

The Oneballer's

# Guide to Ball Cancer







# THE BASICS

Things are happening fast, and it's totally normal to freak out. To help, we need to first address some of the thoughts and feelings you might be having:

- 1. THIS IS NOT YOUR FAULT! Very smart doctors with many prestigious degrees still don't know the cause of testicular cancer. Don't go beating yourself up about it, and don't waste time trying to come up with various tin-foil hat worthy theories. Many men within the vulnerable age range of 15-35 do not know that they are at risk. Don't beat yourself up. You took the proper steps once you noticed something on your testicle and sought medical assistance after the fact. There wasn't much more you could have done.
- 2. AM I GOING TO SURVIVE THIS? There is no doubt that cancer is serious, but thankfully testicular cancer is highly curable. It is the most common primary cancer for men between 15-35 and 1 in 250 men are diagnosed every year with this cancer.
- 3. I'M LOSING A BALL?! You have, will or could have had one ball. You are not alone. In fact, some patients worry about changes to their bodies after surgery. The remaining testicle will pick up the slack and ensure that physiologically nothing changes. If you do not like the idea of having one testicle or are struggling with body image, then many different types of prostheses are also available too! Consult your doctor for more information around prostheses.
- **4. WHAT ABOUT MY SEX LIFE?** Survivors live long and happy sex lives after their treatment. The remaining testicle produces enough testosterone to keep you in the game, just like before so don't delete your Tinder or Grindr just yet!
- 5. WHAT ABOUT HAVING KIDS? Firstly, you have a backup ball left to produce sperm! This often means business as usual. You'll likely want to freeze an army of "Winter Soldiers" prior to chemotherapy if that is applicable to you just in case. This will allow you to have kids through things like In-vitro Fertilization and Artificial Insemination.





# THE JOURNEY AHEAD

With the basics out of the way, now it's time to lay down some knowledge, and give you an idea of what's ahead. Everybody's journey is different, but here are some of the steps you might take along the way. Please note that no two patients are alike. Some of the treatments below may apply to you, while others will not. For example, if your cancer is confined just to your testicle, all you may need is surgery. Your oncologist and surgeon will discuss any relevant treatments with you. Please feel free to reach out to your oncologist, surgeon and family doctor for any additional questions.

**Fertility Clinic - Sperm Bank Deposit:** Not everyone's cancer journey happens in the same order, but one of the first stops you will make is to the fertility clinic if you get chemotherapy. Sadly, your future kids will start to leech money off of you early, as this deposit will set you back about \$750 for the first deposit, and \$250 yearly after that. Don't worry, financial assistance is available. Check out the "Life and Finances" section further down! Oneball encourages that patients getting chemotherapy bank their sperm no matter of the cost. A patient may be 15 and have not aspirations of a family yet, but sperm can be used in the future for artificial insemination and IVF, please speak with your doctor.

**Surgery:** There are two main types of surgery you may encounter early in your journey – an orchiectomy or a lymph node dissection. Other surgeries may be necessary depending on where your cancer may have spread. Your family doctor, oncologist, and surgeon are the best resources to ask more questions, but here is a high-level rundown:

• Orchiectomy (removal of the testicle): This is the removal of the testicle which is where the cancer originated. They go in through the abdomen to remove the infected testicle.

**Chemotherapy:** For cases where the cancer has spread to different organs (most commonly the intraabdominal lymph nodes) or where certain tumor markers (AFP & BHCG, also known as biomarkers) begin to rise chemotherapy will be necessary. The most common chemotherapy regimen typically consists of 3-4 cycles of Bleomycin, Etoposide and Cisplatin. The majority of patients respond very well to chemotherapy. Your oncologist may suggest alternative chemotherapy agents if further treatment is necessary.

**Retroperitoneal Lymph Node Dissection (removal of the lymph nodes):** Lymph node dissections may be required if there is still some residual enlargement of the lymph nodes seen on imaging after chemotherapy has finished. It is an invasive surgery, requiring surgical removal of affected lymph nodes.

