrast, men with earlier stages of prostate cancer are often treated with hormone therapy for a specific and shorter period of time. As the side effects of the treatment tend to reduce or disappear once the treatment has stopped, the perceived impact of side effects may not be as great as for men with advanced disease - either because they were no longer receiving hormone therapy (27%), or because they were aware that the treatment and side effects were likely to come to an end.

“As I knew it was short term it was easier to cope with psychologically.” Anonymous

Access to information on hormone therapy

A significant proportion of men who experienced physical and/or sexual side effects were either unaware that they were at risk of developing these types of side effects before they began the treatment or only knew that they could develop these types of side effects through their own search for information. For example:

- 25 per cent of men who experienced tiredness/fatigue did not know about this side effect before they began the treatment and 16 per cent only knew about it through their own search for information.



- 33 per cent of men who experienced loss of libido did not know about this side effect before they began the treatment and 42 per cent only knew about it through their own search for information.

The survey also found that men were much more likely not to be made aware, by a healthcare professional involved in their care, about the effects that hormone therapy could have on their mental well-being. For example:

- 65 per cent of men who experienced cognitive effects did not know about this side effect before they began the treatment and 21 per cent only knew about it through their own search for information.
- 60 per cent of men who experienced becoming more emotional did not know about this side effect before they began the treatment and 17 per cent only knew about it through their own search for information.

Overall, whilst 44 per cent of men reported that the information they received before they began hormone therapy was ‘about right’, 55 per cent did not receive enough information to prepare them for the effects of the treatment and stated that the information they received was ‘too little’. Consequently, a considerable number of men commented that they were unprepared for the side effects they experienced.

“I would have liked to have known what’s normal.” Anonymous

“I would have liked to have had all information on all aspects of all side effects, so that we could know that these are normal for people in our position.” Geoffrey

It is essential that men on hormone therapy receive information about what to expect from the potential side effects of the treatment so that they are prepared for these effects if they do experience them.

Assessing the needs of men on hormone therapy

Despite the high incidence of side effects associated with hormone therapy many men reported that, after they began treatment, they were not asked whether they were experiencing any side effects by a healthcare professional involved in their care. Overall:

- 27 per cent of men who responded to the survey were not asked whether they were experiencing any physical side effects.
- 51 per cent of men who responded to the survey were not asked whether they were experiencing any effects on their sexual function or desire.
- 67 per cent of men who responded to the survey were not asked whether they were experiencing any effects on their mental well-being.

Comments made in the survey suggest that some men are left feeling unsupported by the healthcare professionals involved in their care, who failed to recognise the impact that the side effects had on their lives.

“Healthcare professionals do not provide much information nor do they seem to appreciate the devastating feelings associated with the side effects. Understanding and guidance would be a good start.” Anonymous



“I felt the health care professionals were not interested in my mental well being, it appeared to me that they felt they gave me treatment for prostate cancer, and now I had to cope with it whatever way I could. I got the impression that they were really only interested in getting the basic job done, side effects were of no interest to them.”
Laurence

The fact that men are not being asked about the side effects they might be experiencing, as a result of hormone therapy, means that they are not having their support needs assessed and are, therefore, not being told about the interventions and support that could help them manage the side effects of hormone therapy.

Awareness of support and advice services

Our research found that men are not being told about the interventions and support services available to help them manage the side effects of hormone therapy. For example:

- 50 per cent of men who experienced hot flushes were not told about medicines (such as tablets and patches) that could help reduce this effect.
- 58 per cent of men who experienced breast swelling were not told about radiotherapy to help prevent this.

- 86 per cent of men who experienced tiredness/fatigue were not told about resistance exercise that could help relieve these symptoms.

In addition, many respondents were not told about support and advice services that are popular amongst men on hormone therapy.

- 52 per cent were not told about written information.
- 32 per cent did not have access to a Clinical Nurse Specialist.
- 64 per cent were not told about peer support services.
- 41 per cent were not told about support groups.
- 66 per cent were not told about counselling from a relationship expert.
- 62 per cent were not told about general counselling services.

Supporting men on hormone therapy

Our research found the provision of support for men on hormone therapy could be improved in five key areas:

1. Information

Overall, many respondents to the survey commented that they wanted “confirmation” of the changes that they were going through and information was key to this. They also said that they wanted information about how to manage the side effects they were experiencing.

