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Four years later, when her husband, Brian, had surgery for prostate cancer, the couple discovered they were on their own. Questions about lasting side effects from the surgery were fobbed off and Jill found herself googling late into the night, reading up on risks of incontinence and erection problems resulting from damage to the penile nerves.



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reading up on risks of incontinence and erection problems resulting from damage to the penile nerves.

"Even when I made an appointment to see the urologist myself, he simply warned there could be difficulties but gave no advice on what to do or where to go," she says.

The couple muddled through themselves, asking around until they found one of the few local doctors offering specialist help with the erection recovery process and a physiotherapist for the incontinence.

With her daughter Leah, Jill now runs the organisation ManUp!, which raises money to train more prostate cancer nurses. There are only 12 specialist prostate cancer nurses in Australia (with new federal funding for an additional 13 next year) compared to 85 for breast cancer. Yet, more men are diagnosed each year with prostate cancer than women with breast cancer (18,560 compared with 14,560 in 2012, according to the Australian Institute of Health and Welfare).

ManUp! hears regularly from men whose urologists have shown no interest in what happens to their patients after prostate cancer treatment. One man left impotent and incontinent after his robotic surgery was told the doctor's job was simply to deal with the cancer.

"That's crazy. It's like a knee surgeon not caring whether the man can walk again. It's appalling how few urologists are making sure men have the help they need to regain erections and continence, yet the impact of these problems can be just as devastating to a man as a mastectomy can be to a woman," Jill says.

This week a world congress on prostate cancer is being held in Melbourne, with up to 300 urologists among 1000 delegates attending from Australia and overseas. Although there are sessions on sexual functioning and continence, many urologists choose instead to attend talks on the latest cutting-edge treatments or diagnostic techniques.

"We have got better with the technical aspects of the surgery to remove the prostate and preserve function, but I think we have a long way to go with all aspects of rehabilitation, including the psychology of facing a serious illness, urinary incontinence and erectile failure," says Prem Rashid, a urologist and associate professor at the University of NSW, who has spent more than 15 years involved with urology training.

Rashid points out that it's hard for busy practitioners to keep up to date with the recently developed erection treatments. "It's also a two-way street, with some men finding it difficult to talk about these issues," he says.

"We really need to be proactive in helping our patients," says Dr Darren Katz, a urology fellow at Fremantle Hospital and a speaker at the conference. Katz is just back from working with world experts in erectile dysfunction and incontinence at New York's Memorial Sloan-Kettering Cancer Centre.

Next year he will open a specialist men's health clinic in Melbourne working with Dr Christopher Love, one of Australia's most experienced penile implant surgeons and experts in the erection recovery process.

As he'll explain at the conference, there's a growing international consensus that men should be treated with pro-erection medications rather than just hoping erections will return years after prostate cancer surgery. Ideally, men should start treatment as soon as possible to maximise their chances of regaining natural erections.

"Regular erections supply oxygen to the penis through increased blood flow. This helps to prevent scarring and keeps erectile tissues healthy until the erection nerves have a chance to recover," he says, explaining this is necessary even if surgery has spared these nerves. Treatments such as radiation can cause similar damage.

Lost erections aren't the only problem. "Some men leak urine when they orgasm and up to 70 per cent report some shortening of the penis after prostate surgery, a major concern for many men," says Katz, explaining this shrinkage can be due to scarring of erectile tissue and the casing of the erection chambers, which can also cause abnormal bending of the penis.

Katz will speak at the conference about "penile rehabilitation" aimed at preventing this shrinkage and helping restore erections. "This usually involves a combination of regular doses of one of the erection pills like Viagra, Cialis or Levitra and, if needed, injection therapy a few times a week and possible use of a vacuum erection device."

Ideally the man's erectile functioning is assessed before and after prostate cancer treatment, leading to an individually tailored treatment plan.

"Many men are really nervous about the idea of injecting the penis, but if they are carefully taught how to use the injection medication that's right for them they discover these treatments are really effective and quite painless," Katz says.

But that's just the problem. Most men receiving treatment for prostate cancer receive little help for their erection problems, let alone careful assessment to determine the exact prescription they need.

Most experts in the field find many men respond better to injection therapy involving a combination of drugs that are available only from compounding chemists. There are pre-mixed injections available, but for many men premixed drugs are less effective and more likely to cause pain.

With only about 15 compounding pharmacies in Australia with the sterile rooms required to produce these drugs, many of these pharmacists report these drugs are being prescribed by only a handful or so of urologists in each capital. That shows how few of our country's 400 urologists are offering comprehensive treatments for sexual rehabilitation.

