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Submission to Senate Community Affairs References Committee: Inquiry into Services and Treatment Options for Persons with Cancer

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Introduction

In November 2004, I had a radical prostatectomy for prostate cancer. It is not unusual these days to have treatment for prostate cancer but living in a small town in central Queensland added a number of challenges in obtaining a diagnosis, treatment and dealing with post treatment issues.

My Story

I am 51 years old, married with four children aged 21, 19, 16 and 14 years. I work for a coal mine in Central Queensland as the commercial manager.

I live 200kms west of Mackay. This is a 6 hour drive to Townsville, or 12 hour drive to Brisbane. We have limited flights direct from home to Brisbane, which require you to spend at least 2 nights in Brisbane to spend a business day in Brisbane. Alternatively, we can drive 2.5 hours to Mackay, to catch the more frequent 1.5 to 2 hour flights to Brisbane.

My 21 year old son lives in Perth, Western Australia; my 19 year old son lives in Brisbane, Queensland; and my 16 and 14 year old daughters were attending weekly boarding school for most of the time after my diagnosis and during my treatment for cancer. My wife was also employed full-time.

In **October 2003**, I underwent a comprehensive medical by a local General Practitioner as part of an employer provided "Health & Wellbeing Program" for employees. The medical included, amongst other things:

- A digital rectal examination (DRE) and
- A blood test for prostate specific antigen (PSA).

The DRE indicated no problems but the PSA reading was 3.97, which is within what is considered the normal upper limit of 4. However, my GP, after discussions with an urologist in Townsville, advised that I have a biopsy.

12 December 2003, I underwent a 6 point biopsy in Townsville. This required a day off work and driving 6 hours to the appointment and 6 hours drive back on the same day. The results were available a week later to the urologist but I had to make an appointment with the urologist to obtain the results. The first appointment available to obtain the results was late January 2004.

I was unable to make the January appointment due to work commitments and the fact that I would need to take a whole day off for the 6 hour drive there and 6 hour drive back for a 30 minute appointment. I requested that I be given the results over the phone or they be sent to the referring GP. I was told this could not be done and I would have to see the specialist. I made another appointment, but had to wait another 4 to 6 weeks. Again I was unable to make this appointment due to work commitments. I was required to cancel a number of appointments due to work commitments.

Thursday 1 April 2004, I actually attended the appointment with the Specialist in Townsville, at the insistence of my wife, who also took 2 days off work, and took our 2 children out of school for 2 days, so that we could drive down and take a long weekend in Townsville. I was advised that I had low grade prostate cancer (Gleeson score of 4), and was given 3 treatment options – surgery, radiotherapy or "watch and wait". I was also required to have an abdomen and pelvis CT and full body bone scan to see if the cancer had spread. As we had come down for the weekend, I was able to do these the next day. I saw the Specialist again on the Friday, who advised that the cancer had not spread and who advised that if I booked in for surgery then, he would be able to do it in June/July.

After discussions with my GP and wife and after doing some research into the various treatment options I decided that before making any decisions we should see a specialist for each of the different treatment options. The local GP advised us that I would have to get referrals for these other specialists from the urologist in Townsville. I attempted to do this over the telephone and left a number of messages with the receptionist but I never received any return calls or referrals. I decided I would have to make an appointment to see the specialist to get the referrals, and again had to wait 4 to 6 weeks.

July 2004, our family again took time off for another long weekend in Townsville to see the specialist to obtain referrals. We drove 8 hours there and 8 hours back, as we had to pick up our children from boarding school for a 15 minute appointment in Townsville.

Late September 2004, we went to Brisbane for a week to see further specialists: an urologist who specialized in low dosage brachytherapy and a radiotherapy oncologist. Neither of the specialists we were originally referred to were available during the school holiday period, so we were further referred on to another two specialists. Both of these specialists were heavily booked and the receptionists of each specialist had to be persuaded to fit us in so that each of the appointments was reasonably close together (5 days apart), so we did not have to make 2 trips to Brisbane. We also required the appointments to be in the school holidays so as to minimize the disruption to our daughter's schooling. Each of these specialists required their own tests to be done, including an MRI and a review of the original biopsy. We spent a week in Brisbane for 2 one hour appointments.