“I would have liked to have been aware of what was ahead of me.” Anonymous

“Written information, not verbal, on medication or vitamin supplements to help overcome and ease the side effects, instead of being left to struggle on your own.” Anonymous

“Good written information at outset on whole range of effects and on ways of countering them.” Anonymous

“Much more information about all the possible side effects and where to go for help with them.” Anonymous

In addition, many men did not receive written information about common side effects of the treatment, such as tiredness (66%), erectile dysfunction (73%) and cognitive effects (87%) from a healthcare professional before they received hormone therapy for the first time.

Helplines can also provide a good source of information for men and their partners. Twenty two per cent of men who responded to the survey reported using The Prostate Cancer Charity Helpline and 12 per cent used other helplines as a form of information and support.

“I would have liked to have received the information that I got from the internet and The Prostate Cancer Charity Helpline, from the Oncology Dept. at the hospital.” Anon

“I have used throughout my diagnosis and treatment The Prostate Cancer Charity website, Tool Kit and have spoken to the ladies on the Helpline on a number of occasions.” Andrew

2. Clinical Nurse Specialists

Access to a key healthcare worker who could provide information and advice about side effects was also considered an important aspect of care that men would have liked to have received.

“To have access to a nurse specialist who is aware of the side effects and able to advise ways of coping with the side effects.”

Roland

“A dedicated one to one with any professional specific to hormone therapy side effects and what could be done about them would have been useful...”

Anonymous

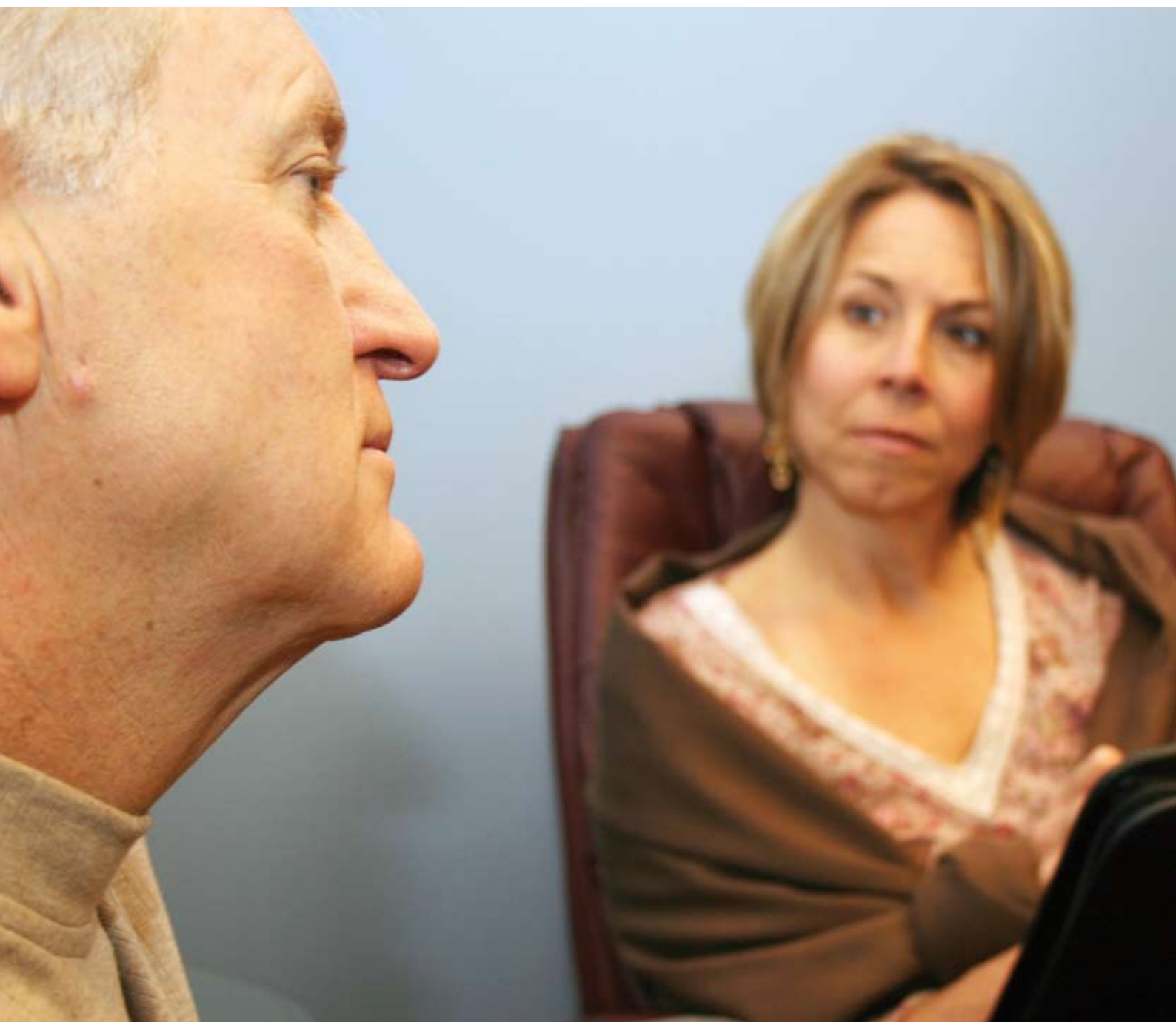
“Just someone to talk to who would give you more than ten minutes.”

