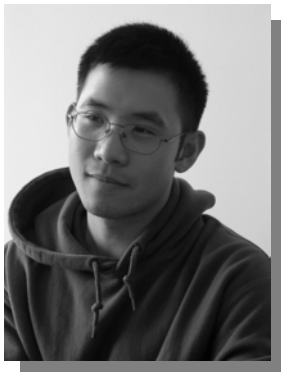


A Courageous Journey: *Experiences with Testicular Cancer*



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A Courageous Journey

Experiences with Testicular Cancer

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*Oncology Patient Education
Princess Margaret Hospital, Toronto*

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Introduction

Welcome to “*A Courageous Journey - Experiences with Testicular Cancer*”.

Men’s health goes beyond physical health to include many social, economic and psychological issues. This booklet was created to help testicular cancer patients and their families understand the facts about testicular cancer and the experiences of other men with the disease, so that they may better cope with their own experiences. Our sincere thanks go out to the more than 40 men with testicular cancer who shared their experiences so openly and thoughtfully. This booklet is their gift to those men and families who are now traveling the same road.

All details and identifying features have been changed to protect the privacy of the contributors. The men we interviewed belonged to a range of different age groups and backgrounds and went through a variety of treatments at different points in time. Each of these patients had different reactions to the diagnosis, treatment, and post-treatment stages of testicular cancer, and they show clearly that there is no one *right* or standard response to a diagnosis of cancer.

This booklet is divided into the following sections:

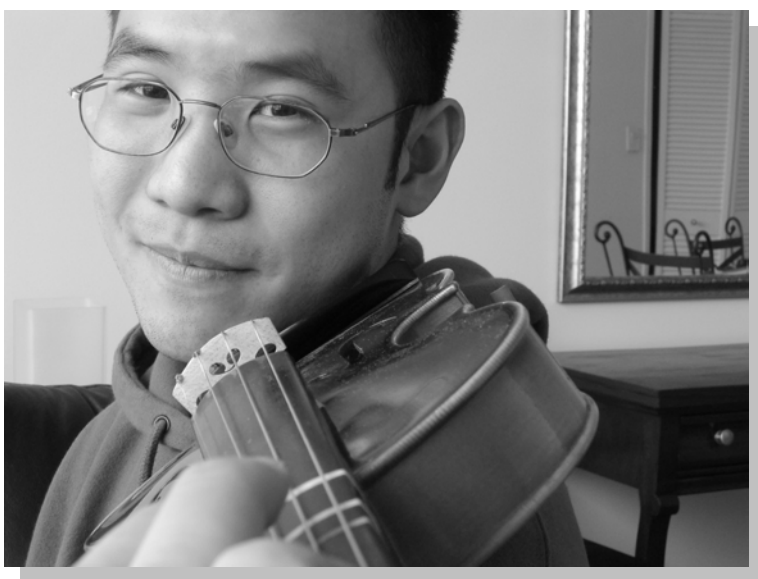
The first section, entitled ‘**Testicular Cancer – Some of the Facts**’ aims to answer some of the general questions men and their loved ones may have about testicular cancer. Next, the stories of two young men with testicular cancer are presented. The third section, ‘**Relationships and Communication**’, uses personal perspectives, narratives, and interviews to show how men with testicular cancer talk about the disease with others. The fourth and fifth sections, ‘**Fertility**’ and ‘**Sexuality**’, address the impact of treatment on these issues using a mixture of factual information and illustrative stories. The section entitled ‘**Perspectives**’ uses anecdotes, stories and an interview to address the impact of cancer and treatment on the patient’s body image. The booklet concludes with the story of one young man, who was diagnosed with metastatic testicular cancer when he was 19 years old. A final glossary of terms will help to explain words that you may not understand.

The material contained in this booklet is made available to you as a service to patients, families and visitors of Princess Margaret Hospital. It may not be a complete or up-to-date statement of medical knowledge in this area. Although we attempt to ensure the accuracy and currency of all material in this booklet, you should not act upon any of the information in this booklet without first consulting your doctor or other healthcare provider. There are many additional materials on various aspects of cancer that are available from the Patient and Family Library at Princess Margaret Hospital and the national office of the Canadian Cancer Society at (416) 961-7223 and ccs@cancer.ca or on their website at <http://www.cancer.ca>.

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Testicular cancer could happen to any of these men.



Testicular Cancer – Some of the Facts

The following information may help answer some general questions you may have about testicular cancer. The material is taken from several resources listed at the end of this section. Please consult your doctor if you have any further questions about testicular cancer.

What is cancer?

Cancer is a disease that occurs when cells in a part of the body start to grow out of control. Our bodies are made up of millions of cells that are grouped together and make up different organs and tissues (i.e., lungs, skin, and muscle). Normal cells grow, divide, and die in a highly controlled way. This control can sometimes be lost, leading to abnormal cells that continue to grow and divide. Abnormal cells often outlive normal cells and group together to form lumps or **tumours**.

A tumour can be either **benign** (non-cancerous) or **malignant** (cancerous). Benign tumours do not usually cause the body harm because they stay in one place. However, malignant tumours can cause harm by invading the tissues around them and spreading to other parts of the body (called **metastases**). It is important to identify and treat malignant tumours quickly to minimize the damage that they cause.

What is testicular cancer?

Testicular cancer is cancer that develops in one or both testicles. The testicles are the two male organs located in the scrotum, a loose skin sac at the base of the penis (see *Figure 1*). They produce sperm and male sex hormones (testosterone).

Over **95%** of testicular cancers start in the cells that produce the sperm (**germ cells**) and are known as **germ cell tumours**.

The two main types of germ cell tumours are **seminomas** (60%) and **non-seminomas** (40%). These tumours are grouped according to their appearance under the microscope, different patterns of spread, and somewhat different responses to treatment. Seminomas

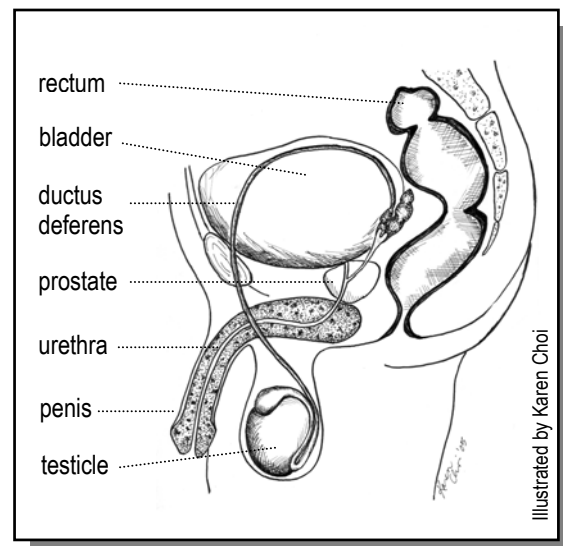


Figure 1. The male genital tract.

are more common among men who are in their late twenties and older, whereas non-seminomas predominate among adolescents and younger adults.

Other less common forms of testicular cancer are **stromal cell tumours**, which grow in other parts of the testicle, and **secondary testicular tumours**, which develop from cancer that has spread to the testicles from other parts of the body.

Who gets testicular cancer?

Testicular cancer is the most common solid tumour in young men, and typically occurs in men between the ages of 15 and 35. Approximately 1 in every 100,000 men are affected; Caucasian men are four to five times more likely than African-American men to get testicular cancer. Native American, Hispanic, and Asian men are also affected by the disease.

There is no known cause for testicular cancer. However, the following **risk factors** can increase a person's chances of getting testicular cancer:

- ❖ Age – between 15 and 45 years old
- ❖ Undescended testicle (**Cryptorchidism**)
- ❖ Family or personal history of testicular cancer
- ❖ Abnormal development of the testicle
- ❖ Some rare genetic conditions

Remember, an increased risk of cancer does not mean you have cancer or will definitely get cancer in the future. Men may even develop testicular cancer without any of these risk factors.

Can testicular cancer be prevented?

Some of the known risk factors (i.e. cryptorchidism, family history of the disease) are unavoidable. Also, many men with testicular cancer have no known risk factors. For these reasons, it is not currently possible to prevent most cases of this disease. However, surgical correction of cryptorchidism below age six does lower the chance of developing testis cancer later in life.

Testicular cancer can almost always be treated successfully, if it is found early. Most of the time, a lump on the testicle is the first sign. All men should perform a monthly **testicular self-examination** from the time they are 15 years old, especially if you have any of the risk factors mentioned above.