We returned home before the results of the biopsy review and MRI became available and we had to telephone the specialists to obtain the results. This in itself was a difficult procedure as the Doctors were not available and would ring back when I was not available or at work where it was difficult to maintain privacy. I was advised that the review of the biopsy had upgraded the cancer from low to high grade (Gleeson score 4 to 7). This meant that low density brachytherapy was no longer an option. We were referred to another Brisbane specialist in relation to high dose brachytherapy.

October 2004 we were fortunate to get an appointment with the above specialist in Brisbane however only with some persuasion as otherwise it would have been another six week wait. The specialist actually saw me in his lunch hour, after I persuaded him that my treatment had already been delayed somewhat due to the waiting time for appointments and that we had tried to see him earlier when he was unavailable and when we had been referred to his colleague who specialized in external beam radiotherapy.

Both high dosage brachytherapy and surgery had waiting lists of about two months, even for a private patient. With some persuasion I was able to get an earlier date for surgery through a cancellation.

15 November 2004 I had a radical prostatectomy in a Brisbane hospital. My wife, daughters and I drove down to Brisbane a few days earlier to see the surgeon before surgery. In all we spent four weeks in Brisbane, and another two weeks in Noosa on the Sunshine Coast so that we still were within easy access of Brisbane. My children missed several weeks of school and my 16 year old daughter flew back by herself to write her end of year 11 exams. My 21 year old son and girlfriend flew from Perth, Western Australia, for one week to provide support for my wife while I was in hospital.

At 4 weeks, when I saw the surgeon, I was no longer suffering from day-time urinary incontinence, but still needed to wear an incontinence pad at night time. I also had total sexual dysfunction and continue to do so.

The Delivery of Services and Option for Treatment of Persons Diagnosed with Cancer

(i) Multi-disciplinary approach to cancer treatment

There was a minimal multi-disciplinary approach to the treatment of my cancer, as each specialist we saw only focused on their particular specialty and was not concerned with other matters. No assistance was given to me or my family in relation to our general health and well-being, including mental health, while we went through this trauma. I believe a multi-disciplinary approach can lead to more positive outcomes and feelings about treatment, which would have the flow on effect of encouraging more men to seek treatment.

A multi-disciplinary approach that could have assisted:

a) **Psychology / Counseling** to assist with:
   - the shock of diagnosis to patient and family and to deal with the stress leading up to treatment, for example, training in relaxation techniques;
   - the decision-making process as to type of treatment, outcomes and side-effects, particularly in relation to quality of life issues versus treatment options.
   - emotional issues dealing with learning to live with side-effects, including relationship issues.

   The medical practitioners while very competent to deal with the technical treatments of the cancer and side-effects seemed totally oblivious to there being any emotional issues involved.

b) **Dietician –** could have assisted with improving my general health after diagnosis and leading up to treatment, so as to gain the best possible outcome from treatment with minimal side-effects. Advice from a dietician would have been particularly useful on discharge from hospital in relation to suitable diet while body is recovering from surgery and anesthetic to prevent constipation and improve liver function, particularly after diagnosis of "halothane hepatitis" and pancreatitis.

c) **Physiotherapy –** to provide an exercise program before and after treatment to:
   - increase fitness levels both before and after treatment;
   - reduce side effects such as deep vein thrombosis and incontinence; and

- assist with side effects after treatment such as backache, incontinence and to build up stomach muscle strength.

I did receive two visits from a physiotherapist while in hospital to get me mobile, to assist with breathing and who gave me information on pelvic floor muscle exercises for incontinence, but it would have been useful to have had some contact prior to surgery and after discharge from hospital.

d) **Naturopath/Alternative Therapy –** Prostate cancer, unlike most other cancers, does not often require urgent treatment, allowing patients' time to consider their options. In my case, it was over twelve months from the first indication that there was a problem until I received treatment. Also, one possible treatment of prostate cancer is "watch and wait" of which the biggest disadvantage is that once a diagnosis has been made patients find it difficult to do nothing knowing that they have cancer. Prostate cancer, in particular, provides patients the chance to change their life-style and undertake alternative therapy to at least slow down the cancer and improve their general health while deciding on treatment or during "watching and waiting".