Anonymous

Studies have shown that men with prostate cancer who have access to a Clinical Nurse Specialist (CNS) report a better patient experience than men who do not. ⁽²⁰⁾⁽²¹⁾⁽²²⁾⁽²³⁾⁽²⁴⁾

CNS's are able to bring a patient-centred approach to cancer care; providing support, advice and information to patients and are able to spend time with them when they need it.

CNS's can also provide initial psychological support, or counselling, to men. This service was popular amongst men, with 22 per cent of respondents reporting that they used counselling services from a CNS.



Overall, respondents tended to report better access to information about support services if they had had access to a CNS. For example, 70 per cent of men who did not have access to a CNS said that the information they received before they began hormone treatment was 'too little', compared to 50 per cent of men who had access to a CNS. Similarly, half of men who had access to a CNS said that the support they received whilst on the treatment was 'about right', compared to just over a quarter of men (28%) who did not have access to a CNS.

The survey findings suggest that access to a CNS can improve the information and support that men on hormone therapy receive. However, the Charity is aware that there are problems with access to CNS's for many men with prostate cancer in England.⁽²⁵⁾ This was reflected in the Charity's research findings, which found that one in three respondents did not have access to a CNS.

3. Peer support

Studies suggest that contact with other people with cancer assists people living with cancer and can have practical, social and emotional benefits.⁽²⁶⁾



Whilst one-to-one peer support from another man affected by prostate cancer was only used by 8 per cent of men who responded to the survey, 64 per cent were not told about this service. One-to-one peer support may be another useful tool for men on hormone therapy and was suggested by focus group participants to be a form of support they would like to be available to them.

Support groups are another form of peer support. The Charity's research found that support groups were considered a particularly useful method of support for respondents, with 24 per cent of men reporting that they used this service after a healthcare professional told them about it. This figure may be influenced by the large number of support groups that were contacted about the survey. However, other studies have demonstrated that support groups are effective at meeting many of the support needs of men with prostate cancer.⁽²⁷⁾

4. Support for relationships

Overall, a significant number of men reported that the side effects of hormone therapy had affected their emotional (21%) and sexual (36%) relationship with their partner a great deal, which they found difficult to cope with.

Some men and their partners need support to help them cope with this impact. Relationship counselling was considered a particularly important service, with 80 per cent of men saying that they 'agree' or 'strongly agree' that all men receiving hormone therapy and their partners should be told about this service. However, we are aware that across the UK there is currently little provision of this service.

5. Counselling services

Counselling may be an appropriate tool to help men manage the effects of hormone therapy on mental well-being.

"My GP recommended a series of counselling sessions (on the NHS) which I found very helpful." Malcolm

"The counselling is fantastic and should be made available to all men as soon as they start hormone therapy. The therapist would then see the man from the beginning of his treatment rather than in the middle and having to guess what the man was like prior to the start of the treatment." Keith

Of the 13 per cent of men who were told about counselling services, from a psychiatrist, psychologist or counsellor, 4 per cent used this service. This suggests that more men may have used this type of support, had they been made aware of it by a healthcare professional.

Research findings 2: The impact on partners

The Charity's research also found that the side effects of hormone therapy could substantially affect the lives of the partners of men who receive the treatment.