❖ ***The testicular self-examination:***

The self-exam is best performed during or after a bath or shower, when the skin of the scrotum is relaxed. To perform a testicular self-exam:

- Hold the penis out of the way and examine each testicle separately.
- Hold the testicle between the thumbs and fingers with both hands and roll it gently between the fingers.
- Look and feel for any hard lumps or nodules (smooth rounded masses) or any change in the size, shape, or consistency of the testes. If you feel any of these, make an appointment with your doctor to have it checked.

What are the signs and symptoms of testicular cancer?

Testicular cancer in its early stages may cause:

- ❖ A lump on the testicle that is usually painless
- ❖ A feeling of heaviness or dragging in the lower abdomen or scrotum
- ❖ A dull ache in the lower abdomen and groin
- ❖ Infertility

Advanced testicular cancer that has spread to other parts of the body may cause:

- ❖ A lump in the neck
- ❖ Pain
- ❖ Discomfort in the back
- ❖ Shortness of breath
- ❖ Breast tenderness or enlargement

Having the following signs and symptoms does not necessarily mean that you have testicular cancer. They could be caused by other problems, so see your doctor to be sure.

How is testicular cancer diagnosed?

The first step is for your doctor to get your medical history and perform a physical exam. The history is done to assess your risk factors for cancer and other diseases. During the physical, the doctor will feel the testicles to detect any sign of swelling or tenderness and the size and location of any mass. The doctor also examines your abdomen to feel for enlarged **lymph nodes**, a sign that the cancer has spread to the lymph nodes found in the back of the abdomen (**retroperitoneal lymph nodes**).

A number of special tests are usually necessary to confirm a testicular cancer diagnosis. They include:

❖ *Imaging studies*

X-rays, ultrasound, CT (computer tomography) scans, MRIs (magnetic resonance imaging) and bone scans can examine organs, tissues and bones in great detail.

❖ *Ultrasound*

In testicular cancer, ultrasound of the affected testicle shows a solid mass that is virtually diagnostic for cancer. A biopsy is usually NOT performed to make a definite diagnosis of cancer, because of the risk of spreading the tumour. If testicular cancer is suspected from the ultrasound, the entire testicle is usually removed for testing. This surgery is called an orchidectomy (or orchiectomy).

❖ *Computed Tomography (CT Scans)*

These scans are done to assess the lymph nodes in pelvis and abdomen – to see if they are enlarged and possibly involved with cancer.

❖ *Blood tests*

Blood is taken and studied to see if the different types of blood cells are normal in number and appearance. **Tumour markers**, such as alpha fetoprotein (AFP) or beta human chorionic gonadotropin (β HCG), may be present in the blood and can indicate the presence of testicular cancer. Tumour markers are molecules occurring in the blood that are associated with cancer and whose measurement or identification can be useful for diagnosing the disease, determining the prognosis of the patient, or monitoring the course of the disease. For instance, a decreasing AFP level may indicate that the cancer is being cleared from the body. Tumour markers are usually monitored for many years after cancer treatment.

These diagnostic tests can also provide information about the **stage** of the cancer, that is, how far the cancer has spread. The stage of the cancer is used to plan the treatment and estimate **prognosis** (chances of survival).

How is testicular cancer treated?

Treatment depends on the type and stage of your cancer. The three main methods of treatment for testicular cancer are **surgery**, **radiation therapy**, and **chemotherapy**.

❖ **Surgery**

Surgery is an operation to remove the tumour and some surrounding tissue. For testicular cancer, it usually involves removing the entire testicle (orchidectomy). Occasionally, usually after the tests are done, the lymph nodes near the kidneys are removed (retroperitoneal lymph node dissection), depending on the type and stage of the cancer.

❖ ***The surgical experience:***

- Prior to the surgery, the patient will be assessed for their ability to undergo the operation. This includes several tests, such as blood work, an ECG, and a chest x-ray. It is important to discuss the operation with the surgeon and anesthesiologist at this time. Sperm banking should also be carried out before the surgery, if it has not been previously done.
- The day before surgery, the patient must drink only clear fluids, such as water, juice, and tea. Food and drink should be avoided at least 6 hours before the surgery. A laxative must also be taken.
- The morning of the surgery, an intravenous (IV) will be inserted into an arm vein to supply the patient with fluids, antibiotics, and pain medication.
- Immediately after the surgery, the patient is transferred to the Post Anesthetic Care Unit (PACU). The patient may be attached to an intravenous line, a nasogastric tube (a tube which passes through the nose to the stomach to drain stomach secretions), a foley catheter (a tube which passes through the penis to the bladder to drain urine), and a central venous pressure (which is like an IV, but connects through a neck vein). Deep breathing and coughing exercises should begin as soon as possible.
- The day after the surgery, the patient should begin to move as tolerated, such as sitting up and walking. Eating and drinking occurs gradually. The length of stay at the hospital is approximately 5-7 days.

❖ **Radiation Therapy (Radiotherapy)**

Radiation therapy uses high-energy x-rays to destroy cancer cells. A carefully focused laser beam is aimed at the tumour and attempts to kill the cancer cells. A drawback to this procedure is that the radiation may also destroy nearby healthy tissue. Other side effects may include a skin reaction, fatigue, nausea, or diarrhea.

Radiation therapy is used most often for seminomas after surgery. Non-seminomas tend to be resistant to radiotherapy, and thus it is rarely used for them.

❖ **Chemotherapy**

Chemotherapy involves the use of drugs that interfere with the cancer cell's ability to grow and spread. Chemotherapy is considered systemic therapy, meaning that the drug enters the bloodstream and circulates throughout the body to reach and destroy the cancer cells. Hence, it is an effective way to destroy any cancer cells that break off from the main tumor and travel in the bloodstream to lymph nodes or distant organs.

The main drawback of chemotherapy is that healthy cells can be affected during treatment. Side effects include nausea, vomiting, loss of appetite, fatigue, hair loss and an increased risk of infection. Testicular cancer often responds well to chemotherapy.

Please refer to the sections on "Fertility" and "Sexuality" to learn how these three treatments may affect fertility and sexual function.

❖ **Surveillance**

For patients who have no evidence of spread of the cancer (Stage I disease), removal of the testicle is all that may be necessary in terms of treatment. These patients are placed on close follow-up with regular visits to the hospital for examination, blood tests and x-rays.

Is testicular cancer curable?

Testicular cancer is highly curable and has a cure rate over 90% for all stages combined. Studies have shown that the **5-year survival rate** (the percentage of patients who live at least 5 years after diagnosis) for stage I testicular cancer is 99%. It is 95% for stage II (cancer spread to nearby lymph nodes) and 74% for stage III (cancer spread beyond the lymph nodes).

It is important to remember that these numbers provide an overall picture, and that each person's situation is unique. Statistics cannot predict exactly what will happen in your case. Talk to your doctor if you have questions regarding your chances of a cure.

Further Reading

For more information on testicular cancer, visit the Canadian Cancer Society's webpage at www.cancer.ca or the American Cancer Society's webpage at www.cancer.org.

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The Stories of Two Men with Testicular Cancer

The following two stories describe the experiences of two men with testicular cancer. The narratives show that cancer can have a ripple effect that touches many, if not all of the relationships surrounding the patient.

Sam's Story

Before Sam was diagnosed with testicular cancer at age 23, he had never really thought about cancer. The diagnosis came as a complete shock.

We spoke to Sam 11 years after his diagnosis and surgery.

Looking back at the diagnosis

Sam explained that when he first noticed the pain in his testicle, he did not see his doctor right away. He felt embarrassed about it and thought it would go away on its own. However, the pain continued and so he decided it was time to seek help. When he finally saw his doctor, things happened very quickly afterwards.

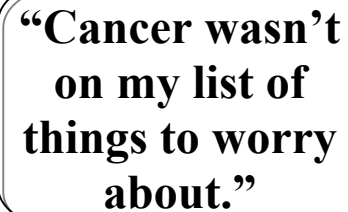
Sam was told he had testicular cancer and was admitted to the hospital later that evening. He had surgery the next morning. Sam said, "I didn't have time to feel sorry for myself. It was fast."

Telling others about the diagnosis

Sam's parents divorced and remarried when he was very young. They have very different personalities and coping methods and Sam struggled at finding the best way to tell each of them about the cancer.

At first, his parents were very stressed about the news. Fortunately, he was able to have a

warm and open conversation with his mother, mostly because of her easy-going attitude. Sam found it more difficult to talk with his father. They spoke briefly about the facts, but they never really discussed what it meant to their lives. His father often



"Cancer wasn't on my list of things to worry about."

showed his anger with the cancer when he visited Sam at the hospital. Their distance made it difficult for Sam to cope with his illness, but he still valued his father's presence.