We did not seek alternative therapies due to a lack of available reputable information. It would be helpful for our medical specialist or general practitioner to refer us to a natural therapist, so that we knew that they were reputable, and so the two could work in conjugation.

A natural therapist would have been useful to assist with improving my general health both before treatment and after treatment, especially in relation to improving my liver function, constipation and low iron levels. A naturopath could have an ongoing role in the recovery process of improving energy levels and libido.

e) **Incontinence nurse –** to assist with day to day issues relating with incontinence and to provide ongoing support.

Discussions with an incontinence nurse prior to treatment could assist in the decision-making process by making the patient more aware of what they could possibly be dealing with after treatment and how incontinence can be managed if it were a problem after treatment. Advice could also have been given on exercises and things that can be done before treatment to reduce the chances or seriousness of incontinence.

Although this was not a long term issue for me, it could have been, and it would have been useful for early contact to be made, so that on going assistance was available if needed. An incontinence nurse would have been useful in the early stages with practical tips and support especially when I initially ceased wearing incontinence pads.

f) **Sex therapist/erectile dysfunction specialist –** could have assisted in the decision-making process before treatment by advising on ways to deal with sexual dysfunction, which is considered to be a problem initially in 100% of patients that have a radical prostatectomy. Although I was referred to a General Practitioner that specialized in male sexual dysfunction after surgery, he again dealt only with the technical treatment of the symptoms and not with the emotional or relationship issues; in fact he even requested that my wife not attend. Again, treatment for impotence could be on a much broader level than just dealing with the technicalities.

(ii) Role and Desirability of Case Manager/Co-ordinator to Assist Patients and/or their Primary Care Givers.

Even though there was not a multi-disciplinary approach to my treatment, we did see a number of specialists after diagnosis to discuss the various treatment options and to assist us with the decision-making process. I was also referred to a specialist after surgery in relation to my adverse liver function, a side-effect of the anesthetic and a specialist for sexual dysfunction. It was confusing to know who should be dealing with what issues or matters and a case manager could assist us with this. Much of the treatment for both the cancer and the side-effects of treatment seemed to be compartmentalized and treated as separate issues, whereas a case manager should have a bigger picture and overview of the patient's overall health and well-being.

There is a strong case to provide an ongoing Case Manager once diagnosis has been made and for a period of time after treatment to assist with:

a) **Decision-making process** - by providing impartial information on treatment options and information about different specialists and their particular specialization. We noted that each of the specialists had a bias towards their particular treatment or procedure. We were unable to locate any medial practitioner that supported "watch and wait" even though this is a recognized alternative to treatment.

   We had difficulty in ensuring we saw the right specialist for each treatment option. For example, all urologists will treat with surgery but only some offer brachytherapy. Even with surgery there are different techniques, including nerve sparing and nerve grafting, which are not offered by all urologists. Radiology oncologists also differ in techniques, from external beam, high dose brachytherapy and low dose brachytherapy. Each time we saw one specialist it became apparent that we should be seeing another in relation to another technique or treatment. We also had a number of difficulties getting appointments with the specialists we needed to see, resulting in us being forwarded on to other specialists, who may not have practiced the particular technique or treatment we were interested in. This was particularly a problem due to the distances we traveled to see specialists and the amount of time we had to take off to visit doctors.

A case manager could also assist with countering the overwhelming information (sometimes contradictory) available on the internet or through other research, providing a more rational objective view or assisting with how to best use the available information.

b) **Support for Patient and Family -** as a mentor and contact point for the patient or any member of family that may have any concerns during any stage of the process.

This would be particularly useful where discharge from hospital is now so early after treatment, it would be helpful to have someone to contact in relation to any concerns as to what to expect in the recovery process and to discuss whether our concerns are minor or major and whether we should be contacting the doctor or not and which doctor to contact.

Many of our problems with dealing with doctors and the medical profession was a lack of familiarity as to how the whole system worked and a case manager could have assisted us in dealing with:

- Making appointments and ensuring we were seeing the appropriate specialist;
- Putting us in touch with appropriate support groups like Cancer Helpline or Prostate Cancer Support Groups;
- Medicare and Private Medical Insurance Claims;
- Claiming travel and accommodation expenses;
- Providing advise on travel and accommodation availability to meet family and patient needs;

- Advice on hiring and assisting with hire or purchase of any medical equipment needed;
- Assisting in obtaining additional medical or other assistance before and after treatment; for example, access to dieticians and physiotherapy.

c) Managing recovery process

- Side affects e.g. incontinence, impotence;
- Mental and emotional issues;
- Abnormal reactions e.g. problem with liver.

