

**male
care**



Malecare is America's leading men's cancer survivor support and advocacy national nonprofit organization.

Malecare sets the standard for best practice of patient peer to peer support. We push the limits of technology to create personalized cancer information delivery. We design great projects for communities ignored by commercial and mainstream organizations. Our goal is to help men and their loved ones live longer and happier lives.

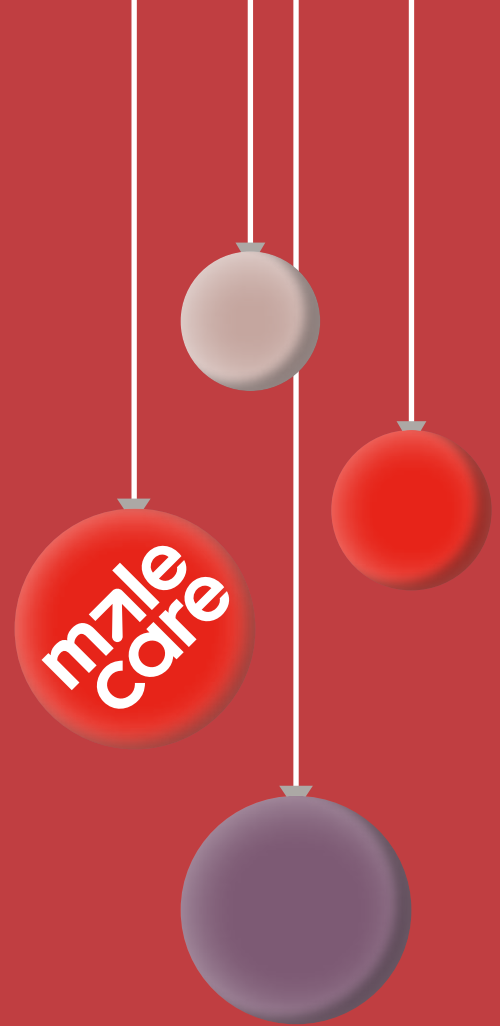
Our "business model" is begging. We do our work, day to day, with resources donated by people like you. We don't raise money with road races, selling ads to corporations or by steering patients to particular hospitals or treatments.

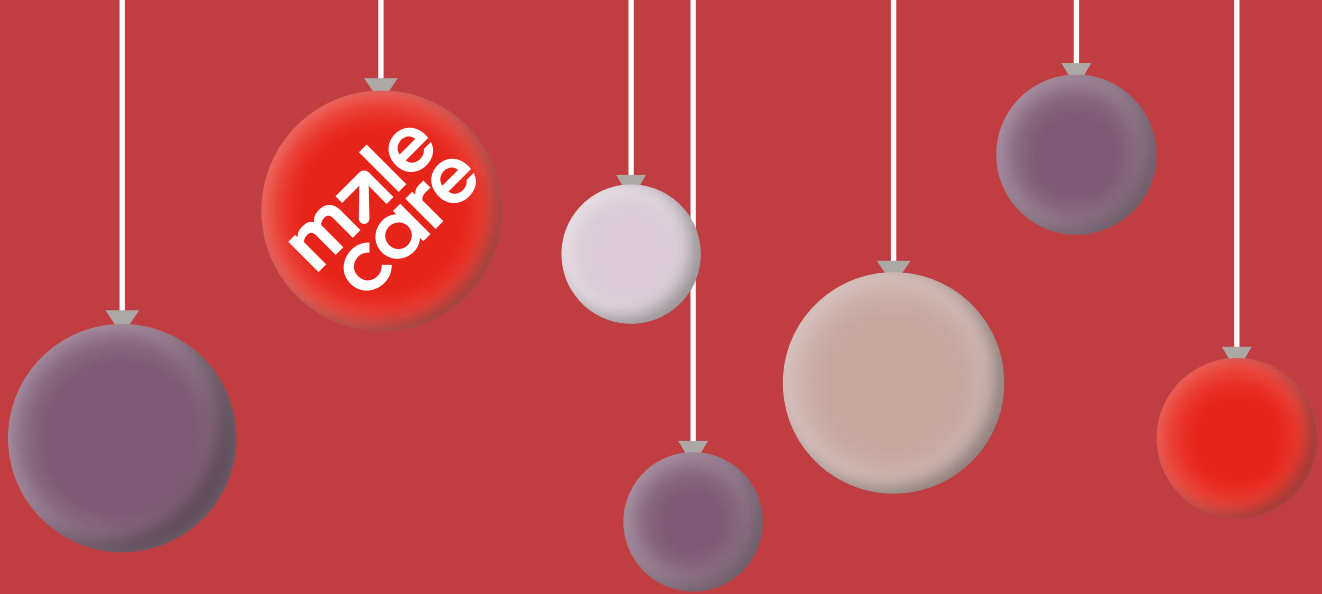
Please support our work with a charitable donation at www.malecare.org/donate

This year, we have created a holiday booklet of helpful hints and teachable stories from Malecare supporters. This booklet is free for you to share. Please feel encouraged to email this PDF to your friends and family, as validation of your brotherhood and sisterhood in our mutual fight against prostate cancer.