Having a support system

Sam decided to move back home with his mother after having lived on his own for several years. Initially, he felt this was a large setback and a loss of his independence. However, his mother provided him a great deal of assistance, such as by taking him to hospital appointments.

Sam appreciated his family's support throughout his illness. "I woke up in the room after the surgery and my dad was there. My mom and stepfather were there as well. It was nice to see all of them." He was especially grateful to his girlfriend (now his

wife) and explained how understanding she was of his illness. She even volunteered to come with him for his first appointment. He laughed as he recalled, “As a matter of fact our first date was at the hospital. I said, ‘I’ve got an appointment tomorrow’, and she said, ‘Oh, I’ll go with you.’”

Sam’s close friends also knew about his surgery. At the time they did not ask any details, but after his recovery, Sam was able to use humour and joke about his “one-ball-less” situation with his friends. Humour helped them to communicate and overcome awkward moments. As Sam says, “Humour is sometimes the best way to get through any problem or situation.”

Physical appearance and fertility

After Sam’s surgery, the doctor told him that he didn’t require additional (adjuvant) therapy. The doctor inserted a prosthetic testicle to replace the diseased one. At first, Sam was worried about his physical appearance. “All of a sudden you feel as if you’re not like the guy next to you. The prosthetic is on the left and it’s a bit higher, so right away I look in the mirror and I know there is a difference.” Through time, he was able to adjust with having the prosthetic and didn’t worry about his appearance.

Sam was also concerned about having a family in the future. He was soon reassured when the doctor explained that one testicle is just as good as two testicles for producing sperm and having children.

Life 11 years after the diagnosis

Sam continues to visit his doctor every year. Eleven years after his diagnosis, he still worries about his yearly appointment. Sam explained, “Uncertainty is the worst feeling. If I’m not sick, then why am I still here? Why do I have to do these tests?” When all of the test results come back as negative, he gets on with his life again.

Sam is now 34 years-old. He is married and has a 6-year-old son, born after his treatment. He works a busy full-time job.

His main concern is supporting himself and his family. Sam has many exciting future plans and is very satisfied with his life. As he sums it up, “I am going to keep living and working hard. I’ve got my family. I’m starting up my own business, and that may be something that can be passed down to my son. Who knows?”

Bennett & Sandra’s Story

Recently married and only 23 years old, Bennett was ready to start a new chapter in his life with his wife Sandra. Neither of them could predict that they would also be faced with the challenge of cancer.

Bennett and Sandra are in their early twenties, supported by welfare, and still learning to live together as a couple. They

come from a small town on the Eastern coast of Canada.

We spoke with the newlyweds shortly after Bennett was diagnosed with testicular cancer and had his surgery. Their story is a shared battle against cancer in the “big city”.

Diagnosis and early treatment

Bennett never had any major health concerns until the day he experienced a sudden overwhelming pain in his testicle while having coffee in a restaurant. He and Sandra immediately went to the hospital. To their relief, they were told that the pain was the result of an infection. Bennett took the prescribed antibiotics and concluded, “Okay, I am fine.”

Two months later, Bennett’s testicle became swollen, rock hard, and very painful. Bennett’s doctor concluded that his condition was more serious than he had first anticipated. Within five whirlwind days, Bennett had an ultrasound, was referred to a urologist, and had surgery to remove the diseased testicle. Sandra and Bennett felt happy that matters were dealt with so quickly, but they were also frustrated because they didn’t have time to process what was happening.

A swift timeline is common for testicular cancer treatment, and its speed often adds to the stress experienced by newly diagnosed patients and their families. The feeling of being in a ‘bad dream’ is very common. Patients often find themselves putting their emotions on hold while making immediate decisions and dealing with huge amounts of medical information.

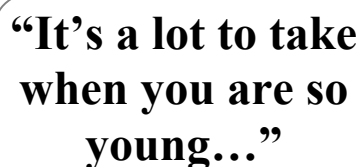
The importance of information

Bennett explained that while the actual surgery went well and the pain was minimal, he had been very nervous and didn’t know what to expect. He didn’t think twice about having the surgery, but it certainly wasn’t what he expected. “They told me, ‘It’s a day surgery. You’re going to be on intravenous, then go to the surgery, and then you’ll wake up.’” Bennett felt he didn’t have enough

information about what was actually going to happen.

In hindsight, Bennett and Sandra were disappointed that very little information was provided to them. They had no idea what to expect. Immediately after the surgery, Sandra had

to carry her very groggy husband to the car, drive him home, and care for



“It’s a lot to take when you are so young...”

him. Sandra commented how scary that was, “I’ve never had to deal with things like that. Bennett didn’t want to wake up! I didn’t know if he was supposed to be like that. I would try to wake him up and give him some juice every hour, but he wouldn’t wake up.”

The couple also explained that they were unaware of what Bennett would look like after the orchidectomy. The incision was red and very scary to them, even though redness and swelling are normal outcomes of surgery.

Their advice to future patients would be to ask as many questions as possible before surgery, and to make sure they understand what will happen to them.

Coming to the “big city”

Sandra spoke candidly about how uncertain the preceding couple of weeks had been. The short notice between each step of the treatment was particularly upsetting. For example, they were told on a Tuesday evening that Bennett had to be in Toronto by Thursday. They had one day to arrange a flight and going to Toronto was “big, big!”

Initially Bennett had been told to come by himself, as the couple was on welfare and Sandra's airfare wouldn't be covered. Sandra recalled, "We had just gotten our check at the end of the month, and then they told us to make flight arrangements for Bennett to come to Toronto!" Fortunately, his grandmother paid for Sandra's ticket. Sandra said, "If Bennett came to Toronto without me, he would have been a wreck by the time he got there." Bennett added, "I was a wreck when I got there!" Sandra continued, "Yeah, but he had me to hug and tell him nothing bad was going to happen today..."

Bennett admitted, "The other thing that I can identify with right now is my fear of surgery. I was allowing them to put a hole in my body." He said, "I'm not good with things like that. I didn't like the fact that I was going to have tubes and things hanging out of my body. I had to be in the hospital thousands of miles away from anyone I knew." Sandra added that the emotional and physical impact of surgery seemed to be neglected by their doctors and nurses, perhaps because testicular cancer is so curable. It made them feel unimportant, like just another cancer patient working through the system and then disappearing again.

Being in a hospital environment can sometimes feel sad and isolating. Therefore, having caring family members, friends, or healthcare workers on your side can make a large difference throughout the treatment.

Dealing with bad news

At the hospital, the anxious couple was told that the cancer had likely spread and Bennett needed to have a node dissection surgery. Bennett commented, "It's like wherever I ended up, I always got a shock!" Sandra agreed, "It was never any good news, such as 'You're going to have chemotherapy

which makes you sterile. You're going to have surgery that can leave you unable to ejaculate.'"

The couple emphasized how reassuring it was to be given clear and complete information about the surgery this time around. Bennett said, "The surgeon went into great detail explaining what they were going to do, what everything in my body was, and how he was going to go about taking out the lymph nodes. So I felt better after this. Well, I felt like shit, because I knew exactly what was going to happen, but I felt better knowing that the person doing it was a professional and that everything was going to be okay."

Bennett and Sandra often found that the treatments turned out to be more difficult than what they were told. To better prepare themselves for bad news, the couple developed a coping strategy of "if they tell us one thing, there's going to be a lot more to follow." Bennett commented, "Today wasn't all that bad. The only surprise I got was the chest x-rays and the blood work. I was kind of expecting that." Sandra laughed, "It wasn't bad, because we were expecting more."

Coping with cancer

Sandra and Bennett felt stressed dealing with the emotional and practical issues involved with cancer. With their families so far away, the young couple was also aware of their lack of a support network. Their initial hope for the cancer treatment had been to get rid of it as quickly as possible and then get back to their normal lives. Now Bennett was facing another round of surgery and perhaps chemotherapy.

Coping with a rapidly changing situation was particularly difficult for Bennett because of his attention deficit disorder

(ADD). As he put it, “Information goes in and out, and I only retain a little bit. This is hard to deal with because I forget a lot of it.” His response to such lapses was often anger. Sandra added, “When Bennett gets scared, he doesn’t show it. The only way I know that he’s upset or he’s really scared about something is if he gets mad and I can see it. He’ll say, ‘Don’t talk to me right now, I need to go for a smoke.’” Bennett explained that smoking gave him the space and time to process what was happening to him. Sandra said, “I’ve come to learn that when he does get frustrated, I should leave him alone. He’ll come and talk when he’s ready.”