The impact on their relationship

A significant number of partners found it difficult to cope with the impact of hormone therapy on their sexual and emotional relationships. Twenty per cent of partners

said that they found erectile dysfunction had affected their life a great deal, which they found difficult to cope with.

*"We used to have an excellent relationship, but these days we argue and fall out frequently. The loss of our physical relationship has resulted in our feeling less close to each other, less like husband and wife and more like patient and carer."
Anonymous*



“We are no longer physical with one another and our relationship is one of nurse-carer/patient. I love my husband dearly and promised ‘to love in sickness and in health’ so will stay with him and care for him to the best of my ability. But forewarning of the possible side effects would have given some preparation for our future together.”
Anonymous

“...I have lost my soul mate and lover. Now I am just in ‘carer’ mode. None of this is explained to you prior to treatment. Nor were they explained to my husband.” Anonymous

A third of partners who responded to the survey said that their partner’s loss of libido had affected their lives a great deal, which they found difficult to cope with. However, only a quarter of men reported the same level of impact of loss of libido on their lives. This suggests that partners have specific support needs around the impact that their partner’s loss of libido has on them.

“I deeply regret and rather resent our lack of any sex life even though I can reason that the therapy is saving his life...I am certain that my husband still loves me but it is quite dispiriting and ego shattering to feel undesirable and that, after over 30 years of marriage, this is it for the next 10/20 years.” Anonymous

“Erectile dysfunction means we no longer enjoy a sexual relationship and the loss of libido means I no longer enjoy the shows of affection which my husband and I shared.”
Anonymous

“We now sleep in single beds and no longer have a marital relationship.” Anonymous

The emotional impact

After the sexual effects of hormone therapy, the side effects that had the greatest impact on the lives of partners were the effects of the treatment on their partner’s mental well-being.

A considerable number of partners reported that cognitive effects (31%), mood swings (29%), feelings of depression (20%), anxiety (19%) becoming more emotional (18%) and feeling less masculine (17%) had affected their lives a great deal, which they found difficult to cope with.

Comments made in the survey suggest that the effects on their partner’s mental well-being caused a need to support their partners emotionally that they could sometimes find difficult to cope with - because they needed support themselves.

“Being in a Gay relationship my partner’s masculinity was a major part of our relationship and he becomes very distressed at the changes in his body. Loss of body hair, shrinking of his penis and weight gain have all effected his self esteem and requires a lot of support and reassurance from me.”
Anonymous

“Not really made any difference other than perhaps having to ‘prop him up’ emotionally more than previously. Hard on me sometimes as I could do with some support.”
Anonymous

Partners also made specific comments in the survey about difficulty coping with their partners’ mood swings.

“His mood swings can be quite distressing as they seem to focus mainly on me.”
Anonymous

“Sometimes the depression of the mood swings he has gets to me greatly.” Thelma

“His mood swings are unbelievable so I am on edge wondering how he’s going to be. I try very hard to help and understand him, I know it must be extremely difficult for him, but at times it’s like being on a rollercoaster you can’t get off.” Anonymous

“...the feeling that my spouse is not the man I married anymore because of the mood swings.” Anonymous

Practical responsibilities

Tiredness and fatigue also affects the lives of partners of men undergoing treatment. For example, partners commented that tiredness and fatigue had prevented their partner from carrying out household chores and DIY. Fourteen per cent of partners who responded to the survey said that this side effect had affected their life a great deal, which they found difficult to cope with.

Comments made in the survey suggest that partners found their partners' tiredness and

fatigue difficult to cope with because it created a new responsibility to do household chores that they had not previously experienced.

“My husband’s weakness has meant he can’t do the tasks about the house he used to. So much of it is left to me.” Anonymous

“He cannot do many of the household chores which he would have normally done and we have had to pay other people to do them, i.e. decorating and some aspects of gardening. This has impacted our disposable income” Anonymous

“He has stopped all DIY and is not interested in doing anything physical. He has always done jobs around the house. This has all stopped.” Anonymous

Supporting the partners of men on hormone therapy

Partners also require information and support to help them cope with the impact of the side effects of hormone therapy. For example, 60 per cent of partners who responded to the survey said that the information they received about the side effects of hormone therapy before their partner began the treatment was ‘too little’.