**Follow up Appointments:** After you have finished your active treatment, you will be followed by an oncologist for several years (5+). It is important that you attend the follow-up appointments to ensure that the cancer is found early if they do recur. Follow-up testing will consist of CT scans and routine





blood work to look at the BHCG and AFP. The appointments will initially be every 3 months after finishing treatment and eventually spread further apart after the first few visits.

### **PREPARATION**

You have a lot going on - mentally and physically. Below are some tips and tricks for both your mind and body that can help as you're going through some of these challenges. The information outlined below is based on the account of a patient who went through three cycles of chemotherapy.

### **MIND**

**Talk:** Whether it's to a loved one, a psychologist, or writing in a journal (maybe even this one!). Cancer is intense and expressing what you're feeling and what you're struggling with can make all the difference in improving your outlook. Being vulnerable isn't a weakness, strangely it's the first step to being stronger, and becoming the victor rather than the victim when it comes to the mental game of cancer.

If you need to talk, there are options available specific to testicular cancer. Talk to your doctor or nurse about what resources are available, such as the psychosocial oncology department at your cancer center (oftentimes at no cost to you).

**Sex and Masturbation:** Yes, we're putting this in the "mind" section. Don't question it – it really can be a stress relief. Desire and libido may be one of the first things to disappear, and one of the last to return following treatment, but don't worry, you can live a long a happy sex life. The important thing is to listen to your body and take small steps. Try masturbation, test it out once the stitches have healed along the abdomen. Think about sex (a novel concept I know) and motivating yourself to have sex. If you have a partner, and if you're ready, start exploring intimacy with them too, and be honest about how you're feeling and what you're thinking. If you do have intercourse and sex wear protection, as the bleomycin chemotherapy drug can contaminate sperm. If you're still experiencing challenges, talk to your doctor about this.

Your sperm may be affected by chemotherapy or radiotherapy. Therefore, if there is any chance of causing a pregnancy, you must use barrier contraception, such as condoms, during chemotherapy or radiation therapy, and for a period of time after that. (Please consult your doctor about the duration of contraception needed as it varies according to your situation)

### **CONCEPTION**

Fertility usually returns to normal some months after chemotherapy, but for some men, it may not recover. Therefore, sperm banking is crucial if you are considering having children. There are many treatment options for infertility (including artificial insemination and in-vitro fertilization), please consult your doctor.





Mindfulness and Meditation: Mindfulness has been implicated to be extremely important in helping recovery from treatment both physically and psychologically. Being mindful or meditating doesn't have to be a yoga retreat in the mountains of Peru in order to be effective – but it can be that too. Mostly, it's about finding moments to give your brain space – sometimes it can be doing a repetitive task like washing the dishes or mowing the lawn, or simply going for a walk with the dog in the park and clearing your mind.

### **BODY**

**Hair:** Sadly, treatment may result in the loss of hair - and not just your head. Everyone responds differently, but you may see loss of beards, eyelashes, and hair elsewhere on your body. Don't panic. That being said, you might want to consider shaving your head before the start of chemotherapy. Seeing it fall out can be unsettling.

**Sleep:** Sleep is one of the most important things you can do to keep strong. You might experience uncomfortable or restless sleeps, but here are some quick tips:

- 1. Have a bath before bed
- 2. Have a second sleeping arrangement
- 3. If you're restless, get up and do a boring task until you're drowsy
- 4. Establish a sleep routine
- 5. If an overnight bottle (or "chemotherapy pump") is part of your chemotherapy regimen, find a safe place to put it at night that is comfortable so that it doesn't tangle or fall.

**Diet and Hydration:** Staying hydrated in general. Good hydration helps you keep up your strength and energy, and hydration is especially important if you're vomiting. One strange thing that can happen during chemotherapy is that it can change how food tastes, and keeping it down might not be easy. Stick to simple foods and a balanced diet. Consult your doctor if you need a referral to a dietician to help make a plan (again, often at no cost).