Sandra’s coping difficulties came from holding back her emotions. “We’ll be watching TV, and it will all of a sudden hit me. He’s going for surgery, some major surgery. Then I’ll sit there and cry. That’s my way of letting out my emotions.” Bennett noted that Sandra would “store it up until she had a meltdown.”

Bennett compared his response to stress. “When I have something to deal with, I just go blank, or I come up with some smartass comment.” That was tough for Sandra, who called herself “the more serious one”. As she put it, “I have to be upset for him and for me.” Yet Sandra recognized that Bennett’s sense of humour helped to lighten up situations and made it easier for them to talk to family and friends.

Major concerns: infertility

Sandra and Bennett’s biggest fear was being unable to have children. Bennett was told to donate sperm in case he was infertile after

treatment, but it was expensive, especially for a young couple struggling to make ends meet. Artificial insemination and adoption were also financially out of the question, and simply “weren’t the same” as having their own children. Sandra said sadly, “If we were 60 and we had this problem, we’d already have the family that we wanted. It’s hard. Someone tells you, ‘You can’t have children.’ That’s just the end of it. It doesn’t seem to matter to anybody but us.”

It is important to discuss fertility and sexuality with your doctor at the start of treatment, as both of these aspects can be affected by cancer. There are also several options in dealing with these issues (see sections on Fertility and Sexuality & Sexual Function).

The upside of it all

Both Sandra and Bennett commented that the diagnosis and treatment process has brought them closer together as a couple. As Sandra put it, “Before this I thought that as long as I live, Bennett will be there.” The young couple now realizes that disaster can strike at anytime, and they strive to live each day to the fullest.

Sandra said, “It’s almost sad that something like cancer has brought us closer.” Bennett agreed and commented, “You realize how much you really need each other, and then it all branches out from there.” They concluded that as a couple they were having “a violent shove into growing up and taking what comes their way.”

Relationships and Communication

The extent to which a testicular cancer patient can talk about his illness depends upon his personality and his support network. Reactions range from avoiding the topic completely, to communicating with family members and co-workers. Sometimes the patient's partner may wish to take an active role in his treatment by attending appointments and discussing options, while other times the partner does not choose to become involved. The decision about who and when to tell about the diagnosis varies among patients. There is no one correct approach to communicating about cancer. It depends on the individual.

Patients often mention the invaluable role of their family and friends in providing emotional support throughout their illness and recovery. Men without a social network may rely on other forms of support, such as support groups and various resources (i.e. Internet, books, videos, etc.), to help them cope. Patients often describe an increased appreciation for life and a need to live each day to the fullest after surviving cancer. Many achieve this goal by making more time for loved ones.

The following sections include personal perspectives, narratives, and interviews of various men with testicular cancer on their relationships and how they communicated their disease to others.

Personal Perspectives

Talking about your body

Dan is 22 years old and was diagnosed with testicular cancer two years ago. He had a unilateral orchidectomy.

“When I first noticed a swelling in my testicle, I didn't want to tell anyone. I was too embarrassed. The first person I told was a good female friend of mine. I felt more comfortable telling her than any of my male friends because she is really open and easy to talk to. In the end she encouraged me to see a doctor.

“I have noticed that guys in general don't talk about their bodies. They would rather just bottle up their concerns. I used to agree, but testicular cancer changed that. I am open about my

experience with cancer and encourage my friends to self-examine. I think that men should be more educated about testicular cancer, particularly in high school.”

Family and friends – a valuable support network



Ben is 24 years old and was diagnosed with testicular cancer last year. He had a unilateral orchidectomy

“The same evening I was diagnosed with testicular cancer, I drove home to tell my parents. My father didn’t believe me at first and phoned the doctor. They were so shocked. They didn’t know quite how to react. Parents want the best for their kids and feel paralyzed when something horrible happens beyond their control. They were really worried, and I felt awful to have

burdened them with such a big concern. My friends soon found out about the diagnosis through my parents, since we’re all very close. The person who I found the easiest to talk to was my sister. She’s two years older and she has always been around to listen and console. My girlfriend was also a source of support.

“When you live through cancer, you realize how valuable people are in your life. I’m lucky because I had a tremendous amount of support from my loved ones. I wouldn’t have known how to cope with my situation without that. Now that the cancer is behind me, I try to live each day to the fullest, by spending more time with family and friends.”

A one-man battle

Ivan, a 35 year-old, was diagnosed two years ago with cancer and underwent a unilateral orchidectomy and chemotherapy.

“I was devastated when I was first told I had testicular cancer. I felt very much alone, since I had no relatives in Canada. As soon as I could calm down, I used the Internet to learn about this type of cancer and discovered that it had very high survival rates. This knowledge was uplifting. Educating myself was a way of coping, since I had no one else I could talk to about my situation. I didn’t tell my relatives back in Russia, since I didn’t want to worry them. So my experience with testicular cancer was a ‘one man battle’.

“Because I had no one to turn to, I became more religious. I needed to believe in something. I started going to Church once a week. I also changed my lifestyle after cancer. I eat healthy foods and exercise regularly. I’m healthy again and that’s my most important concern. My experience with cancer helped me identify what I want in life.”

Telling others about the diagnosis

Marcus is 39 years old and was diagnosed with cancer four years ago. He underwent a unilateral orchidectomy and radiation therapy

“I never really think about cancer anymore. It’s something that happened to me and I have moved on. When I was diagnosed, I was married with two children, aged 8 and 12. My wife and I attended the appointments together. She was very intent on learning about the different treatments, and she even took notes during the discussions we had with the doctor. I think my illness affected her more than it affected me, since she felt there was nothing she could do. She was concerned about my well-being and about making the right choices regarding treatment. We decided together about what to tell our children. We didn’t want to upset them because they were so young. They knew about the surgery, but we won’t mention that I had cancer until they’re older. I decided not to tell my parents until after I recovered from the surgery. I love them dearly and I didn’t want them to worry so much at their age.

“I told two close friends about my illness but didn’t tell another friend who recently lost a parent and some relatives to cancer. I also kept my condition hidden from my employees at work. I am a director of a small computer firm that services companies and I didn’t want news to get out that I was ill. That could be bad for business. Longstanding clients would say to potential customers, ‘Give him a break. Don’t go to him.’

“Now that the ordeal is over, I have come to recognize what I value in life. I have slowed my days down and have made more time for my wife and kids.”

Narratives

Support from the community

Diego is 19 years old and from a small town in Manitoba. He was diagnosed last year with cancer and underwent a unilateral orchidectomy and chemotherapy.

Diego was not overly concerned when his family doctor first told him that his swollen testicle could be due to cancer. He was 18 years old at the time, and he was concentrating on a basketball tournament he had that weekend. He did not believe he had cancer and wanted to wait for the opinion of a specialist first.

Diego didn’t tell his parents about the possibility of cancer because he didn’t want them to worry if the results were negative. He didn’t want anyone to worry about him as he preferred to take care of himself.

The next week, Diego had an ultrasound and the results showed that he required a unilateral orchidectomy and biopsy to confirm whether he had cancer. Before the surgery, Diego told his family and friends

about the suspected cancer. They were all very concerned.

Unfortunately, the biopsy of his testicle was positive for cancer. Diego then started immediate chemotherapy.

The treatment prevented him from doing many things. He didn't have the energy to play basketball or to spend time with friends on weekends. They would still come and visit him in his home, but he couldn't go out to the bars with them. He didn't feel like "one of the boys" anymore.

However, when he lost his hair during chemotherapy, he was touched when several

friends on his basketball team shaved their heads to show their support.

After the chemotherapy, his doctor found a lump in his abdomen that might have been a tumour or scar tissue. The doctor recommended that Diego go to Toronto for treatment.

His school board rallied together, to raise money for the trip. They raised \$8,000 for Diego, who became a mini-celebrity in the school district. Although Diego normally didn't want people to worry about his well-being, he felt uplifted by the number of people who lent a helping hand.

It's okay to cry

Josh is 27 years old and was diagnosed with cancer last year. He underwent a unilateral orchidectomy and chemotherapy.

When Josh was diagnosed with testicular cancer, he reacted with a lot of fear and anger. He didn't know that cancer of the testicle existed and was shocked to learn that someone like himself, who ate carefully and exercised regularly, would even be at risk.

He became depressed, since he thought all cancer patients faced a gradual decline and eventual death. Although the doctors explained the high survival rates and effective treatments available, he only managed to regain a positive outlook with the strong support of his family and friends. Without their support he claimed he would not have been able to handle his diagnosis. His family felt limited in the amount of support they could offer since they couldn't do anything to ease the pain and side effects

of the treatment. But to Josh, they played an invaluable role. They were a shoulder to cry on. His wife and newborn son lifted his spirits and motivated him to beat the cancer.

