



## **Life after Prostate Cancer Treatment – “The New Normal”**

*Many men who are treated for prostate cancer complain that before their treatment they were not given sufficient information about the treatment side effects. Until recently the psychological consequences of treatment on quality of life have not been addressed.*

*This is an extract (without footnotes) from an article “The struggle towards ‘the New Normal’: a qualitative insight into psychosexual adjustment to prostate cancer” by 3 Researchers at Sydney University; Narelle Hanly, Shab Mireskandari and Ilona Juraskova. The article originally appeared in BMC Urology 2014. A full version of the article can be found online at: <http://www.biomedcentral.com/1471-2490/14/56> We are grateful to the authors for making their article an Open Access article distributed under the terms of the Creative Commons Attribution Licence.*

*The researchers interviewed 21 men recruited by responding to an advertisement in a prostate cancer support group newsletter.*

### **Background**

At 3 years post-treatment, urinary dysfunction (e.g. urinary incontinence) is more common amongst men treated with radical prostatectomy (up to 15%), and bowel problems (e.g. faecal incontinence and bleeding from the bowel) are more commonly reported by men treated with radiotherapy (up to 15%). Sexual dysfunction three years post-treatment is common across all modalities (nerve sparing RP 68%, non-nerve sparing RP 87%, external RT 68%, brachytherapy 36%, ADT 98%). Treatment-induced changes in sexual function include erectile dysfunction (ED), absent or diminished ejaculate, changed orgasmic sensation, urine loss during arousal or orgasm (climacturia), decreased libido and penile shortening. In addition to these physical side-effects, men also report impaired body image and self-esteem. ADT may also result in fatigue, weight gain, loss of muscle mass and body hair, hot flushes, sexual dysfunction, diminished genitalia size, depression, mood swings and reduced cognitive function with associated decline in quality of life. Given the high survival rate, the majority of men diagnosed with PC are living with these physical and psychological consequences of treatment which have persistent effect on their quality of life.

Until recent years, how men felt about the impact of treatment side-effects was not addressed in any detail. Sexual function was usually evaluated quantitatively, in terms of erections and the ability to achieve vaginal penetration, with much less emphasis on diminished desire and intimacy, and the

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### **Our Next Meeting**

Date: **Wednesday 10 June 2015.**

Time: **10:00 am to 12.30 pm**

Place: **Ivanhoe Uniting Church, Seddon Street, Ivanhoe** (Melways 31 F8)

- Meetings are open to anyone interested in getting support or information on a prostate cancer journey. Partners or carers are welcome to all meetings.
- **There is no charge for attending.**

impact of sexual problems on relationships. Current research which recognises the broader psychosexual impact of treatment-related functional changes has found that many men report a negative association between physical side-effects and their intimate relationships, and self-perception, including reduced quality of sexual intimacy, decreased sexual desire and sexual confidence, impaired feelings of masculinity, lower self-esteem and poorer body image.

It is not surprising then that post-treatment side-effects have been found to increase anxiety and depression which can impact on already reduced sexual function. Men may also grieve for their diminished sexual quality of life, decreased libido and lost sexual fantasy life, as a result of their decreased self-worth and a depleted view of their masculinity.

Studies have shown that after PC treatment, men express unmet needs related to sexuality. Smith et al. found that 47% of participants in their study described unmet needs related to changes in sexual feelings and the associated impact on relationships. In contrast, men who believe they received adequate information to enable informed treatment decision-making have been found to be less likely to report being unhappy with their doctor or distressed about side-effects.

Further investigations of men's experiences of treatment-induced side-effects is required to gain a better understanding of the issues underlying the complex post-treatment changes in the men's lives. .... The aim of the current study was to further explore the experiences of men treated for PC and their psychosexual adjustment, as well as identifying unmet information and support needs. ....