In particular, ensure patient and family get referred to proper specialists for any ongoing problems, and that all test results are reviewed and patient is getting adequate care for all problems. We had a particular problem after surgery when my health deteriorated and I was referred to the Physician and Intensivist that there were a number of blood tests, and scans being ordered by and results being sent to a number of different doctors and with no clear indication as to who was meant to be dealing with what.

After treatment has ceased and the patient returns to work and “normal life” it is very easy to ignore any ongoing problems, or miss check-ups etc. A case manager could ensure that this was not happening and maintain regular contact with the patient to ensure everything is on track.

The case manager should be accessible to regional patients via emails, telephone or video-link up. For rural patients, it may be appropriate for the local GP to be the case manager, but this would require appropriate training. However, it would also be useful for families to have a single contact person, who is familiar with local facilities, for support in the place where treatment is obtained.

(iii) Addressing Psycho/Social Factors in Patient Care

Beyond advising us that there were organizations such as the Cancer Helpline and Prostate Cancer Support Groups, there was little acknowledgement by medical professionals that there were psycho/social factors to deal with. In particular, there was failure to address these issues during the decision-making process of what treatment to have. Side-effects such as incontinence and impotence were important factors for us to consider due to my age and career.

Although we were given information about support groups, little consideration was given to accessibility to these due to:

- our regional location and the amount of time and energy required to get to and from specialist appointments leaving less time and energy to seek assistance from the above organizations;
- men's general reluctance to talk about these matters and therefore their reluctance to contact such organizations; and
- confidentiality in small regional centres where there is no anonymity.

As a result to the above barriers, we did not seek assistance from any of the above groups and did not receive assistance in relation to psycho/social issues. We would have preferred these matters to be dealt with by the specialist or general practitioner at time of consultations but also acknowledge that medical practitioners have little time to deal with anything more than the technicalities of the treatment.

All specialists we saw seemed to have little understanding of the difficulties we were facing in trying to access medical services from our regional centre and in particular what limited facilities were available to us. There could have been greater discussion between our GP and specialist so that we could be better advised on the time we should spend in Brisbane after treatment and in relation to on going management of side-effects and review.

We faced the added trauma of being in unfamiliar surroundings and not being supported by family or friends while undergoing treatment which added to an already stressful time.

Failure by the Government to place medical treatments for sexual dysfunction on the Pharmaceutical Benefits Scheme (PBS) and for some private medical insurance funds to not cover such medicines under their pharmaceutical schemes indicates a lack of understanding of the psycho/social factors relating specifically to the treatment of prostate cancer. There is an argument that such medications be made available on the PBS for those patients that have undergone treatment of prostate cancer. This may encourage more men to seek treatment for prostate cancer and to seek treatment for side effects.

(iv) Delivery of services and treatment options to regional Australia and Associated Barriers.

This was of particular concern to us at all stages through the process and created some challenges of its own. We were often expected to accept a lesser standard of service due to our regional position and ability to access medical facilities.

a) **Diagnosis**

My diagnosis was made specifically due to my employer providing and encouraging all employees to have regular full medicals. Other occupants of our regional centre do not have the advantage of a “health and well being program”. The government should actively encourage such programs through education and providing Medicare rebates for such medicals. There is a particular need to focus on those that live and work on remote rural properties.

Being in a regional centre may hinder diagnosis due to:

- **Less choice of doctor and opportunity to get a second opinion.** For example, I was particularly lucky because my doctor considered a PSA important and referred me for a biopsy even though the PSA levels were within normal range. Other doctors would not have considered doing a PSA at my age nor would they have considered it necessary to do a biopsy. In larger centres there is more choice as to which doctors you use, while in a regional centre there is a chance that the only doctor in town does not do PSA readings.

- **Time required for diagnosis.** I needed to take a day off work to travel 6 hours to get a biopsy and then travel 6 hours return, for this reason I not only delayed in getting the biopsy but also in getting the results. There is little understanding of these difficulties by medical professionals and therefore inadequate advice about how to go about getting tests and results.