Josh had what he called a "stereotypical male approach" to emotions before his illness. He viewed crying as a sign of weakness. He was surprised to find himself crying frequently after his diagnosis, and that helped him. His wife would always be there for him, taking time off from work to help him after the surgery and to talk about what they were going through together. She was a pillar of strength for Josh. Occasionally they would have 'good crying sessions' together, especially at the end of a long period of chemotherapy, when they were drained from the treatment, the traveling, and the emotional strain. They would let it out of their systems and then cheer each other up.

Avoiding talk about cancer

Harold is 38 years old. He was diagnosed with cancer 4 years ago and underwent a unilateral orchidectomy and chemotherapy.

Harold's experience with cancer drew him closer to his family and friends. He felt most comfortable talking about the cancer with his brother and mother. His wife, on the other hand, didn't feel comfortable discussing his illness. Harold said that her philosophy was that "if you don't talk about it, you don't have to worry about it."

Harold wanted to communicate with others about his cancer. He found that sharing his story with co-workers and friends was a good coping strategy. Harold regretted that his wife didn't come to his appointments and now wonders whether there should be support groups for spouses of cancer patients.

Despite her lack of communication, Harold claimed that his cancer did not change their relationship of 15 years. He knew that she

cared for him deeply and was too afraid to talk openly about his illness.

In contrast, their six-year-old daughter was very inquisitive about Harold's illness. They went to the appointments together at the hospital and Harold would answer any questions she had regarding his cancer. Harold felt it was important to be honest with his child, and they have grown closer as a result.

Today, Harold is back to feeling like his old self. He believes that the most effective approach to overcoming testicular cancer is getting back to work as soon as possible, exercising, and spending time with family and friends. He says, "The more you keep yourself busy, the easier it is to forget about the cancer and to resume a normal lifestyle."

Interviews

Being open with others

Dennis is a 36 year-old, who makes his living as the owner of a bar. He was diagnosed two years ago and underwent a unilateral orchidectomy and chemotherapy.

I: How did your family react to your diagnosis of testicular cancer?

D: They were worried and wanted to help as much as they could. My parents drove in from out of town to

stay with my wife during my treatment. So that way, my wife didn't have to take time off work and I always had someone to accompany me to the hospital when I had chemo.

I: How did your wife deal with all this?

D: She was remarkable. I guess just being surrounded by people who you love, who are there to support you no

matter what happens, gives you a sense of security. I realized how fortunate I am.

I: *What about work?*

D: I own a bar, so I'm close to all my employees and some of the clientele. I told them a few days after the diagnosis what was going on. I had

people that could oversee affairs in my absence.

I: *Was it ever an issue telling them you had testicular cancer?*

D: No. I had no problem telling them what kind of cancer I had. I think it was actually beneficial to me in that it increased my ring of social support.

A personal matter

Ray is a 29 year-old accountant. He was diagnosed with testicular cancer two years ago and underwent a unilateral orchidectomy and chemotherapy.

I: *How did you cope with your cancer?*

R: I faced it head on and I did what I had to do to get cured.

I: *What role did your family play?*

R: My wife and parents were very supportive. Relatives would call me, but they didn't know how to talk to me about the cancer. I felt uncomfortable discussing it, especially at the early stages of treatment when I was still trying to deal emotionally with what was happening.

I: *What about work?*

R: I took 6 months off work, but that wasn't a problem since I had benefits.

I: *How did your co-workers react?*

R: They knew what I was going through, but they didn't pry. I don't like getting too personal. They just asked if everything was okay.

I: *Did you have any problem telling them what type of cancer you had?*

R: Yeah, I didn't tell them that the cancer was of the testicle. That was my own personal matter.

Fertility

The following information describes some of the changes in fertility that can occur as a result of testicular cancer and its treatment. It is followed by several narratives on the same topic.

What about my fertility?

Men may not be aware of their feelings on **fertility** until they have been asked directly. This is often because testicular cancer affects mostly young men, many of whom have not thought about having children yet.

Even if fertility is not a concern for you right now, it may be helpful to think about what you might want five to ten years from now. You may be in a different stage of your life when having children is more important.

How can testicular cancer affect my fertility?

Some studies have shown that as many as 50-60% of men with testicular cancer show less than normal sperm counts, even before treatment. The exact mechanism for this decrease in fertility however, is not known. It is still possible for these men to regain a normal sperm count after cancer treatment.

How can treatment for testicular cancer affect my fertility?

Reduced fertility is a frequently reported adverse effect of testicular cancer treatment. Your fertility will depend on the treatment you receive. Treatment for testicular cancer depends on the stage and type of the cancer. The main types of treatment are surgery, radiation therapy, and chemotherapy.

❖ **Surgery**

In general, the surgical removal of one testicle will not change a man's fertility. If both testicles are removed, sperm cells cannot be produced and a man becomes **infertile**.

Retroperitoneal lymph node dissection (RPLND) is an operation to remove the lymph glands at the back of the abdomen where the cancer may have spread. This surgery will not alter a man's ability to have an erection or an orgasm, but there is a small risk that the nerves controlling ejaculation may be cut. Without these nerves, the bladder neck does not close during ejaculation and the sperm may end up in the bladder instead of

exiting through the penis (a condition called **retrograde ejaculation**). This results in infertility and dry ejaculations.

To preserve fertility, surgeons have developed a type of retroperitoneal lymph node surgery called **nerve-sparing surgery** that has a very high rate of preserving the nerves and normal ejaculation.

❖ **Chemotherapy**

There are many different kinds of chemotherapy drugs, which can have minimal to severe effects on fertility. Chemotherapy decreases fertility by interfering with the production of normal sperm in the remaining testicle. Many men will recovery fertility within 3 years following therapy.

If you require chemotherapy and want to have children, you should strongly consider banking your sperm.

❖ **Radiation Therapy**

Radiation therapy has not been shown to cause significant fertility problems, since the treatment doses used for testicular cancer are low. Special protective devices are placed over the remaining testicle to preserve fertility.

Can I still have children after treatment for testicular cancer?

Yes, many men will regain their fertility after treatment for testicular cancer. However, this may take several years following treatment. **Sperm banking**, or the freezing and storage of sperm, is a logical way to guarantee post-treatment sperm availability after cancer treatment.

The cost of reproductive technologies, such as sperm banking, may be important when you are considering your fertility options. For example, it costs several hundred dollars a year to store a frozen sperm sample. When choosing to use the banked sperm, the physician will select the most appropriate fertilization procedure. Depending on the procedure, the cost may range from one thousand to over ten thousand dollars.

You should consider banking sperm even if you have a low sperm count. Thanks to techniques like **in vitro fertilization** (IVF), even a poor semen sample can achieve a pregnancy.

❖ ***In vitro fertilization:***

In vitro fertilization is a method of assisted reproduction that involves combining a man's sperm and a woman's egg in a laboratory dish, where fertilization occurs.

The procedure:

- Eggs are surgically removed (aspirated) with a needle from the woman's ovary.
- The eggs and sperm are mixed in a laboratory dish.
- After about 40 hours, the eggs are examined to see if they have become fertilized by sperm and are dividing.
- A fertilized egg is then placed in the woman's uterus.

The success rate of IVF is similar to that of normally conceived pregnancies.

Ask your doctor about banking sperm before you begin treatment. Banking sperm does not mean you have to use it in the future. It just provides an insurance that allows for the use of a reproductive technology in the future.

Some men also choose to adopt children after testicular cancer treatment.

Narratives

Timing can be everything

The following two stories about Donald (29 years old) and Tyler (28 years old) describe how chemotherapy can affect fertility, and the importance of fully exploring fertility options before treatment. Banking sperm may save a lot of worrying later on.

Donald was diagnosed with testicular cancer in his late twenties. His first emotions were shock and disbelief because he considered himself to be healthy.

When he learned that one of his testicles would need to be removed, Donald was immediately concerned about his fertility. He and his wife already had one child, but were hoping to have more.

Unfortunately, it was too late for Donald to bank his sperm since he had already started on chemotherapy. This was very frustrating to both of them, since they were unaware of the effects of the treatment.

Afterwards, Donald discovered that there were still some options available for him and his family, mainly a possible regain in his fertility after chemotherapy and adoption.

The couple remains in good spirits and focuses on Donald's recovery and their daughter for the time-being.

When Tyler was diagnosed with testicular cancer, he was living alone and did not have much social support. He was offered very little counseling or information about the disease, and his next appointment was still a month away. Tyler was devastated by the diagnosis and felt like he had been given a death sentence.

