

SURVIVING BOWEL CANCER

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Surviving bowel cancer is not just about avoiding death. This article may not contain the means of achieving that end, but describes a personal journey which has suggestions for the patient and observations which may add to a medical professional's understanding. My survival story would not have been possible without the important assistance of family, professionals and friends. My reflections on the experience of diagnosis, treatment and recovery are described with some candour, while recognising that individual approaches vary enormously. The body of research into the long-term survival of cancer patients has grown rapidly, and the material available from health professionals, researchers and cancer organisations is respected and recommended as a critical resource. It is hoped that the comments here contribute further to that understanding.

Background and diagnosis

In 1993, I felt overwhelmingly sick. After weeks of increasing pain and discomfort, the discovery of a malignant tumour was not as devastating as it sounds. At least there was a diagnosis and the prospect of remedial action. It must be shattering for someone who receives a cancer diagnosis when otherwise fit and well. Perhaps some individuals have approached their local general practitioner to assess a small lump, with the thought of cancer as a horrifying possibility at the very back of their mind. They will become unwell, whether from the tumour or the treatment, and their life may thus be threatened. I could at least hope for improvement, if things went well.

Let the battle begin. The clichéd description of a battle may wrongly give the impression that a patient's prospects of survival may be influenced by their actions. Sadly, I'm sure there are instances where there is as much likelihood of changing the ultimate outcome as there is battling an on-coming train. The professional advice comfortingly suggested that my prospects of survival were quite good. As the surgeon listed the risks, I felt that my age and general health would give me a head start in the survival stakes.

Even before any pathology, the tumour was diagnosed as almost certainly malignant. Its size and location gave away its deadly nature. The tumour was large, located in the upper right area of the transverse colon and had breached the wall of the colon into the duodenum. While still groggy from the colonoscopy sedative, the information being conveyed did not have the impact on me that others frequently describe. There were no emotional outbursts or feelings of impending doom. Step one in the journey was clear: just do what would be necessary to get better and continue. That meant surgery.

It had taken weeks to progress from my doctor's comforting suggestions of minor bowel problems. In reality, that delay could have been avoided. At 33 years of age, I was on the radar of those specialists researching families with unusually high rates of bowel and other cancers. It was the early nineties and the research was embryonic, but I had been warned. Even then, testing by way of colonoscopy was recommended for at-risk family members over 30. At some future point, I imagined I would start the screening program. Why rush, when I was relatively young, healthy and feeling bulletproof?

The faulty mismatch repair gene is genetically inherited from my mother's side of the family. Not only was I unaware that I had inherited the gene, but that my mother would succumb to colorectal cancer almost 10 years later. I can reflect now on the concept of a battle and be comforted by the knowledge that there can be benefits and successes, even during an ultimately futile campaign.

I really don't know if I made a conscious decision to plan my approach to a cancer diagnosis. Perhaps I made a decision to really avoid making a decision, just to continue on with as minimal disruption as possible. Have the surgery, discuss the need for chemotherapy, get back to work, go to cricket training. Simple approach. That might be achievable if there were others to absorb and work the details. Like the sportsman who thinks he need only be left alone to perform, the work done by others is easily forgotten, allowing the player his room to perform. Everyone has an important job to do.

When the mind is emotional and scrambled, the details conveyed by specialists, surgeons and others are easily confused or forgotten. The presence of a partner in all these consultations is more than just emotionally supportive. Preferably, bring at least one clear thinking and inquisitive brain to all consultations. In that regard, I was extremely fortunate. Not only was the advice able to be analysed, but the entire journey was observed and recorded. This proved enormously valuable as the process developed. As incidents occurred later, I had the recorded memories and resources to which I could refer.

That same brain came with a heart and soul that carried me through the early days, handling all the communication with friends and family when my only focus was to survive. The decision to go public and to select a comfortable level of detail apparently causes difficulty for many patients. For me, there was never any thought to do other than issue detailed medical updates to family and friends and work colleagues. In the era prior to social media, this required bulletins for work noticeboards and frequent phone calls.

The response to these bulletins was intriguing. Not surprisingly, those with frequent and open contact can approach discussions with ease. Their questions and enquiries are without embarrassment and discomfort and the details can be discussed. For example, in a shared dressing room, discussing reactions to surgery and chemotherapy can be frank and a bountiful source of humour. By knowing how different people have varying levels of comfort in their enquiries, an environment of ease can be created.