## Themes

Analysis of the participants' interviews revealed three main themes relating to men's post-treatment psychosexual adjustment: i) psychosexual impact, ii) communication and support, iii) integration process

### **Theme 1: psychosexual impact**

#### *Significant sexual and urinary difficulties*

Physical changes reported by participants included erectile dysfunction, urinary incontinence, urine leakage during arousal or at orgasm, reduced penile size, lack of or reduced ejaculate, change in intensity of orgasm, reduced desire and pain.

The inability to achieve and/or maintain an erection and therefore have penetrative intercourse precluded some participants from sexual intimacy, as many viewed sexual interaction as equating with penetrative intercourse.

*"...minimal erections, so there's no penetration....The major issue has been around penetration and the inability to be able to get an erection." [age 65]*

Some men noticed that, unlike previously when erections had been spontaneous, they now consciously thought about what was happening during arousal, thinking about how long their erection would last, what their partner was thinking and whether they could "perform" – all of which further negatively impacted arousal and sexual experience.

*"You do think about it [erection]... and that probably takes away from the moment." [age 59]*

*"...when it does come to having, coming close to – whether it be penetration or just physical*

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*foreplay, I get very tense or just lose interest completely.” [age 51]*

Changes in orgasm including diminished intensity or even complete absence of orgasm, lack of or reduced ejaculate, negative changes in emotional experience of orgasm, and changes in libido and desire were also reported.

*“I don’t have sexual difficulties because I don’t have any sexual urges. When I say that, my wife and I aren’t intimate, we cuddle but that’s about it, cuddle and kiss.” [age 61]*

*“You feel a bit detached... It’s a bit like doing it with someone else’s dick... the feeling dies off quickly and there’s no “afterglow” like there was before.” [age 59]*

Many men reported that the side effects of ED therapies, their cost and the effort required to use them were prohibitive. Additionally, ED therapies did not work for some men or were not an acceptable option (e.g. penile injections).

*“With Viagra I can actually partly engorge my penis in a crouching position ... I bought a vacuum kit with the rubber bands so I can achieve enough of an erection to have penetrative sex ...it’s a bit of a production.” [age 62]*

Urinary incontinence and ongoing urine leakage was a significant issue for a number of men. One participant refused to use pads and wore dark clothes to disguise wet patches, yet described leakage-related embarrassment. A participant explained how it affected his quality of life:

*“[Urinary incontinence] stopped me...before I used to do a lot of walking. But one of the things it really inhibited was going for a swim. Because you can’t swim with a pad on and you*

*can’t go to the beach with your pants starting to get wet all the time.” [age 62]*

Urine leakage during arousal and/or at orgasm was found to be a difficult and embarrassing issue, sometimes leading to avoidance of physical intimacy for these men and in some instances, for their wife/partner.

*“...a couple of times it [urine leak] happened and [my wife] got so angry, she jumped up and went and had a shower and I felt terrible...she refused to even talk about sex anymore...can’t blame my wife and I couldn’t blame myself because you just can’t control it.” [age 58]*

### **Tainted self-perception and identity**

Several men reported PC and its related physical changes had significantly affected their self-perception and self-esteem. Sexual difficulties resulted in feeling less confident, particularly for single men some of whom chose not to engage in new social interactions with potential for intimacy. Men described feelings of inadequacy and embarrassment due to urinary leakage, ED and smaller genitalia.

*“I think my impression of myself now as a man is a bit lower than before I had that operation.” [age 60]*

*“It’s very hard to put it into words... it [being able to have erections] is part of your self-image, your self-confidence...when it [ED] happens it really does change you.” [age 54]*

*You’re suddenly different, non-performing... you’re almost like ...the eunuchs ...you feel like you’ve been neutered almost. A normal healthy, heterosexual male as far as I know, feels that [erection] is a powerful thing for him and to have it taken away, takes a bit of you away.” [age 54]*

Impotence was found to have a deep impact on self-perception, above and beyond sexual

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interactions. Lowered self-esteem due to impotence was reported by one man as affecting his confidence to four-wheel drive in the same pre-treatment “aggressive” manner.