  For example, I should have been advised to stay overnight or to bring a support person to assist with driving after the biopsy. I should have been advised not to drive there and straight back after the biopsy on my own.

  People that own rural properties, who do not have sick leave, cannot afford to take the time from their properties, particularly in times of drought. This prevents people on rural properties from seeking medical help and getting a proper diagnosis and treatment even when they have symptoms.

  The urologist showed little understanding of the difficulties in traveling such long distances for results or referrals. It was only by chance that when I eventually got my results that my wife was with me, otherwise I would have been given the news while I was on my own, and then had to drive all the way back by myself, while in complete shock.

It was also only by chance that I was in Townsville the next day and could undergo the CT and bone scans otherwise I would have had to make a return trip for these to be done, which would have meant further delays. We recommend that results can be provided by:

- Telephone, with information on what we needed to do next, such as make appointments for CT and bone scans and then visiting the urologist with these results to discuss the options. The information booklet that we were provided with at the appointment could have been posted to us and we could of had time to overcome the shock and think about our options and questions before seeing the specialist so that we could have gained more from our visit to the urologist;
- Providing results to the local GP who had referred me to the urologist with an explanation that we would need to have CT and bone scans done and then see the urologist. Again the GP could have provided us with the information booklet and allowed us time to absorb the diagnosis before seeing the specialist.
- Video conference or telephone conference appointment with us and the local GP in attendance would have been our preferred option. The local hospital has video conference facilities which should be made more use of.

We should definitely have not been required to drive to Townsville and back to get referrals to other specialists, these should have been available by phone or through our local GP. The urologist should have been available to have phone/video conference appointments.

- **Standard of tests.** I had a 6 sample biopsy with no sedation in Townsville, while the standard procedure in Brisbane was 12 point biopsy with sedation. This issue became important in determining whether nerve sparing was an option or whether I should have nerve grafting and my surgeon had serious concerns making this decision with limited information available from the 6 point biopsy.

  My original biopsy results from Townsville were reviewed in Brisbane and upgraded from a Gleeson score of 4 to a Gleeson score of 7; this drastically changed the treatment options, chances of success and urgency for treatment.

b) **Treatment**

- **Availability**
  There are less available treatments in regional centres. For example, surgery without nerve sparing or grafting was the only available treatment in Townsville.

  It is normal procedure to check for bladder cancer through cystoscopy prior to a radical prostatectomy. So that I did not have to make a special trip to Brisbane for this I instead had a urine test, arranged through my local GP and the cystoscopy in theatre prior to my surgery. If any cancer had been found in the bladder during the cystoscopy, it would have been removed then and I would have had to wait another 6 weeks for the radical prostatectomy.

I was advised that I would have to receive some blood during surgery and was advised that I could donate up to 3 bags of my own, which would usually be enough. I decided to do this for both health reasons and from an ethical point of view, so that I did not use up blood reserves that would be required in an emergency. However, to do this my wife and I traveled to Mackay (at least a 4 hour round trip) once a week for 3 weeks prior to my surgery.

- **Time**

  Difficulties with travel and time taken out to obtain treatment, both for the patient and the family, may directly influence treatment options of patients rather than medical outcomes. The time required to travel to speak to different specialists may prevent a patient seeking advice on all the different treatment options and therefore making a decision on treatment type that will best suit that patient. Low dose brachytherapy is particularly appealing for regional patients due to the procedure being completed in one day, however, may not be as successful. I was fortunate to have sick leave which I could take to have surgery, however, men prefer treatment options where they have minimal time off work and where they did not need to provide an explanation for long absences.

  I had been advised that I would be unable to return to work for 6 weeks but it was less clear as to how long we would have to be in Brisbane. We had to book accommodation in Brisbane in advance, so we decided to book 4 weeks. After the surgery, I was advised that I could probably leave about 4 days after the catheter was taken out, which was taken out 10 days after the surgery. I do not believe this advice would have been given had the surgeon had a better understanding of the travel required to return to my home town and limited medical facilities both here and Mackay.