The research also found that partners are not always receiving the support they need to help them cope with the impact of the side effects of hormone therapy - 71 per cent of partners who responded to the survey said that the support and advice services made available to them, to help them cope with the impact of the side effects on them, was ‘too little’.

The partners of men who receive hormone therapy must also receive information about the treatment and its side effects, have their support needs assessed and be signposted to appropriate support and advice services in order to help them cope with the impact the treatment can have on their lives.



Current guidelines

England and Wales

In England and Wales, guidelines relating to the effective treatment and care of men with prostate cancer and their partners have been developed. They set out standards of care that should be met for all men, regardless of where they live.

The National Institute for Health and Clinical Excellence (NICE) has published two pieces of guidance relating specifically to prostate cancer and one relating to the supportive and palliative care of people with cancer.

1. Prostate Cancer: Diagnosis and Treatment (2008)⁽¹⁾ – this guideline recommends that:

- Men with prostate cancer should receive individualised information.
- Men and their partners should be told about the adverse effects of prostate cancer treatments on sexual function, physical appearance, continence and aspects of masculinity.
- Men should be told about psychosexual support services.
- Men and their partners should have access to specialist erectile dysfunction services.

2. Improving Outcomes Guidance for Urological Cancers (2002)⁽²⁸⁾ – this guidance recommends that:

- Men with advanced and metastatic prostate cancer should have all hormone therapy options and the associated adverse effects discussed with them.

3. Supportive and Palliative Care for Adults with Cancer: The Manual (2004)⁽²⁹⁾ – this guidance recommends that:

- Patients and their carers should have access to a range of high quality information about cancer and cancer services.
- All patients should receive psychological assessments and have access to appropriate psychological support.

Scotland

In 'Management of Core Cancer Services' (2008) guidance⁽³⁰⁾, NHS Quality Improvement Scotland (QIS) has developed guidelines on the core standards for the management of cancer services and care in Scotland. NHS QIS recommends that:

- All patients with cancer should have individualised care plans, detailing their clinical and non-clinical issues (such as their financial, social, spiritual and psychosocial needs).
- Patients and carers should be provided with tailored information about the disease, treatment (and associated side effects) and care options.

- All patients with cancer should have access to a healthcare worker with experience and knowledge of their current needs.

There is no specific national guidance in Scotland on the treatment and care of men with prostate cancer.

The Royal College of General Practitioners

In addition, the Royal College of General Practitioners (RCGP) has issued guidance to GPs across the UK, based on the NICE guideline, *Prostate Cancer: Diagnosis and Treatment* (2008), about the care that GPs should provide to men with prostate cancer.⁽³¹⁾ The RCGP recommend that GPs should:

- Inform men and their partners about the effects of prostate cancer treatments on aspects of health such as sexual function, physical appearance, continence and other aspects of masculinity.
- Monitor the side effects of treatment as part of the follow up care for men who have been treated for prostate cancer.
- GPs should provide good information to men with prostate cancer and signpost or refer men to relevant services.

The implementation of current guidelines

The Charity's research suggests that many men across the UK who receive hormone therapy for prostate cancer, are not receiving the level and quality of care set out in national guidelines.

Discussion

This research demonstrates just how significant an impact hormone therapy can have on the lives of men affected by prostate cancer – and their partners.

Despite the considerable distress and discomfort experienced by many men who are receiving hormone therapy, our research shows that too many men are not given adequate information about side effects prior to treatment. This means that they are not prepared for what could be ahead of them and do not know that the side effects they go on to experience can be a “normal” result of the treatment.

To improve the provision of information about hormone therapy, all men considering the treatment must receive written and verbal information about the treatment and its potential side effects. This information should be appropriate to their individual information preferences.

Those men who go on to receive hormone therapy must be given detailed written information providing advice and direction on how to best manage side effects and cope with the impact of treatment on their lives.

In particular, men should be told about appropriate interventions that can help prevent or alleviate the side effects they experience. This includes information about medical interventions for erectile dysfunction, medicines and complementary therapies that can help reduce the effect of hot flushes and treatments for breast swelling, such as radiotherapy and the drug Tamoxifen.