*“The self-esteem gnaws away at you in really unusual situations...sexuality is important but self-esteem and self-confidence tends to hang off that issue.” [age 62]*

Men who reported a good response to medical therapy to achieve erections reported the additional benefit of restored confidence in themselves as males.

*“Since having the needles it’s given me a lot more confidence...It’s a lovely feeling, you feel very proud of yourself. You put the needle in and everything’s working again. Being a selfish male and my ego....” [age 58]*

### **Altered intimate relationships**

In general, men described their partners as being supportive in terms of diagnosis and treatment, even if issues related to treatment side-effects were problematic. Most married men reported that their diagnosis and treatment had an impact on their relationship with their wife. In some cases, men reported a positive impact of PC diagnosis on their relationships:

*“I do feel that I’m in a very loving relationship and I am very well loved. I think that has always been the case but it is probably more so after the operation.” [age 62]*

*“It is not just the sexual stuff, it’s about your feelings for each other. As a man, it’s not just about satisfying yourself but it’s about making sure that you’re satisfying each other.... that’s with the sexual aspect, the emotional aspect, the communication. I find myself cuddling my wife a lot more often. I find myself being very considerate and watching her and anticipating...I’m more in tune with maybe how*

*she’s feeling or how she’s responding now.” [age 53]*

Some men worried about their partners and how they were affected by the changes in their sexual functioning.

*“... I thought that the fact that I couldn’t make love properly anymore had affected my wife. She says it didn’t but I know. She even asked her sister how many times they make love... and I’m thinking, this was an issue for her.” [age 58]*

For men who defined sexual intimacy as penetrative intercourse, lack of erections meant no sexual intimacy.

*“It doesn’t worry me not having sex - we’ve discussed it that there’s nothing we can do, so there’s no sex life in our place...there’s no sexual intimacy.” [age 61]*

Some partners who were otherwise supportive were not always willing to try non-penetrative sexual activity, particularly if such activities had not previously been part of their sexual repertoire.

*“I’m not comfortable with things like that [outer-course, manual stimulation or oral sex]...they are not an option for her and I.” [age 61]*

A gay participant’s embarrassment due to ED and urine leakage led to reduced socializing and significant reduction in sexual encounters.

*“You take headache tablets before the Caverject and have a wee...and have a towel in bed. It’s always been spontaneous...pick someone up and go home with them...I can’t go to their place, I’ve got to think of what I’ve got to do so they can’t see what I’m doing.” [age 67]*

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Understandably, couples who had pre-existing relationship and sexual issues appeared to face greater challenges adjusting to treatment side-effects.

**Theme 2: communication and support**

Men who reported they had good communication with their partner, doctor and other health professionals reported better adjustment to PC, especially regarding sexual outcomes.

***Doctor-patient***

Men reported great trust in doctors who provided them with adequate information and ample opportunity to ask questions.

*“I wrote all the questions and asked him [doctor] when I went in there and he said ‘don’t worry about the other people in the waiting area you’re in here now and I will take the time to answer all your questions’ and he did.” [age 69]*

Some men noted that they felt uncomfortable talking about sexual issues and if their doctor did not raise the subject, neither did they.

*“He didn’t tell me the [sexual] after effects and to be quite honest I didn’t ask.” [age 61]*

A number of participants noted that their doctor raised the topic of sexual function often which was appreciated, particularly if the man was uncomfortable having that particular conversation.

*“Honestly, my urologist said ‘why I keep bringing it up is because some people won’t talk about it [sexual side-effects]’ and I suppose that’s right.” [age 63]*

A few men reported their urologist had failed to pick up on the emotional cues indicating

emotional distress, and hence they sought help themselves elsewhere.