**Exercise:** Do what you can. Light activity can be very helpful in the healing process. It's okay to feel like crap and do nothing but play video games. We get it. Listen to your body and ask your doctor about the right fit for you.





# LIFE AND FINANCES

Unfortunately, real life doesn't stop, even if cancer rears its ugly head. Most importantly though, **KEEP ALL OF YOUR RECEIPTS!** Parking at the hospital, medications, all of it. There may be several resources available to you to cover certain expenses and make sure financial stress doesn't layer on top of your cancer stress.

As part of your cancer team, you will have access to social workers who can help you navigate all the life and financial challenges that you may face along your journey. This is not a comprehensive list, but here are some things to ask and think about:

**Work:** There may be options around short- and long-term disability coverage. Ask your HR representative for more information.

**Insurance:** A number of resources may be available to you to cover your costs, including Employment Insurance during leaves of absence

- 1. Parents: Check with your parents to see if you're still under them (25 and under may still be considered a dependent)
- 2. School: Check with your school to see if you have opted into their health policy. You may have some coverage!
- 3. Work: Checking to see what coverage you have through work!
- 4. Private Insurance: If you have private insurance, be sure to talk to representative on the best way to help you get the most coverage!

**Employment Insurance (EI) Sickness Benefits:** You may be eligible for some benefits here. Check out www.canada.ca/en/services/benefits/ei/ei-sickness or call 1-800-206-7218 for more information (we'd recommend pressing zero to talk to someone... it's faster).

**Bank/Debt:** See what coverage you might have through things like your mortgages or lines of credit. If money is tight, you can discuss payment plans with them too.

- 1. Credit Protection: Review your credit protection coverage on all your credit products: loan, lines of credit and mortgage. Most banks offer critical illness or disability protections that can lessen the burden if you accepted the coverage.
- 2. Skipping Payments: Ask your bank about their policy on skipping credit product payments.

  Most banks offer flexibility for a few payments if you are unable to make payment for unexpected





expenses. It may not be necessary immediately, but you can benefit further down the road.

- 3. Automatic Payments: Set-up automatic minimum payment authorizations on your credit cards and line of credits. Forgetting even a few payments can damage your credit.
- 4. Online Banking: In cases where you may be unable to attend the bank, set-up online banking and phone authentication services with your bank. You will be able to complete almost all transactions needed like address changes, bill payments, investment purchases and sales, transfers, etc..
- 5. Statement of Accounts (for financial assistance): Ask for a financial statement of all accounts held at the bank and store it somewhere safe. This is practical if ever someone else has to help manage your finances. Some of this might be necessary in order to access various forms of financial assistance.
- 6. Build a relationship with someone at the bank: Create a relationship with someone at the bank and keep returning to that individual. They will know your story; it will save a lot of time explaining your situation and they will be able to have a better picture of your situation.

**Financial Assistance:** It's hard enough for most people to pay for the basic amenities on a low income, imagine how hard it would be if you're young man who is having to pay thousands of dollars for live saving medication?

The common first major financial transaction a man has to prepare for is the initial deposit and year of storage for their sperm at the regional fertility clinic. These are private corporations with no provincial or federal assistance available. The first payment is around \$750 and Oneballers may need assistance with the initial payment, which is why there are several financial assistance programs that may be applicable to you and your situation. Oneball has financial assistance available as well!

Oneball offers the **Davis Falnuik Financial Assistance Fund**. This is a first of its kind in Canada with all transitions being completely digital. If you, or a Oneballer who needs help, please contact <a href="mailto:support@oneball.ca">support@oneball.ca</a> or get in touch with Tom Baker Cancer Centre's Department of Psychosocial Oncology at 403-355-3207.