After diagnosis, patients have expressed a temptation to make impulsive decisions. Having said that, I just wanted to continue my life unchanged, but there were nevertheless occasions when my thoughts turned to seemingly urgent matters. Fortunately, I was surrounded by family and work colleagues who rejected such ill-considered thoughts as: "Do I check my superannuation arrangements and resign from work immediately?" In recent years, Cancer Council Victoria has created two comprehensive information booklets for people who have finished active treatment for cancer. They are *Living Well After Cancer* and *Loss and Grief*.

Surgery and chemotherapy

My surgery would be urgent and radical. My plumbing through the stomach, duodenum, small and large bowels would be irreversibly altered and would become idiosyncratic. There should however, be an immediate improvement. The pain, discomfort and cramps should disappear with the tumour. But even if successful, it would bring on inconveniences and represent only the first step in the overall plan for recovery. The surgery was successful and the pathology indicated that the cancer had not spread to the lymph nodes. It was only then that the specialists confided their surprise at the containment of the cancer, given its apparent aggression.

Chemotherapy started with several consecutive days of treatment, followed by a break, before commencing the weekly sessions. The plan was to have weekly chemotherapy on Mondays, so as to feel well enough to play cricket by Saturday. I could sit behind a desk and tackle the requirements of the rest of the week, although my contribution to my employer and the economy may have been minimal on some days.

Attending chemotherapy sessions was not accompanied by the dread that many would expect. The group of about a dozen patients was cheerful and chatty as they sat around attached to their intravenous drips. Nurses who administered the treatment helped to create a positive mood. Sadly, the reality of the situation was brought home when some patients stopped attending and there was the obvious apprehension associated with making enquiries about their fate.

The combination of post surgery factors and chemotherapy implications took a while to grasp. While some general advice about coping with chemotherapy was useful, it was the personal discoveries that really worked. Chemotherapy left me with difficulty overcoming a chemical taste and smell that would take days to disappear. It wasn't in the instruction manual, but a session of massage and

aromatherapy succeeded in overcoming that taste and smell. However, the unfortunate consequence is that the scent of lemongrass, used in those massage treatments, is now forever associated in my mind with feelings of nausea and discomfort. I am reminded of the possibly true story of a patient, who years after receiving chemotherapy, was exposed to the same perfume as that worn by a nurse during her treatment, who unexpectedly vomited in the cosmetics section of a department store.

The drugs caused dryness and cracking of my skin, especially on my hands. Going to bed wearing rubber gloves over my hands smothered with moisturiser was not some strange predilection, but a worthwhile adjuvant treatment. It was an unexpectedly pleasant surprise that my hair did not noticeably thin during treatment.

Eating became problematic. I became fussier than a delicate child and took on passions and fetishes for food usually associated with pregnant women. For me, it meant that Japanese food was compulsory on Mondays. Alcohol became less appealing. Beer and wine were only manageable for social purposes and it often felt that they were only imbibed through social habit, not desire. My bodily reactions suggested that fish and vegetables have a well deserved reputation for promoting health. At one time, I couldn't get enough fruit cake. At another, grapes became compulsory eating.

Irritability has also been known to occur with chemotherapy patients. My opinions became strongly held, extremely valid in my mind and forcefully presented. That hasn't changed, and I don't know whether that can be associated with treatment or just being a grumpy older man. My previous concerns about being a fence-sitter disappeared quickly.

Chemotherapy, particularly when used as a preventative measure, is speculative. The drugs I received at that time were professionally recommended, but not necessarily universally adopted. There was also much discretion in the prescribing of anti-nausea drugs in combination with the chemotherapy. It was therefore interesting to have two sessions of chemotherapy while travelling overseas. The abiding memory is of the cost of medical services in the United States. However, the exposure to a variety of anti-nausea drugs proved valuable and resulted in a change to my local treatment.

Recovery and consequences

There is considerable research available on the psychological impact of suffering and recovering from cancer. Post-traumatic stress disorder has become a recognised affliction and I can identify aspects of that syndrome in my subsequent behavior. Alcoholism and depression are not a necessary consequence of cancer, but the possibility of suffering both appears to increase. To adopt a sporting metaphor, batsmen respond differently after a dropped catch gives them another opportunity. Some take extra caution to ensure the most of the opportunity, while others engage in riskier shotmaking. I will admit to a few agricultural shots as my innings continues.

