

Doctors are failing prostate cancer sufferers

When Brisbane woman Jill Costello received treatment for breast cancer seven years ago, she found herself surrounded by expert care and support. Her “fairy-godmother,” a breast care nurse, just made things happen. Her questions were fully answered, her doctors went out of their way to make sure she had proper advice and every possible aid to her recovery.

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. “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,” Jill 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 organization ManUp which raises money for 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. More men are diagnosed each year with prostate cancer than women with breast cancer (18,560 compared to 14,560, according to 2012 Australian Institute of Health and Welfare figures)

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,” says Jill.

A world congress on prostate cancer is soon being held in Melbourne, with up to 300 urologists amongst 1000 delegates from Australia and overseas. Although there are sessions on sexual functioning and continence what inevitably happens at such events is 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 University of NSW urology associate professor Prem Rashid who's spent over 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 adds.

"We really need to be proactive in helping our patients" says Dr Darren Katz, a speaker at the conference who was just back from working with world experts in erectile dysfunction and incontinence at New York's Memorial Sloan-Kettering Cancer Center. Katz, a urologist and prosthetic surgeon, has established a specialist men's health clinic in Melbourne (www.menshealthmelbourne.com.au) 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 (even before the surgery) 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'¹ 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," adds Katz.

But that's just the problem. Most of men receiving treatment for prostate cancer receive little or no help for their erection problems let alone receiving the careful assessment to determine the exact prescription they need. As Katz explains, the Sloan Kettering clinic finds many men respond better to injection therapy involving a combination of drugs, like Trimix or Bimix, available only from compounding chemists. There are pre-mixed injections available, like Caverject, 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 that these drugs are being prescribed by only a handful or so of urologists in each city. That strongly suggests most of our country's 400 urologists are not doing their job.

Some urologists do refer patients on to ED specialists, like Melbourne urologist Chris Love, or Sydney sexual health physician Michael Lowy but experts working in this area all acknowledge most of their referrals are coming from a small group of doctors. Michael Lowy: "Most patients who find their way to me have searched for proper help themselves after prostate cancer treatment. 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 Urology Society of Australia and New Zealand, believes men deserve proper care to recover their sexual functioning. "If a patient is not getting the help they need they should seek another opinion, preferably from urologists providing the multi-disciplinary team needed for rehabilitation," he says, adding many doctors struggle to provide these services with so little funding for training of prostate cancer nurses.

Many of these men end up in the hands of shonky organizations which charge thousands of dollars often for ineffective treatments. One of the key offenders, Advanced Medical Institute, makes over \$70 million a year ripping off Australian men. Our media, particularly the Fairfax newspapers, have published many reports about this company's practices: lies about the effectiveness of their treatments; sales people 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, then the National Chairman of Prostate Cancer Foundation of Australia.

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 following 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," says Pam.

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 wonderfully 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 Philip Kataralis provides a comprehensive service which includes a psychologist and nurse educator to explain the erection treatments and teach the 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 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.

“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 6-12 weeks of prostate cancer surgery,” says Shan Morrison, Director of Women's and Men's Health Physiotherapy in Malvern, which specialises in treating men with this problem.

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 what they received was 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,” says Lumbroso.

Patrick Lumbroso also provides counselling to couples, helping them adjust to the impact of prostate cancer treatments on their sex lives. (www.sexafterprostatecancer.com.au). Like most experts in the field, he'd 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.”