Fortunately, he discovered that education was a good way of coping with the situation. For instance, Tyler became more hopeful when he learned that testicular cancer had a high survival rate from the Internet and medical books.

Tyler was never really sure whether he wanted to have children, but the cancer changed all this. The cancer appeared when all of the hard work he was investing in his career was starting to pay off. Tyler realized

that all of his success would go to waste without having children to pass it on to. This saddened him and he realized, “You want to give it to somebody. Who else would it be other than your own kids?” As a result, he decided to bank his sperm before he began chemotherapy.

Tyler is currently recovering after chemotherapy. His sperm count is not yet normal, but he feels reassured because he banked his sperm. “It’s a great option to have.” With the banked sperm, he doesn’t worry too much about his fertility. Instead, he concentrates on his main goal—getting better.

Tyler watches his diet, exercises regularly, and monitors his health much more closely now. He feels there isn’t any limit to how far he can go. He plans to have three children.

When all seems lost

The following story is about a young man, Thomas (27 years old), who wanted to bank his sperm, but was unable to due to his health. He still found a way to fulfill his love for children through adoption.

Thomas had a particularly challenging experience with testicular cancer. Before his doctors figured out that he had testicular cancer, he was sick for a long time and had many visits to the hospital.

Thomas had severe metastases, which required him to begin chemotherapy immediately. Sadly, he was too sick to bank sperm. This has always bothered Thomas, since he will not likely be able to have his own children. He said, “I’d love to have

children and the chemo is going to affect that, but those are the decisions you make to survive.”

For the time being, Thomas’ main concern was to remove the cancer. Unfortunately, after his surgery, Thomas had a recurrence of the cancer and he had to go through another round of chemotherapy.

Although he is likely infertile, Thomas still gets his sperm count checked, mainly to help bring closure and deal with his change in fertility. He now realizes, “God will have a way. I can adopt a child. There are lots of kids that need parents and they deserve a chance.”

An unexpected surprise

The following story about Doug (35 years old) shows that fertility can sometimes be maintained after treatment.

Before Doug was diagnosed with testicular cancer, he and his wife already had one child and were attempting to have another child without much success.

After Doug's orchidectomy, he learned that he would also require radiation therapy. He was asked if he wanted to bank his sperm. However, since he and his wife had been infertile for several years, Doug figured that

having another child was unlikely and decided not to bank.

Much to the couple's surprise, Doug's wife became pregnant. The pregnancy gave Doug something to look forward to and helped him get through the radiation therapy. He said, "It took away a lot of stress."

Persevering with a positive attitude was extremely important to Doug; it allowed him to beat the cancer.

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Sexuality & Sexual Function

Changes in sexuality and sexual function experienced by some men with testicular cancer are explored here. The information is followed by several personal perspectives, narratives, and interviews with cancer patients.

How can testicular cancer affect my sexuality and sexual function?

Testicular cancer can affect a man's sex-life in several different ways, depending on the cancer itself, the type of treatment he has received, and his self-perception.

❖ **Surgery**

A unilateral orchidectomy does not permanently alter a patient's sexual function. However, the psychological impact of losing one or both testicles can affect sexual performance and satisfaction.

The patient has the option of implanting a **testicular prosthesis** surgically in his scrotum to restore a more "natural" look. When in place, it looks and feels like a testicle.

As described previously, retroperitoneal lymph node dissection (RPLND) does not affect the ability to have an erection or an orgasm, but there is a small risk that the nerves controlling ejaculation may be cut, resulting in a dry ejaculation.

❖ **Chemotherapy and Radiation Therapy**

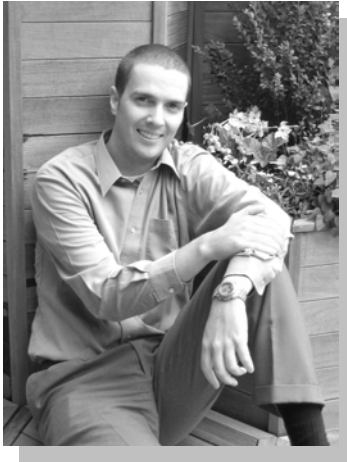
A patient may experience a loss in sexual desire (libido) due to fatigue during chemotherapy and radiation treatments. These therapies are not known to cause permanent damage to sexual function (i.e., erection, orgasm, ejaculation). Recall however, that chemotherapy can decrease a man's fertility.

Superimposed upon the effects of treatment on a man's sexual ability is his perception of himself as a sexual being. Some men feel less confident about their sexuality after losing a testicle. They may also feel less desirable due to prominent scars from a RPLND and may fear the reactions of a new partner. Married men commonly report fewer of these anxieties and usually report no change in intimacy after recovery. Some men claim that their sex lives improved after their experience with cancer, since they were able to communicate better with their partners.

The accounts provided below explore the various effects of testicular cancer on the sex-life of the patient.

Personal Experiences

No change in performance



Raymond is 26 years old and was diagnosed with testicular cancer five years ago. He underwent a unilateral orchidectomy.

“Being diagnosed with testicular cancer at age 21 was a scare. I hardly had any time to think about it. I had the surgery a week after my diagnosis. Before the surgery, I remember being anxious about not being able to have children. But a day or so before the operation, Dr. G explained that I could still be fertile with one testicle. That was reassuring! After the surgery, life went back to normal. My girlfriend and I enjoyed being intimate again and there was no change in the frequency or the enjoyment of sex.”

A change in self-perception

Tyrone is 27 years old and was diagnosed 3 years ago. He has had a unilateral orchidectomy, chemotherapy and lymph node dissection

“I was in the prime of my life when I was diagnosed with testicular cancer. You go around thinking you’re invincible and then your whole world gets turned upside-down when you hear the diagnosis. I thought that this was the end. It wasn’t until I started using the Internet and learning about the illness that I discovered it was a highly curable cancer.

“By the end of the treatment my energy levels were back to normal, but I felt different. My confidence levels were down. I avoided sex for a time, though I knew there was no change in my performance ability. Physically I could do the same thing. I just needed time to get accustomed to the large scar on my belly. Before the cancer, I was very sexually active with multiple partners, but now I take it easy.

“My confidence level has been building slowly. After the treatment I lost weight and started exercising regularly, so I feel better about myself. Now I’m thinking about the future, about meeting a partner and having a family.”

Back to normal

Jack is a 37 year-old and was diagnosed last year. He underwent a unilateral orchidectomy and chemotherapy.

“When I was diagnosed with cancer, I reacted with fear and anger. My aunt died from cancer a while ago and I had watched her steady decline. I had a far more curable and less aggressive cancer, but I didn’t know that at the time.

“I was also frustrated. I lead a healthy lifestyle, exercised regularly, and ate well. I found myself asking, ‘Why me?’ Despite that, I had a strong will to survive. I wanted to be there to raise my son. He was three months old.

“My wife was my main support throughout this ordeal. She would accompany me on all the appointments and was there for me emotionally, helping me relax and cope with my treatment. We have always been close. We talk to each other with ease and can express our needs. During the chemo, even though we couldn’t be as physical as we normally were together, we could still be intimate. Now we are able to have a full and regular sexual relationship again. I couldn’t be happier.”

Treatment and sexuality

Damond is 41 years old and was diagnosed two years ago. He underwent a unilateral orchidectomy, lumpectomy, and chemotherapy.

“Within a week of the diagnosis of testicular cancer, I had the surgery. Unfortunately, it did not end there. Six months later at a check-up appointment, the oncologist picked up a lung metastasis on a chest x-ray, so they removed the affected part of my lung. After a month-long recovery, I underwent a lot of chemo. During this time I was extremely tired and my activity was limited. I think my wife suffered too. It was hard on her. I also couldn’t make love to her because my energy levels were too low and I wasn’t able to hold an erection. I would still have urges, but I would be too tired to do anything about it. Most of the time, I wasn’t even in the mood.

“I wasn’t too concerned at the time, because my doctor told me that this was only temporary. I would regain function once the therapy ended. Sure enough after the chemo, our sex life was back to normal.”

Narratives

A noticeable change

Ramsey was diagnosed with testicular cancer two years ago, at the age of 47.

During surgery to remove the affected testicle, tumors in Ramsey's lower abdomen were found and treated with radiation. He found the radiation tiring and felt quite nauseous. He was not concerned about the impact the radiation had on his fertility because he already had two children and had a vasectomy. Unfortunately, the radiation treatment did not shrink the tumor and he needed chemotherapy.

Today, almost two years after the chemotherapy, Ramsey complains of a change in his sexual activity. He feels physically different when making love to his

wife. His erections are not as strong and do not last as long as they did before treatment. He also noted a change in his orgasms.