Some urologists do refer patients on to ED specialists, like Love, or Sydney sexual health physician Michael Lowy but experts in this area all acknowledge most of their referrals are coming from a small group of doctors.

"Most patients who find their way to me have searched for proper help themselves after prostate cancer treatment," Lowy says. "Men often tell me their urologist gave them little or no advice whatsoever about what to do about their loss of erections."

Professor Mark Frydenberg, vice-president of the Urological Society of Australia and New Zealand, says that while isolated anecdotal cases of dissatisfaction with urologist management may occur, "in the majority of cases men receive appropriate and empathic care to recover their sexual functioning following prostate cancer treatments and there is no hard evidence to the contrary".

He does suggest that if a patient is not getting the help they need, they should seek another opinion. "Issues surrounding erectile dysfunction following prostate cancer treatments are complex and multi-factorial and often require the help of a multidisciplinary team including urology nurses and psychologists with special expertise in both cancer and sexual health."

Many of these men end up in the hands of shonky organisations that charge thousands of dollars for often ineffective treatments, such as that provided by Jack

Vaisman's Advanced Medical Institute, which makes more than \$70 million a year "treating" Australian men. Vaisman is facing a ban from corporate life for "unconscionable conduct" after an action by the Australian Competition and Consumer Commission.

There have been many reports about this company's practices: lies about the effectiveness of its treatments; salespeople illegally withdrawing money from a patient's credit cards; dubious tactics to avoid money-back guarantees; failure to properly check medical histories or warn of dangerous side effects. The clinics offer compound injection treatments but charge up to 10 times the cost of legitimate compounding pharmacies with no proper medical examinations or education.

"Vulnerable men end up paying big money for ineffective treatments because they aren't getting the help they need from their own doctors," says David Sandoe, national chairman of the Prostate Cancer Foundation of Australia. His organisation is planning national education campaigns aimed at giving men the information they need and encouraging them to choose doctors who care about their sex lives.

It's an issue close to Sandoe's heart. With his wife Pam, he's spent years talking publicly about his own experiences with various erection treatments after his prostate cancer surgery. This remarkable couple regularly entertains conference rooms full of doctors and consumers with stories of the first time they used the injection therapy. David rushed home from the doctor's surgery with a full erection only to discover their house was full of painters - they were in the middle of a renovation. That didn't stop them. "With a couple of lame excuses we made it to the bedroom and put 'it' to good use," Pam says.

The couple are regular travellers and found the vacuum pump led to funny moments at airports as they explained to embarrassed customs officers exactly what it was. David is now the proud owner of an inflatable penile prosthesis, which works exceptionally well, even though the noise of the pump as it pushes liquid into the penis still gives Pam the giggles.

The Sandoes were lucky in their choice of urologist, as Sydney-based Phillip Katelaris provides a comprehensive service that includes a psychologist and nurse educator to explain erection treatments and teach pelvic floor exercises essential for incontinence.

Many men are forced to suffer the humiliation of spending years wearing nappies or pads due to incontinence after prostate cancer treatments. Research from the

Cancer Council NSW found five years after a radical prostatectomy, three-quarters of the men have erectile dysfunction and 12 per cent are still incontinent.

Associate professor David Smith, one of the authors of the study, suggests the erectile dysfunction numbers are twice what you'd expect through the ageing process and the incontinence figures are also too high.

Shan Morrison, director of Women's and Men's Health Physiotherapy in Malvern says: "Most men aren't aware that they needn't live with long-lasting embarrassing continence problems. A physiotherapy pelvic floor rehabilitation program usually results in continence within six-to-12 weeks of prostate cancer surgery."

Sydney psychologist Patrick Lumbroso, who is undertaking doctoral research into erection problems after prostate cancer surgery, is frustrated at how poorly these issues are handled: "Problems such as incontinence and erectile dysfunction can have a devastating impact on a man's confidence and masculine self-image, leading to depression, relationship problems and sexual difficulties for the partner."

His research reveals why so many men in this circumstance fail to receive proper advice on erection treatments, finding most men are given little or no information by their urologists, and if they are given advice it is often inaccurate and poorly handled.

"One doctor asked his patient, 'Have you ever considered jabbing a needle into your penis to get an erection?' That was hardly a sensitive approach given the squeamishness of most men to using injections," Lumbroso says.

Lumbroso also provides counselling to couples, helping them adjust to the impact of prostate cancer treatments on their sex lives. Like most experts in the field, he would like to see much more being done to reach people in this situation. "It's tragic how many couples are left floundering on their own when so much could be done to help them resume sexual intimacy."