Furthermore, all men receiving hormone therapy should be told about ways they can manage the side effects of hormone therapy themselves, including:

- The benefits of exercise to help alleviate fatigue and manage weight gain.
- The diet and lifestyle changes that can help reduce the risk of hot flushes, osteoporosis (bone thinning) and heart disease.
- The possible benefits of some complementary therapies, such as acupuncture and sage tea for hot flushes.
- The benefits of communicating openly with their partners about the side effects of the treatment.

This information could be provided to men in the form of a booklet, such as The Prostate Cancer Charity's '*Living with hormone therapy: A guide for men with prostate cancer*' booklet.

For healthcare professionals to be in a position to support men and their partners, they need to be aware of the potential side effects associated with hormone therapy and proactively engage men in discussions about any physical, sexual and mental side effects they might be experiencing.

It is especially important that healthcare professionals are aware that:

- (i) even if some side effects have a small incidence level they can still have a significant impact on the men who experience them;
- (ii) and that even if the majority of men can cope with a side effect, some men may find it more difficult to do so and may need support.

Sadly, the Charity's research has found that many men are unlikely to be asked if they are experiencing side effects by the healthcare professionals involved in their care and do not have their support needs assessed.

The assessment of the needs of men who receive hormone therapy is essential to ensure that all men on the treatment receive the interventions and support services appropriate to their needs. Therefore, it is vital that healthcare professionals involved in the treatment of men with prostate cancer have an assessment tool to enable them to effectively assess the needs of men receiving the treatment.

As GPs and Practice Nurses are the healthcare professionals that most commonly administer hormone therapy to men with prostate cancer, particular attention should be paid to informing them about the need to assess the support needs of men who receive this treatment and to signpost and refer these men to appropriate support services. In the UK, more cancer follow up is gradually expected to be delivered locally.⁽³²⁾⁽³³⁾ It is, therefore, increasingly important that primary care practitioners receive the information and tools they need to support men who receive this treatment.

Overall, the provision of information, support and advice to men receiving hormone therapy would be greatly improved if all men had access to a key named worker, such as a Clinical Nurse Specialist. This would provide men with a named contact whom they

could contact to discuss the effects of the treatment, as and when issues arise.

It is clear that the side effects of hormone therapy that men experience can also have a huge impact on their partners. Healthcare professionals should, therefore, also consider the information and support needs of the partners of men and be considerate of how sexual orientation may affect these needs.

Essential to the improved provision of support to men and their partners is the availability of support services. Local health services should be aware of the support services that are available in their areas. Many national organisations, like The Prostate Cancer Charity, provide a wide range of services that are available to all men across the UK – these services include a Helpline and one-to-one peer support. It is important that local health services can signpost men to all available services.

The Prostate Cancer Charity is aware that some support services, such as psychosexual and relationship counselling, are not currently widely available across the country. To ensure that men receive the support they need, wherever they are in the UK, it is vital that where services are currently unavailable, local healthcare commissioners and providers seek to provide new services.

The Charity's research has shown that there is an urgent need to improve the provision of information and support to men (and the partners of men) receiving hormone therapy. To address this need and provide the quality of care outlined above for men on hormone therapy, The Prostate Cancer Charity is calling on Government Health Departments across the UK, the National Cancer Survivorship Initiative in England and the Scottish Cancer Taskforce to review its research findings and take action in accordance with the recommendations set out in Part VII.

The Prostate Cancer Charity's recommendations

1. All men considering hormone therapy for prostate cancer should be informed about the potential side effects of the treatment by a healthcare professional.

1.1 Men should be provided with written information about all the treatment options available to them, which they can take away with them for further consideration.

1.2 Oncologists, Urologists and Clinical Nurse Specialists should tell all men considering hormone therapy about the potential key side effects of hormone therapy and provide written information about these side effects.

2. All men receiving hormone therapy should be given verbal and written information about how they can manage the side effects of the treatment and where to go to receive support for these effects.

2.1 Cancer Networks, Primary Care Trusts (PCTs) and Managed Clinical Networks should ensure that all healthcare professionals involved in the care of men receiving hormone therapy for prostate cancer are educated about the side effects associated with the treatment and the information and

support services available to men who experience these effects.

2.2 In particular, GPs and Practice Nurses, should be informed about the side effects of hormone therapy and the support services available to men who experience these side effects.

2.3 The Royal College of General Practitioners should raise awareness amongst GPs of the physical, sexual and mental well-being side effects associated with hormone therapy, the support needs of men who receive this treatment and the information and support services that should be available.