*“With the resultant depression I became extremely distressed and morose and ... I asked my GP to refer me to a psychologist which he did.” [age 69]*

***Partner-patient***

Communication difficulties which existed for some couples prior to diagnosis were compounded by problems associated with PC. Couples who had previously communicated well on difficult issues reported communicating similarly well about difficulties associated with treatment.

*“Well, what you get afterwards is only a product of what’s been going on beforehand isn’t it?” [age 54]*

Some men discussed hiding their need to use some ED treatments from their partners.

*“I think my wife would be absolutely shocked if she knew. I think that deep down when she found out I was taking these tablets [Viagra], she wasn’t happy with that, and I think if she found out I was having injections – geez. I haven’t told her about the injections, I’ve sort of kept that one to myself.” [age 60]*

Some participants explained that while medical procedures were discussed with their partners, the possible impact on their sexual life had not been discussed.

*“Even though I talked about the treatment, what I was going through, and wanting to find the doctor that could ensure erections after the operation, we didn’t actually talk about what will happen after the operation. She [wife] knew what I was going through, she knew why I was going to see all these different doctors and all this, but we didn’t actually sit down and say ‘ok, when the operation takes place and*

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*whatever happens afterwards, what's it going to be like?' We didn't talk about that." [age 59]*

***Other health professionals-patient***

Out of 21 participants, nine had been referred to another health professional (such as specialised prostate cancer nurse, psychologist) for support at the time of diagnosis and all the men reported this as being very helpful.

*"Talking to the nurse at the hospital and the staff from the Cancer Council Telephone Support Group, talking to the psychologist ...I got the message that 'there is light at the end of the tunnel, there is hope'." [age 53]*

***Other men with prostate cancer and support groups***

Men who had attended a support group described it as a reliable source of information and a confidential and safe opportunity to discuss their concerns.

*"Those meetings are pretty good. I understood more about things...I learned a lot really. And it's good to hear other people's problems and what they had". [age 60]*

***Information and support needs***

Those who had access to adequate information, felt they were better prepared for treatment side-effects and found it easier to adapt to ongoing changes. Some participants felt they should have received more information about side-effects, the likelihood of their occurrence and available management strategies. A frequent comment was that in the early phase of their diagnosis men did not know enough about prostate cancer and its effects to know what questions to ask.

*"I sat in the hospital and didn't know what was going to happen to me. It's alright to say 'oh,*

*you're going to have an operation' but what does it mean." [age 61]*

For some men potential sexual rehabilitation options were not discussed in any detail by their doctor and they felt uncomfortable initiating the discussion.

*"It was just in passing one day [the doctor] said to me, 'Oh, why don't you try this drug. It's better than Viagra' and of course it had no effect. And then about a year later he said 'oh, why don't you try the Caverject'." [age 58]*

Most men believed early referral for ongoing support from other health professionals other than their doctor (e.g. nurse, psychologist), would have reduced their anxiety and improved their understanding of treatment procedures, side-effects and management options.

*"I think there probably does need to be an opportunity, away from the surgeon, for discussion about those physical details in more detail than I received." [age 62]*

Some men commented that health professionals should provide men and their partners with information regarding feelings they may experience, and encourage and support couples to explore sexual activities other than penetrative intercourse.

**Theme 3: integration process**

***Lifestyle adjustments***

To accommodate the functional changes resulting from treatment, many men reported making positive lifestyle changes such as improved diet and exercise which had lead to better overall general health.

*"One of the big benefits that's come out of it is that I now really do look after myself." [age 63]*

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Men with post-treatment urinary incontinence discussed lifestyle changes such as reducing general fluid and alcohol intake, and planning activities and travel around availability and access to toilets.

### *Emotional struggles*

Living with the consequences of PC and its treatment was difficult for many of the participants who described experiencing emotions such as shock, anger, depression, disappointment and a sense of loss associated with ongoing changes in sexual function, penile shortening and loss of libido.