Ramsey has chosen to take Viagra to help deal with these changes. He says he has undergone only a physical change and not a psychological one.

Ramsey's wife is a physiotherapist and is very supportive. They are open with each other and joke about the need of a "Viagra boost". Despite the changes, Ramsey still enjoys sex but finds his reliance on Viagra somewhat unromantic.

A fear of losing intimacy

Adam was diagnosed with testicular cancer six years ago and underwent a unilateral orchidectomy and lymph node dissection. Now at the age of 26, Adam reflects on his experience with testicular cancer as a gay man.

After his cancer treatment, Adam found his sexual experiences less pleasurable. He attributed this change to his inability to ejaculate, due to a detached nerve from the node dissection surgery. Adam did not notice any other changes in his sexual functioning, such as holding an erection.

Since Adam had no interest in fathering children, he wasn't worried about losing his fertility. Instead, he worried about a decline in intimacy in his relationships.

After his treatment, Adam met his long-term partner, whom he called his "first love". Initially, he was not open about his cancer since he feared a negative reaction. When Adam eventually told his partner, he was very accepting and supportive.

Together, they have explored further ways to bond.

Interviews

An improved sex-life

Paul is a 23 year-old university student who was diagnosed last year with testicular cancer. He underwent a unilateral orchidectomy.

I: How did the surgery affect your sense of self?

P: Well my sense of self was the same. I mean I didn't feel less manly or anything. I think the biggest change is that I have become more open. I'm more of a man for what I've been through at such a young age.

I: In what way have you become more open?

P: I feel that I can communicate more now than before, which has been better for my relationships. As a result, I've also had more partners now than before the diagnosis.

I: Have you noticed any change in being with your partners?

P: In terms of sex? No. It didn't seem to slow my sex drive and everything is the same as before.

A rare and undesirable side effect

Henry is a 35 year-old chef, diagnosed with cancer 9 years ago. He underwent a unilateral orchidectomy and a lymph node dissection.

I: How did you cope with cancer?

H: It was quite the ordeal. At first I had a lot of fears around my manhood.

I: What kind of fears?

H: Around the time of the diagnosis, I got anxious and I couldn't hold an erection, which made me nervous. I started analyzing sex instead of enjoying it.

I: Are you still anxious about sex?

H: Yes, but in a different sense. I ejaculate prematurely, and I couldn't maintain erections long enough to satisfy my wife.

I: Is it psychological?

H: No, the psychological component is no longer there. That was gone a

couple of months after I healed from the surgery. The doctor had attributed it to the operation. Regardless, it's a purely physical change.

I: How does that make you feel?

H: It's tough. I have to use a device in order to perform sexually.

I: How is your relationship with your wife?

H: We actually separated 2 years ago.

I: How do you feel about a new relationship?

H: I had always been comfortable about my appearance with my wife, since she was with me when I went through the treatment. But I'm a bit nervous about what other women think, so I'm going to get a prosthesis to achieve a more natural look.

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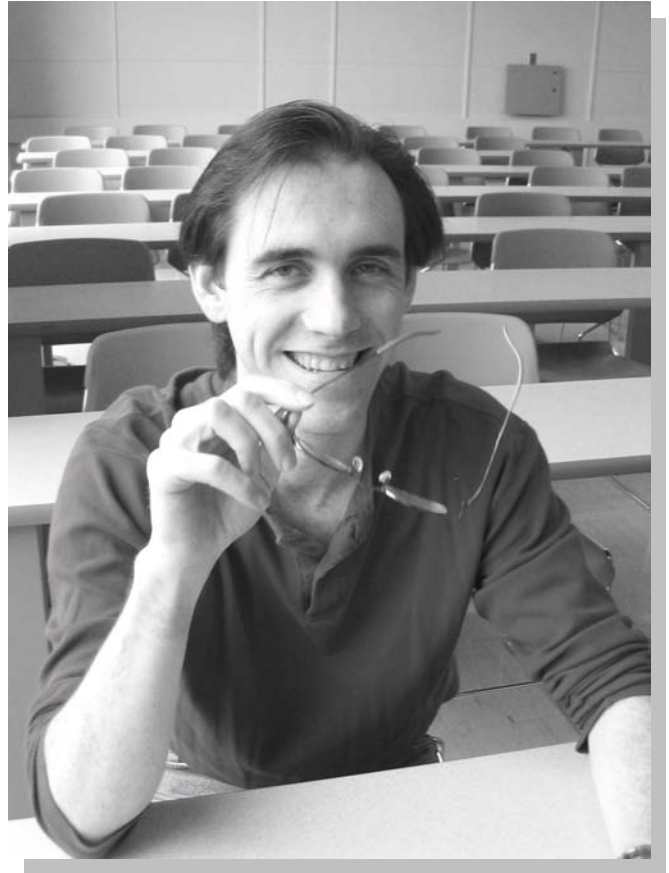
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There are many ways to deal with testicular cancer.



Perspectives

The reaction to testicular cancer varies among men. Some men view the testicle as forming an important part of their masculine identity and feel less confident about their bodies when losing a testicle to cancer. They may choose to get a testicular implant or prosthesis to help the scrotum appear normal. Other men do not view the testicle as defining their manhood and are not concerned by their change in appearance after an orchidectomy. An adjustment period is usually needed after the surgery to regain confidence and become accustomed to their new appearance.

If the cancer has spread to local lymph nodes, patients may require a lymph node dissection, which can leave a large abdominal scar. Such scars can be noticeable and therefore affect a man's perception of his body in different ways.

The following are a series of accounts that help to illustrate the spectrum of responses to changes in body image after treatment. They are written as personal perspectives and stories.

Personal Perspectives

A self-confident patient

Richard, an 18 year-old, was diagnosed last year with testicular cancer. He had a unilateral orchidectomy and chemotherapy.

“The past year has been a complete whirl-wind, first with the diagnosis and surgery and then with the chemotherapy. Now my life is back to normal. I'm in school and I'm playing sports again. I could convince myself that the whole episode had been a bad dream, if it weren't for the small scar and the obvious fact that I'm missing a testicle. But that doesn't bother me. None of the guys on my hockey team seem to notice or care. My girlfriend Sheila was very supportive and we have grown closer during the treatments.”

What makes a man

Brice, a 29 year-old, was diagnosed two years ago. He underwent a unilateral orchidectomy

“The whole idea that my manhood is inseparable from what I look like is absurd! It is not what is below the belt that defines you; it is your strength of character and the way you treat others in your life. There are men in peak physical condition that mistreat their partners or cheat on their wives. They aren’t whole or complete men.

“Going through testicular cancer has made me more of a man. What I have lived through has forced me to think about my life and about my relationships. I feel stronger and more mature.”

Getting back into the family routine

James, a 42 year-old, was diagnosed last year. He had a unilateral orchidectomy and radiation therapy.

“As a consultant and father of two boys, I am a very busy man. Cancer was the furthest thing from my mind the day I visited my family doctor due to a swelling in my right testicle. Treatment in the following weeks went by quickly, and thankfully I could swing back into my normal routine less than a month after treatment. Nothing really has changed. My sons (9 and 11 years old) joke about my missing testicle. One day my wife and I will tell them about why I had it removed, since they are at increased risk of getting cancer as well. I’m glad that they can make light of the surgery, as my family’s sense of humour has helped me greatly.”



Narratives

Fears for the future

Simon is a grade 12 student who was diagnosed last month with testicular cancer. He is currently recovering from a unilateral orchidectomy and awaiting results to see if he requires further treatment.

Simon has tried his best to hide his cancer from his friends and rarely talks to his

family about his condition. He wishes to maintain a sense of normalcy and feels that by not addressing his illness, he limits the impact it has on his social life. He is embarrassed about having lost a testicle and refers to himself as a ‘Cyclops’.

Simon has had two girlfriends in the past with whom he was never intimate. He worries about future relationships, such as whether the girls will notice and what they will think. He says he feels a bit less like a man but believes that if he does not tell

others about his surgery, he will protect his image.

Simon has requested a counseling service at the hospital to help him express his fears and explore his approach to his illness.

Humour heals

Nathan was diagnosed with testicular cancer at the age of 22. He was a third year university student and taking a full course load.

The surgery Nathan underwent to remove the affected testicle interrupted his term but did not prevent him from passing the semester. Nathan would describe himself as a “glass half full kind of guy”. A positive outlook has helped him to cope with the diagnosis and treatment. His close friendships and family ties have also helped him to handle the stresses of cancer.