2.4 In England, Cancer Networks should ensure that Information Prescriptions for men receiving hormone therapy include information about the side effects of this treatment and the interventions and support services available to help men manage these effects.

2.5 Information on hormone therapy, the associated side effects and the appropriate interventions and support services for men on this treatment should be available on local cancer information pathways in England.

2.6 In Scotland, information on hormone therapy, the associated side effects and the appropriate interventions and support services for men on this treatment should be included in the new National Health Information and Support Service.

2.7 In the UK, all men who receive hormone therapy, should receive information about the lifestyle changes they can make to help them self-manage some of the side effects associated with the treatment and where to go for help with side effects if they need it. This information could be provided in the form of a booklet, such as The Prostate Cancer Charity's *'Living with hormone therapy: A guide for men with prostate cancer'*.

3. All men receiving hormone therapy should be regularly assessed for the side effects of the treatment and associated support needs.

3.1 All healthcare professionals (within primary or secondary care) responsible for providing regular hormone therapy to men with prostate cancer should be responsible for assessing whether men are experiencing any side effects and have any associated support needs.

3.2 In England, a new indicator should be introduced to the Quality Outcomes Framework for Cancer to ensure the effective long-term management of cancer patients within primary care - it should recommend regular assessments of the physical, psychological and sexual well-being of cancer patients and any support needs.

3.3 An assessment tool to aid primary and secondary healthcare professionals involved in the care of men receiving hormone therapy should be developed through the work of the National Cancer Survivorship Initiative in England and the Scottish Cancer Taskforce.

3.4 Following this assessment, healthcare professionals involved in the care of men receiving hormone therapy should be responsible for referring or signposting men to the appropriate intervention and/or support services.

3.5 All men experiencing side effects from hormone therapy should be offered an appointment with a Clinical Nurse Specialist to discuss the effects of the treatment and their support needs in detail.

4. Appropriate medical interventions and support services that can help men manage the side effects of hormone therapy should be available to men across the UK.

4.1 All men receiving hormone therapy in the UK should be told about and have access to the following medical interventions and services:

- Medicines for hot flushes – that can help to prevent or reduce them.
- Advice on the benefits of resistance exercises – to help relieve tiredness and control weight gain.
- Lifestyle and dietary advice – to help reduce the risk of hot flushes, weight gain and osteoporosis (bone thinning).
- Radiotherapy and, where appropriate, Tamoxifen – to help prevent gynaecomastia (breast swelling).
- Erectile dysfunction services – to enable men to receive appropriate interventions to help them improve sexual function.
- A prostate cancer/cancer helpline telephone number – such as The Prostate Cancer Charity's free and confidential nurse-led Helpline.

- One-to-one peer support – such as The Prostate Cancer Charity telephone-based peer support service.
- Details of local support groups – a UK-wide list of support groups is available on The Prostate Cancer Charity website.
- Counselling services – this should include relationship and psychosexual counselling.

4.2 Cancer Networks, PCTs, Managed Clinical Networks and Health Boards should assess the current provision of support services for men on hormone therapy within their network, or area and identify gaps in services.

4.3 Where gaps in the provision of interventions or support services are identified the National Cancer Survivorship Initiative Steering Group in England and Scottish Cancer Taskforce should work on strategies to fill gaps in the support services available to cancer patients.

5. Further research should be conducted into the impact of hormone therapy on the lives of men (and their partners) who receive the treatment and interventions to help them cope with, or manage these side effects.

5.1 The research community should investigate:

5.1.1 The experience of men (and partners of men) on hormone therapy – looking particularly at the impact of the stage of prostate cancer and of the different systems of follow up care that men experience.

5.1.2 Best practice models of co-ordinated follow up for men on hormone therapy.

5.1.3 Interventions that can support men (and their partners) to cope with hormone therapy side effects, particularly the impact on sexual function, desire and mental well-being.

6. In England, the National Cancer Survivorship Initiative (NCSI) should review the Charity's research findings and recommendations and consider the action it can take to improve the support and information provided to men receiving hormone therapy.

6.1 The NCSI Assessment, Care Planning and Immediate Post Treatment working group should develop an appropriate assessment mechanism to effectively identify the needs of men receiving hormone therapy being cared for in primary or secondary care and develop individual care plans.