*“And it’s hard sometimes, some days it’s very hard. And you get disappointed but you know, you’ve got no choice.” [age 58]*

*“I don’t have crying fits, I used to, but I don’t now.” [age 61]*

In some instances struggling with PC had acted as a catalyst for psychological distress around issues unrelated to cancer diagnosis e.g. retirement. Men with progressive disease reported greater emotional impact and more difficulties adjusting to ED and incontinence.

### *Striving for acceptance and integration*

Not all the men felt they had successfully accepted the changes following treatment and reported believing that it is an ongoing process.

Men described using various coping strategies from the time of diagnosis to living with post-treatment side effects. Denial behaviour was discussed by some men such as not reading information provided, or leaving the room while doctors were providing information. Some men reported minimising the occurrence/impact of possible sexual side-effects, as they believed they would not suffer any side-effects, or they would not be significant and they would be able to adjust.

*“I really didn’t think about it [ED] then. I thought I was very strong and fit, would get through it and it wouldn’t really affect me. I was very positive that ‘well, I’ll get over it and there won’t be any problems with me and if they’re minor, I’ll adjust to them’.” [age 58]*

A few men engaged in unhelpful behaviours such as excessive alcohol intake despite the potential for embarrassing urinary leakage.

In contrast, a number of men discussed that their general positive attitude had helped them through the difficulties they had experienced.

*“I guess it’s a mindset that says ‘today is going to be a new day’. I’m better than what I was before.... I have a positive aspiration.” [age 53]*

Some reported that talking to other men who have been through treatment and to experienced PC health professionals, helped in accepting the post-treatment changes and ‘getting on’ with their life after cancer.

Some men reported they had re-evaluated aspects of their life and this had helped them adjust to their new circumstances.

*“When things finally settle down and you think ‘this is what it’s going to be like forever’ then you accept it. I came across that [concept] on one of those health shows on TV, talking about people having to accept ‘the new normal’ and I thought that’s a lovely phrase. I could relate it to me.” [age 58]*

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**In next month’s newsletter we will continue looking at the effect of prostate cancer treatment on sex and relationships.**

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*Prostate Heidelberg provides information, education and support for those affected by prostate cancer. At the meetings, we*

- 1. Show respect to members and speakers;*
- 2. Allow people to speak and we listen;*
- 3. Respect confidentiality;*
- 4. Allow new ideas to be shared.*

We meet on the 2nd Wednesday of each month (February to December) from 10:00am - 12:30pm.

We meet at the Uniting Church Meeting Room, Seddon St, Ivanhoe (behind the Commonwealth Bank in Upper Heidelberg Rd).

Free parking is available in a large public parking area at rear of the church. Ivanhoe railway station is nearby.

Meetings are open to anyone interested in getting support or information on a prostate cancer journey. Partners or carers are welcome to all meetings

**There is no charge for attending.**

After the meeting you are welcome to join us for lunch in a local Thai restaurant.

If you can't attend daytime meetings, the Diamond Valley Prostate Cancer Support Group has evening meetings: <http://www.dvpcsg.org.au/>

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**COMMITTEE:**

Max Shub, Facilitator 0413 777 342  
Paul Hobson Secretary 0405 086 869  
Chris Ellis  
Spiros Haldas  
Patrick Woodlock

**Annual subscription - \$5** from 1<sup>st</sup> January  
per individual, couple, or family.

**CORRESPONDENCE**

Prostate Heidelberg, PO Box 241 Ivanhoe Vic  
3079  
[ProstateHeidelberg@gmail.com](mailto:ProstateHeidelberg@gmail.com)

**CALENDAR** Meetings: **10:00am -12:30pm**

Wed 10 June '15  
Wed 8 July '15  
Wed 12 August '15  
Wed 9 September '15  
Wed 14 October '15  
Wed 11 November '15  
Wed 9 December '15 (Christmas lunch)

**WEBSITE**

[www.ProstateHeidelberg.info](http://www.ProstateHeidelberg.info)

Please contact Paul Hobson to redirect or cancel receipt of this Newsletter.

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