He has found that humour helps in dealing with the change. He and his friends joke about his “lack of a full set”, which makes him feel like anybody else in his close circle of friends since they poke fun at their differences.

Nathan claims that he often has to tell his girlfriends about the past surgery, since they never notice, even after being intimate. Nathan says his relationships have not suffered.

A Final Story...

When we interviewed Peter, he was delighted with good news he had received from the doctor. He explained, "This is my ten-year check up. Ten years in remission!" Peter was diagnosed when he was 19 years old with metastatic testicular cancer. He had surgery and a testicular implant, followed by chemotherapy.

Pre-diagnosis delays

Peter had no family history of cancer and recalled, "I never had the mumps, measles, or chicken pox. I never had a broken bone, stitches or any other problems."

It took Peter nine months to finally see his family doctor, even though he had been seeing the same doctor all his life. "I saw the lump and I did nothing for nine months. For nine months! I know it was bad. I knew it was wrong, but I was too shy to see a doctor. It wasn't until the cancer had spread and my testicle was the size of a tennis ball that I finally went to see the doctor."

Peter's family doctor immediately referred him to a urologist. However, the urologist was fully booked for eight weeks. By this time, Peter was very frightened and took it upon himself to find a more readily available urologist. "I opened up the yellow pages and started calling doctors, and I finally got a hold of one. I credit the secretary for saving my life. I told her, 'Look, these are the facts, and I know it's bad. I need to see the doctor.' And she said, 'Hang on. I'm getting the doctor.' When I spoke to the doctor, he told me to visit him the next morning."

"I got sick, I got strong, and I got focused."

Peter's Story

Peter reflected on his pre-diagnosis delay and shook his head. "It was so clear. The testicle was literally the size of a tennis ball. It was six by six centimeters. It was huge. It was black. It didn't hurt though."

Diagnosis, treatment, and growing up

Peter had surgery and a silicon prosthetic implanted within four days of his diagnosis. He recalls having a very difficult time with chemotherapy, "I had every side effect I think I could possible have. I was allergic to the anti-nausea drugs and so I couldn't take anything for the nausea. I had broken blood

vessels in my eyes. My weight dropped to 116 lbs. I was so sick they had to weigh me in a wheelchair." Peter continued, "People have always said, 'Oh you're so brave' and stuff. I've always said you don't have much of a choice. You either give up or do what the doctors say you have to do. It's not about being

brave. It's about your health, so this is what you have to do."

Peter says his experience required him to mature very quickly. He recalled, "I was pretty much a child in college and then bam, bam, boom, everything collapsed and I was forced to grow up. I was a very different person before this started, but I was also very late with puberty and everything else. I was 17 when I started college. I was a very late bloomer, so this experience pushed me into adulthood."

Talking to others about illness

After his first urologist appointment, Peter went home and told his parents about the cancer. Peter felt that he had to be strong for his mother's sake, explaining that his parents were well into their sixties when this happened. His mother's initial reaction was one of denial. She called him a hypochondriac and then burst into tears. "I was like, don't worry mom. We'll get through it. And she asked the doctor if it was because I drove a motorcycle. She thought that the vibrations of the motorcycle could have caused the cancer. The doctor and I both laughed at that comment."

In the interview, Peter recalled how easy it was for him to tell his classmates in college about his illness. "I had a very close circle of friends at college. We all had the same classes. When I came back to school, I already had my surgery. I told them what happened and that I was starting chemotherapy. I told them I would have no hair in three weeks. They were all very good and supportive."

"Three weeks later, my hair came out and I just shaved my head. I shed for one day, and I shaved my head."

As with many cancer patients, humour was an important way of coping with cancer for Peter and he developed a "wicked" sense of humour to deal with the unexpected reactions of others to the cancer. For instance, he said, "This shaving my head all happened on the weekend. When I went back to school on Monday morning, a girl who was sitting behind me burst out laughing and said, 'What is that, fraternity initiation?' And I turned around and said, 'No, it's cancer', and turned back and faced the blackboard. I didn't mean to hurt her feelings, but once she had said it, she put her foot in her mouth and she was pretty

mortified. So I turned around and I said, 'Don't worry, it was a good guess.'

Peter had an easier time telling his long-time childhood friends. They had so many shared experiences over the years that "it was easy to be free with them". He said, "Any joke they would make, I would make, and there was no offense. They always made it clear that I wasn't taking any offense at what they said. I always knew my friends had good intentions."

Starting a relationship

Peter fell in love when he was 24 years old, after being in remission for five years. He bought a house the next year and left home to live with his new partner. As Peter put it, "he was my first love." Peter contrasted how difficult it was for him to share the details about his cancer with his new partner compared to his school friends. "I had never hidden it from anyone, but these were just friends and acquaintances and teachers and all that stuff. There was never the love issue. That was difficult."

At first Peter didn't give his partner all the details of his illness, even though his silicone implant was no secret. Peter said, "I didn't tell him right away. I gave him the highlights without saying the cancer word. It wasn't until we'd been seeing each other for about six months that I told him that it was because I had cancer." Ultimately, he was accepting as well as hopeful about the cancer, and they have been together for five years.

A life-changing experience

Coping with cancer has been a life-altering experience for Peter. He concluded, "I bought my first house when I was 25. That's an indication of how cancer just smartened me up. I've focused on my studies, focused

on my future and been geared toward financial happiness and independence. And that's not the way I was dealing with life at

19. I got sick, I got strong, and I got focused.”



Glossary

Adjuvant therapy	Treatment that is added to increase the effectiveness of a primary treatment. In cancer, adjuvant treatment usually refers to chemotherapy or radiation therapy after surgery to increase the likelihood of killing all cancer cells.
Benign tumour	A non-cancerous or non-malignant tumour.
Cancer	The uncontrolled, abnormal growth of cells.
Chemotherapy	The treatment of disease by using chemicals (drugs).
Conception	The onset of pregnancy.
Cryptorchidism	The failure of one or both of the testicles to descend.
Diagnosis	The act of identifying cancer from its signs and symptoms.
Fertility	The capacity to conceive and have a child.
Five-year survival rate	The percentage of patients who have survived at least five years after diagnosis.
Germ cell tumour	A tumour that develops from cells producing sperm or eggs.
In vitro fertilization	A method of assisted reproduction in which a man's sperm and woman's egg are combined in a laboratory dish, where fertilization occurs. The resulting embryo is transferred to the uterus to develop naturally.
Infertile	The inability to have a child.
Lymph nodes	Small, bean-shaped organs located throughout the lymphatic system. The lymph nodes contain special cells that can trap cancer cells or bacteria that are traveling through the body in lymph fluid.
Malignant tumour	An abnormal growth of tissue that can invade nearby or distant tissue.
Metastases	Cancer growths that started from cancer cells in another part of the body.
Nerve-sparing surgery	A type of retroperitoneal lymph node surgery that has a high rate of preserving the nerves and normal ejaculation.
Non-seminoma	Testicular cancers that arise in special sex cells called germ cells. Non-seminomas include embryonal carcinoma, teratoma, choriocarcinoma, and yolk sac tumour.
Oncologist	A doctor who specializes in the diagnosis, treatment and rehabilitation of individuals with cancer.

Orchidectomy	Surgical removal of the testis.
Prognosis	The likely course and outcome of cancer.
Prosthesis	An artificial substitute for a missing body part.
Radiation therapy	Treatment with high-energy laser beams.
Retrograde ejaculation	Discharge of semen backwards into the bladder instead of forward through the penis.
Retroperitoneal lymph node dissection (RPLND)	Surgical removal of the lymph glands at the back of the abdomen where cancer may have spread.
Retroperitoneal lymph nodes	Lymph nodes located at the back of the abdomen, near the kidneys.
Risk factor	An occurrence or characteristic that can increase the chances of getting a particular disease.
Secondary testicular tumour	Cancer that has spread to the testicles from other parts of the body.
Seminoma	A cancerous tumour of the testicle thought to arise from primordial germ line cells, usually occurring in older men.
Sperm banking	The freezing and storing of sperm for future use.
Stage	The size of a cancer and the extent to which it has spread from its original site to other parts of the body.
Stromal cell tumour	A tumour that arises from the connective tissue cells of the testicle.
Tumour	An abnormal mass of tissue that results from cell division that is uncontrolled and progressive, also called a neoplasm. Tumours can be either benign (not-cancerous) or malignant (cancerous).
Tumour marker	A substance in the body that usually indicates the presence of cancer.
Undescended testicle	<i>See cryptorchidism.</i>
Unilateral orchidectomy	The surgical removal of one testicle.
Urologist	A doctor who specializes in the diagnosis and treatment of diseases of the urinary tract and urogenital system.