What improves men's experience of surviving prostate cancer?



When it comes to improving survival from prostate cancer, exercise is a standout.



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in AFR on 3 Oct 2018

It may come as a surprise, but the high rate of survival from prostate cancer in Australia is a mixed blessing.

While 95 per cent of diagnosed men will still be alive five years later, a great number will not be surviving well.

"The problem is that advances in early detection and treatment have been so rapid, they have outrun our ability to deal with the side effects," says Professor Jeff Dunn, an expert in how men adapt to prostate cancer.

Even if survivors are okay medically, many are struggling with the impact of the cancer on their emotional state, their personal relationship and their social interactions.



"You can't just take the breast cancer booklets and turn the pink to blue. It doesn't work for fellows," says Professor Jeff Dunn.

Often, they have high levels of distress, can't manage the consequences of their condition and don't know how or where to get support.

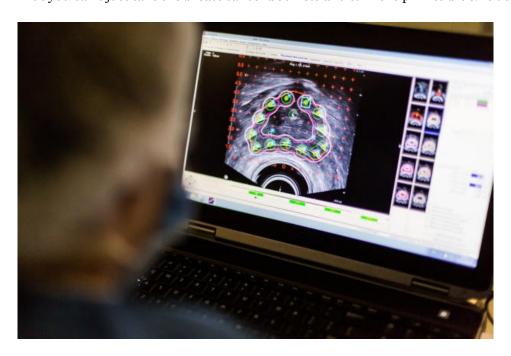
"With more men being diagnosed and more surviving the disease for longer, there is an ever-increasing number of blokes out there with challenging side effects. And there is not enough going on about how to look after them," he says.

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"A lot has happened in prostate cancer, relatively quickly, and while the fast pace is a challenge for health professionals it is much harder for men themselves."

As the awareness of breast cancer is far ahead, some have tried to modify that body of knowledge and apply it to men.

"But you can't just take the breast cancer booklets and turn the pink to blue. It doesn't work for fellows," he says.



Monitoring for recurrence or for new cancers is a crucial part of prostate cancer survivorship – but the best way to get men to do it, is yet to be determined.

Major study

Dunn, chair of social and behavioural science at the University of Southern Queensland, has just led a major study aimed at trying to improve the survivorship experience for men.

As a first step, he says it is important to look at the available evidence on what actually helps, so there is guidance on where to invest time and resources.

"Before we run off and do things that appear to benefit men, we need to see what the evidence shows."



In the bush men are particularly disadvantaged and are 32 per cent more likely to die from their cancer

It's a serious matter. The side effects of this disease and its treatment include fatigue, erectile dysfunction, incontinence, loss of muscle, depression, an increased risk of cardio-metabolic disease and secondary cancers.

In Australia, the population of men with prostate cancer is characterised by a high level of being overweight/obesity and sedentary lifestyles which usually worsen an already declining quality of life.

Survivors also have an increased risk of suicide, especially in the first 12 months after diagnosis and when the disease becomes advanced.

In the bush, men are particularly disadvantaged. They are 24 per cent more likely to be diagnosed when their disease has already spread and 32 per cent more likely to die from their cancer.



Exercise improves cardio-respiratory fitness, muscular strength, fatigue levels, incontinence, physical activity levels and quality of life in survivors

Dunn, who is on the board of the Geneva-based union for International Cancer Control, says although geographical disadvantage occurs in other countries too, it's time for Australia to share its knowledge and resources equally with its citizens in regional and rural areas.

As a starting point to tease out what genuinely helps, his research team looked at America's Prostate Cancer Survivorship Care Guidelines published four years ago.

Compiled by the two global giants in this field, the American Cancer Society and the American Society of Clinical Oncology, they aimed to promote optimal health and optimal quality of life, and ensure survivors have comprehensive follow-up care.

Gaps in evidence



Having a care plan is one of the most important aspects of survivorship, says Professor Dunn

The guidelines are based on a combination of expert opinion, professional consensus and evidence.

Dunn's team was not interested in the well-intended opinions and consensus, and focused only on evidence.

But when they went through the guidelines and available evidence with a fine-tooth comb, they found great gaps.

This week, their findings are being published in *Psycho-Oncology*, the official journal of the International Psycho-Oncology Society. In it, they lay out exactly where evidence is strong, patchy or absent.

The US guidelines are built around five key areas.

The first is health promotion. For this they recommend survivors maintain a healthy weight, exercise regularly, have a good diet, limit alcohol and avoid smoking.

The second is monitoring the cancer with regular blood tests and an annual digital rectal test. Men should be vigilant not only about the increased risk of recurrence but of occurrence of bladder and colorectal cancer. Symptoms should be evaluated to detect a second cancer early.

Next is tailoring the management of long-term side-effects such as anaemia, bowel dysfunction, sexual dysfunction and cardiometabolic risks, to the type of treatment the man received.



Beyond simply hoping things will be OK, there are active steps men can take to improve their survivorship experience

Fourth, at various stages along the way, a "distress thermometer" should be used to detect men's psychological and quality of life concerns.

Finally, to improve care coordination, all men should be provided with "a survivorship care plan".

Dunn's team scoured the literature for evidence to back these recommendations and found exercise was a standout.

It was effective at improving cardio-respiratory fitness, muscular strength, fatigue levels, incontinence, physical activity levels and quality of life in survivors. There was some evidence on the value of preserving and improving lean mass.

For men on active surveillance programs (regular monitoring) the evidence suggested exercise may delay their transition to active therapy, but further details are needed.

Dunn says this remains a neglected area of survivorship research.

While the evidence for nutritional interventions being able to slow the progression of disease was inconclusive, dietary changes can assist with weight loss, which is useful.

Psycho-social interventions including peer support, cognitive-behavioural therapy and psycho-education were effective in improving quality of life and mental health, and reducing depression and anxiety and decision-related distress.

Alarmingly, in relation to monitoring for cancer recurrence and for surveillance of other cancers, there was a lack of evidence for effective strategies to improve men's compliance.

Care plan

Research has shown up to 30 per cent of men in active surveillance no longer adhere to the protocols two years after diagnosis.

What Dunn was really concerned about was the evidence gap for best practice in care co-ordination.

This involves co-ordinating all the medical opinions, medications, tests and related appointments and is one of the most important aspects of managing survivorship.

He says many Australian men will not get a care plan and while urology nurses likely could help, they are relatively new and there are far too few of them.

While Dunn's team has undertaken the largest study to date to validate the effectiveness of distress screening for men with prostate cancer, it is not yet standard practice.

With much of the published research based on the experience of well-educated, heterosexual, white men, there was a clear lack of targeted interventions for men of minority ethnic backgrounds, for those living in rural areas and for gay and bisexual men.

"It's extraordinary that when it comes to the most commonly diagnosed cancer in men in Australia and the second most common globally, that we do not have a clear evidence base to support comprehensive survivorship care for men diagnosed and treated for prostate cancer and their partners," he says.

Jill Margo is an adjunct associate professor at the University of NSW