6.2 The NCSI Self Care and Self-management working group should review the Charity's research and make specific recommendations about models of post treatment support, self management education courses and support materials for men living with the effects of hormone therapy and about healthcare professional training models to support these men.

6.3 The NCSI Detecting, Recording and Managing the Late Effects of Treatment working group and the NCSI Managing active and progressive recurrent disease working group should review the Charity's research findings and make recommendations about new interventions that need to be put in place to improve the range and effectiveness of support services for men receiving hormone therapy for prostate cancer.

6.4 The NCSI Detecting, Recording and Managing the Late Effects of Treatment working group should investigate the provision of counselling services for people living with cancer (especially psychosexual and relationship counselling) and make recommendations about how the availability of this service can be improved for men and their partners.

6.5 Particular attention should be paid by all NCSI working groups to interventions to help men manage, or cope with the sexual effects and effects on mental well-being of hormone therapy.

6.6 NHS Improvement, through the NCSI test site communities should develop, test and evaluate new approaches to the care and support of men receiving hormone therapy for prostate cancer.

6.7 The NCSI Research working group should ensure that it includes the need for the research outlined in recommendation 5 in its survivorship research recommendations to the Department of Health.

7. In Scotland, the Living with Cancer Group of the Scottish Cancer Taskforce should review the Charity's research findings and recommendations and consider the action it can take to improve the support and information provided to men receiving hormone therapy.

7.1 The Living with Cancer Group should review the Charity's research findings and recommendations to develop its understanding of some of the survivorship needs of men with prostate cancer and develop strategies for improving the care of men who receive hormone therapy. In particular, the Group should investigate and make recommendations about:

7.1.1 The need for an appropriate assessment tool for primary care and secondary care professionals to use to assess the side effects experienced and associated support needs of men receiving hormone therapy.

7.1.2 The new interventions that need to be put into place to improve the range and effectiveness of support services for men receiving hormone therapy for prostate cancer.

7.1.3 The availability of counselling services (especially psychosexual and relationship counselling) in Scotland and how access to this service can be improved for men and their partners.

7.1.4 The need for further research into the support needs of men (and the partners of men) who receive hormone therapy.

8. To ensure men receiving hormone therapy in Scotland receive high quality care, NHS Quality Improvement Scotland (QIS) should develop Standards for Cancer Services for prostate cancer.

8.1 When developing standards of care for prostate cancer, NHS QIS should review the Charity's research findings and recommendations to ensure that the issues around the care of men receiving hormone therapy are considered and included within the standards.

9. The partners of men receiving hormone therapy should be informed about the side effects of the treatment and signposted to support services, by the healthcare professionals involved in their partners care.

9.1 All healthcare professionals involved in the care of men on hormone therapy should be aware of the information and support needs of partners who attend appointments and provide written information about the side effects of treatment to them.

9.2 This information should include information about the range of support services available to them.

9.3 Healthcare professionals involved in the care of men on hormone therapy should be mindful of the sexual orientation of men receiving hormone therapy and how this may impact on their and their partner's support needs.

10. National guidelines relating to the effective treatment and care of men with prostate cancer must be fully implemented to ensure that all men receiving hormone therapy receive a high standard of care.

10.1 In England, the recommendations set out in the following National Institute for Health and Clinical Excellence (NICE) guidance should be fully implemented for men receiving hormone therapy for prostate cancer:

- Prostate Cancer: Diagnosis and Treatment(1)
- Improving Outcomes Guidance for Urological Cancers (2002)(30)
- Supportive and Palliative Care for Adults with Cancer: The Manual (2004)(31)

10.2 In Scotland, the recommendations set out in the NHS Quality Improvement Scotland guidance on the Management of Core Cancer Services' (2008)⁽³⁰⁾ should be fully implemented for men receiving hormone therapy for prostate cancer.

A more detailed explanation of the standards of care set out in these pieces of guidance can be found in Part V.

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Our Mission

Fighting prostate cancer on every front -
through research, support, information and campaigning

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Free and confidential Helpline

0800 074 8383*

Mon – Fri 10am – 4pm, Wed 7pm – 9pm

Email: helpline@prostate-cancer.org.uk

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* Calls are free of charge from UK landlines. Mobile phone charges may vary. Calls may be monitored for training purposes. Confidentiality is maintained between callers and The Prostate Cancer Charity.

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