Jefford reviews the evidence which supports the view that psychosocial support results in broad benefits for patients.

From a clinical viewpoint, the challenge is to identify those at risk and with unmet needs.¹ Supportive care is widely available and the various bodies have significantly extended the promotion and availability of their services inside and outside the clinical setting.

People ask whether I need to be careful with my diet. The answer is that from a health perspective, my requirements are no different from anybody else. However, a really exciting and useful by-product of my bowel surgery, is that my body immediately registers the quality and nutritional value of food I eat. Within minutes, I will feel genuinely nauseous after eating highly fatty or processed food. Vanilla slices may win awards, and at times, they can't be resisted, but their impact is diabolical. My body's responses have enabled me to prepare a league table of food quality. It has become clear to me that the products of a particularly well known hamburger chain should not be eaten and that a well known pastry manufacturer's party products should not be eaten at the conclusion of cricket committee meetings.

In the immediate post surgery period, there are extremely vivid memories. Travels and events are remembered because of the inconveniences that arose. With only minimal large bowel remaining, I have a need to do about five times a day what others accept as a daily ritual. During chemotherapy, I had to carefully plan when and what I would eat prior to a boat trip on a Louisiana bayou. Even golf and walks on the beach took some planning. Sad as it may be, my memory of Rottneest Island in the weeks after initial chemotherapy, revolve around discretely vomiting. Similarly, I became well acquainted with the bathroom of a famous New Orleans restaurant after foolishly attacking the local oyster shooters.

As time has moved on, my bodily functions have fortunately become more predictable. I am grateful for the enormous improvement in public facilities over the last 20 years. The French have, if it can be said, taken leaps and bounds in this regard.

As a genetic victim, are there any other matters which arise? Being a statistic and research model has its advantages. It is comforting to receive individual treatment. However, requests posed to me for assistance with research usually involve frequent blood tests. The increasing privacy requirements make the sharing of information between interested parties more difficult to arrange. This has its frustrations. After a year of chemotherapy, my veins may not cooperate and it can be a test of nursing staffs' abilities to extract blood samples.

Our health system does not provide an obvious integrated model for a patient's overall care. Each type of need can be met by accessing the appropriate provider, but it can be difficult to co-ordinate an overall plan. The earlier comments about needing a supportive, clear thinking

and well-organised companion are particularly true in this context. Reconciling the sometimes conflicting views, and avoiding falling into any cracks in care, takes considerable concentration. It is not part of a patient's typical care plan to arrange a meeting between the colorectal specialist, the surgeon, the dietician, the oncologist and the physiotherapist. There are times when such a meeting could be valuable.

My good fortune was to be recommended to a team of specialists and surgeons in which I could have total faith. In addition, their age at the time and their ongoing involvement has provided a continuity of care. Being able to access immediate advice is comforting and has proved valuable on numerous occasions.

A real risk arising from abdominal surgery, is the threat of adhesions. Within six months of the initial surgery, I experienced the first enormously painful blockage, which rectified itself overnight with the assistance of morphine. However, they became more frequent and worrying. The diagnosis was uncertain without further investigative surgery. Typically the dozens of attacks would come at the most inconvenient times and require a dash to emergency and an overnight hospital stay. The first surgical treatment was a scheduled event, but the two subsequent procedures within the next two years, were unplanned. Something worked and there have been no blockages since 1995. But all that surgery must have had some physical impact. Some years later, my duodenum, for unexplained reasons, perforated and required another unexpected, middle of the night callout for my surgeon.

Screening is still an annual event, but, with only minimal large bowel, I am absolved from the discomfort of taking the widely despised bowel preparations. As well, the improvements in anaesthetics are a boon. At a recent colonoscopy, or more accurately, a flexible sigmoidoscopy, I enquired if such a relaxing anaesthetic was broadly available for recreational purposes. Apparently, it was the same type used frequently and understandably, but not successfully, by Michael Jackson.

After 20 years of observing my reactions to events, I should know the triggers for depressive behaviour. While compiling these reflections, I am aware of signs which should be recognised. They include survivor guilt about inadequately showing gratitude for the assistance of family, friends, work colleagues and cricket mates, and pressures and consequences of not maximising opportunities. This coincided with the date of my late mother's birthday and while anticipating a weekend interstate trip.

References

1. Jefford M. Support provided outside the clinical context for people affected by cancer. Cancer Control. Oxford University Press UK, 2010.