# THE BASICS FOR PLUS ONES

Hey you! Partners! Family! Friends! You're a key part of your loved one's cancer kicking team, and we need to make sure you, the Cancer "Plus Ones", are taking care of yourselves too. Here are some tips on how you can help your loved one, and help yourself:

- IT'S OKAY TO STRUGGLE: You're allowed to struggle, mentally and physically, as a caregiver. Embrace being vulnerable and ask for help if you need it. Practice self-care consistently and don't feel guilty about taking some time for yourself. Schedule time to reflect on your journey with your loved one, how you are doing and what you need. Burn-out is real and it can make this journey way more difficult.
- **2. YOU ARE NOT ALONE:** Whether it is family members, friends or other caregivers, embrace having a support system for you and the person you're caring for.
- 3. COMMUNICATE AND SET BOUNDARIES: Create a game-plan with your loved one to determine what information is shared and what is kept private. Communicate regularly to ensure you are on the same page (there are important decisions that are made during a cancer journey!) Being a caregiversometimes just means agreeing that this situation sucks and being a listening ear for your loved one.
- **4. TAKE ADVANTAGE OF PSYCHOSOCIAL ONCOLOGY:** The mental health resources available for testicular cancer patients and their caregivers through psychosocial oncology are provided at no cost and are available at any stage of your journey.
- 5. STAY ORGANIZED: Have a dedicated place for all of the paperwork that you collect (there's a lot!) and keep any receipts you gather together. Making a habit of writing appointments on a specific calendar that is checked daily limits forgotten commitments and ensures everyone is on the same page.
- **6. KNOW YOUR HEALTHCARE TEAM:** Build relationships with your loved one's medical team. Don't be afraid to ask questions; they're there to help you through!
- 7. ASK FOR HELP: There are several resources available to you and your loved one that can make the journey less overwhelming. Asking your doctor is always a great place to start! A list of external resources can be found at the end of this guidebook.





# WHO ELSE CAN HELP?

**Family Doctor:** All matters related to your cancer journey can be brought to the attention of your contact at TBCC but all other matters should be brought to the attention of your Family Doctor. They're going to be with you throughout your cancer journey.

Get a family doctor if you do not have one as you will be required to have one before being discharged from Tom Baker Cancer Centre at the end of your journey. Have your Family doctors number on hand for all matters.

# Tom Baker Cancer Centre / Holy Cross - 403-476-2701

This is your point of contact within the AHS system for all things related to your cancer journey. Your medical team can be contacted via phone or email during working hours.

# Holy Cross, Psycho-Oncology Department - 403-355-3207

This is a free service covered under AHS. If you or your support network need to speak to someone about what you are going through, this is the place to go.

# Oneball Charitable Cancer Organization - support@oneball.ca

Oneball, in a word, is ballsy. We fund life changing research, we help pay the various expenses not covered by our health care, and we provide critical information in a relatable way – like talking to a friend. We've got your back for anything you and your loved ones needs in navigating the testicular cancer journey.

# Health Link Alberta - 811

Health Link can provide you were direct contact to AHS Health Care professionals who can provide important information about your medical questions.

# Canadian Cancer Society Transportation Service - 1-800-263-6750

Volunteer drivers provide travel assistance to and from cancer-related appointments, and also provide assistance accessing funding for public transportation options.

# Mental Health Helpline - 1-877-303-2642

Provides toll-free, confidential, 24/7 telephone service, which offers help for mental health concerns for Albertans. They also provide information and referrals to mental health programs and services.

# Wellspring Calgary - 403-521-5295

Wellspring programs include group movement and meditation classes, expressive therapies,





educational speakers and workshops, energy work, and a discussion series. A lending resource library provides a comprehensive range of information on the social, emotional and psychological aspects of cancer. A variety of external cancer support groups also hold meetings at our Wellspring community.

# **LIFE AFTER CANCER**

CANCER IS A JOURNEY, AND THE DISEASE IS JUST ONE PART OF IT.

Check us out for help navigating the next steps: www.oneball.ca