I do not believe I was well enough to have traveled back to my home town two weeks after the surgery and so was fortunate that I had not made arrangements to return home. In addition, I ended up with chemically induced hepatitis and pancreatitis from the anesthetic. Symptoms appeared a week after surgery and I was only diagnosed 2 weeks after surgery. I then needed a liver scan, and regular blood tests for the next 2 weeks and I was referred to a Physician and Intensivist Specialist. If I had returned to my home town my GP would have had to deal with this complication and no liver scan would have been available.

- **Additional Costs**
  There are the additional costs involved in travel and accommodation, for:
  - seeking second opinions or to talk to different specialists in relation to the different treatments; and
  - in obtaining treatment.

  These costs need to be covered for both the patient and their family. Neither Medicare nor our private medical insurance covers these costs. There is apparently a government scheme to claim such expenses but it is considered so difficult to claim for such a minimal refund that most people do not bother to claim it and in our case it was just another complication that neither of us had the time to deal with. It would be more appropriate that we could claim these expenses through Medicare and in addition because of our limited facilities here we should be able to obtain a regional income tax refund.

c) **Recovery and Side Effects**

I believe normally a follow-up appointment would have been made with the surgeon 6 weeks after surgery and then every 3 months after that for further PSA tests and ongoing review. I saw the surgeon at 4 weeks after the surgery, before leaving Brisbane and will have my ongoing reviews and PSA tests through my local GP. My GP is also required to treat any ongoing side-effects such as my sexual dysfunction and again there is limited opportunity for specialist care without further travel and expense.

The limited range of medical facilities and the need to travel to get specialist care, at a time when one just wants to get on with life, means many people may not seek assistance for side effects and may be living with adverse situations unnecessarily. This may have the affect of people feeling negative about their treatment, which in a small community can prevent others from seeking treatment.

There are enough challenges already dealing with cancer and regional Australians should not be left with the burden of further challenges. We need to make it easier for regional Australians to access and benefit from major city resources.

Recommendations for delivery of services and options for treatment for persons diagnosed with cancer:

- Health programs targeting high risk cancers aimed at individuals, families, employers, unions;
- Encourage general medicals through Medicare and health programs;
- Educational programs to shift the "I'm all right attitude" especially in males;
- Financial assistance for patients and families, current system not clear and difficult to claim;
- Medicare rebates recognizing regional needs e.g. accommodation, travel;

- Educate and assist major city specialists to understand and provide greater assistance to regional patients e.g. flexibility with appointment times, treatment, referrals;
- Ensure standard of tests and treatments are consistent through out Australia, particularly between regional and metropolitan areas.

Assessment of less conventional and complementary treatments

(i) Extent to which less conventional and complimentary treatments are researched or supported by research

In particular, little research or empirical evidence had been done on the “watch and wait” treatment making it difficult to objectively compare this with other forms of treatment. In addition, no medical practitioner was able to provide us with a procedure or guideline as to how this should be done, such as:

- how often one should have a PSA reading done;
- at what point should one get concerned and look for further treatment;
- what other tests such as biopsies, MRI and CT scans should be regularly done and with what frequency.

It was obvious to us that any treatment that was not advocated by the medical profession or did not require some action by the medical profession was considered out of bounds by the medical profession. This meant that there was little or no research done for such treatments and little or no available information that was reputable to use in your decision-making process as to the type of treatment to proceed with.

(ii) Efficacy of common but less conventional approaches to cancer treatments

Little reputable information was available on this, although there were advocated treatments that were represented as being efficient and had the appearance of being reputable. There seems little regulation on advocating less conventional treatments and it can be confusing to patients to know if they can be trusted.

(iii) The legitimate role of government in the field of less conventional cancer treatment

Governments should be providing financial assistance for research into less conventional treatments and encouraging participation by the medical profession in research into these less conventional cancer treatments.

Medicare rebates and educational campaigns should be provided for those treatments that are found to assist patients, even if this assistance is mental or to their general health and well-being rather than a specifically scientifically proven reaction of their cancer to the treatment.

Governments should regulate the use of less conventional treatments in much the same way as it does normal medicines and medical procedures thereby ensuring that those less conventional treatments that are available are at least reputable. Where a treatment has not been proven, it should be treated as an experimental treatment and this should be disclosed to the patient. Patients should not be prevented from being given hope from unconventional treatments but their hope and use of less conventional treatments should be based on realistic disclosure and informed consent.