"It's so hard, isn't it?" he said. "I think there are many people who bring a whole lot of baggage from their past and a whole lot of anxiety about the future to the present moment. What's so great is that people can be in relationship with each other for the now."

Mr. Rogers





I lost my Dad to prostate cancer because he was afraid. He believed that most men don't need regular PSA tests, and that a benign biopsy result was good for life. My Dad was a talented research engineer; I am a biologist. My Dad was diagnosed at an advanced stage 4. He survived for another three years. My entire family and I will miss him forever.



If you need more time choose a treatment, ask your Doctor for an anti-androgen called bicalutamide (Casodex). It's just one pill a day, and you can stop if the side effects became an issue. I felt like I was taking action while giving me time to learn about the other treatments.



In January 2016, I was diagnosed with Stage 4 prostate cancer. An MRI showed cancer had metastasized to seven places in my spine. My PSA was 99. I was admitted to a hospital in Nairobi, Kenya, where I lived.

My urologist recommended castration, saying it was the gold standard treatment for Stage 4 prostate cancer. He put it this way, "We need to shut down the factory," that is, shut down the production of testosterone. This procedure is very controversial and quite culturally sensitive in some parts of the world, such as Africa and the Middle East. I am an American, and the response from my wife was, "I would rather have half of you than none of you."

After the castration surgery, I received 20 rounds of radiation therapy for the seven tumors in the spine. I continued with 50 mg of Casodex, which I am still taking. My PSA has remained at .002 for the past three years. When I visited the US in May 2016, I saw a clinical oncologist. She said the treatment I received in Kenya was excellent, and it could not have been any better.

I'm the wife of an aggressive prostate cancer patient. Caregivers are often left in waiting rooms, without any offers from the staff to go further than the general wait lounge. My husband always includes me in introductions to the health team and makes it evident that he and I are in this together. We realize there are limits, i.e., radiation therapy spaces, but by being as near to my husband as I'm able to make this experience a bit less foreboding.



After been diagnosed with PC (stage 2), I've started a process that not only has taken me into a physical and emotional but also into a spiritual roller-coaster as well.



Almost two years after surgery, I have a minor issue with incontinence and very significant ED. Thank goodness for the vibrator.



Your biopsy results – the Gleason score – forms the basis for choosing treatments...it's important to get as accurate an understanding as possible, and that is only possible after at least two different pathologists read and analyze your biopsy slides. I recommend getting a second opinion from your biopsy slides from Johns Hopkins. (Mention "Malecare" in your request) It was only about \$200, covered by Medicare, and came back within about a week after submission.



Prostate cancer is going to challenge everything to your absolute core. Find a deeper connection with life itself, and the end of life. Spend precious moments with loved ones and hug them as much as you can.

I was diagnosed with Stage 4 PC in February 2018, after breaking my hip. Genetic testing determined that I had a BRCA 2 mutation and an ATM variant. After several months on Zytiga, I became castrate-resistant, and my PSA began rising again.

Since I met two basic requirements, castration resistance, and BRACA 2 mutation, I was prescribed Lynparza/Olaparib, a Parp 2 Inhibitor. My PSA went down and is now at 0.3.

My advice to anyone just being diagnosed - do genetics testing. If you have a mutation, find an oncologist who specializes in treating such patients.



You have to quarterback your own treatment. You are given choices, not remedies. Live with the consequences, enjoy life, and move on.



I am a 73-year-old gay man with a wonderful younger partner. I had radiation therapy in 2015, but they didn't get it all, so I have been on Lupron ever since. My PSA has remained low, but the side effects include hot flashes, disturbed sleep, and zero sex drive.

I have been out and sexually active since the early 70s, so the loss of libido was a big shock. I read about having a penile implant. I talked with guys and decided to have it done. Best decision since my cancer treatment. The first month of recovery was not a picnic, but since, it has been all I could want. In fact, when my urologist asked about how I was adjusting to it, I told him that my partner gave him an A+ for his work! Lol. I can't cum, but I do still have a form of orgasm, and it's great to have an erection any time and for any amount of time I want!



Chemo wasn't bad (worst was fatigue), but side effects were horrible. Worst was lymphedema (of both legs, which itch, get irritated, swell, and get 'hard'); have to wear expensive compression garments the rest of my life. Do that or run the risk of growing protein appendages (gross photos available on the internet).



I was diagnosed at stage 4 in January 2017 and immediately went on Lupron and will be on for life, according to my oncologists. The worst parts of Lupron/ADT for me are hot flashes and fatigue. I suffered through two and a half years of hot flashes before beginning Estrogen patches (.05mg dose). Two months later, my hot flashes totally disappeared, making my life 100% better! I would encourage anyone suffering hot flashes to consult your oncologist. Under my insurance plan, my cost is only \$34/month. There is the risk of blood clots, but I am willing to take that risk.



Don't take any PSA on its own face value. They may vary from day to day. Look for trends. Graph paper is your new best friend.



Talk to a urologist but also an oncologist and radiologist to get their opinions on treatment options.



Don't jump to conclusions and cross bridges before you come to them. What you fear may well not happen.

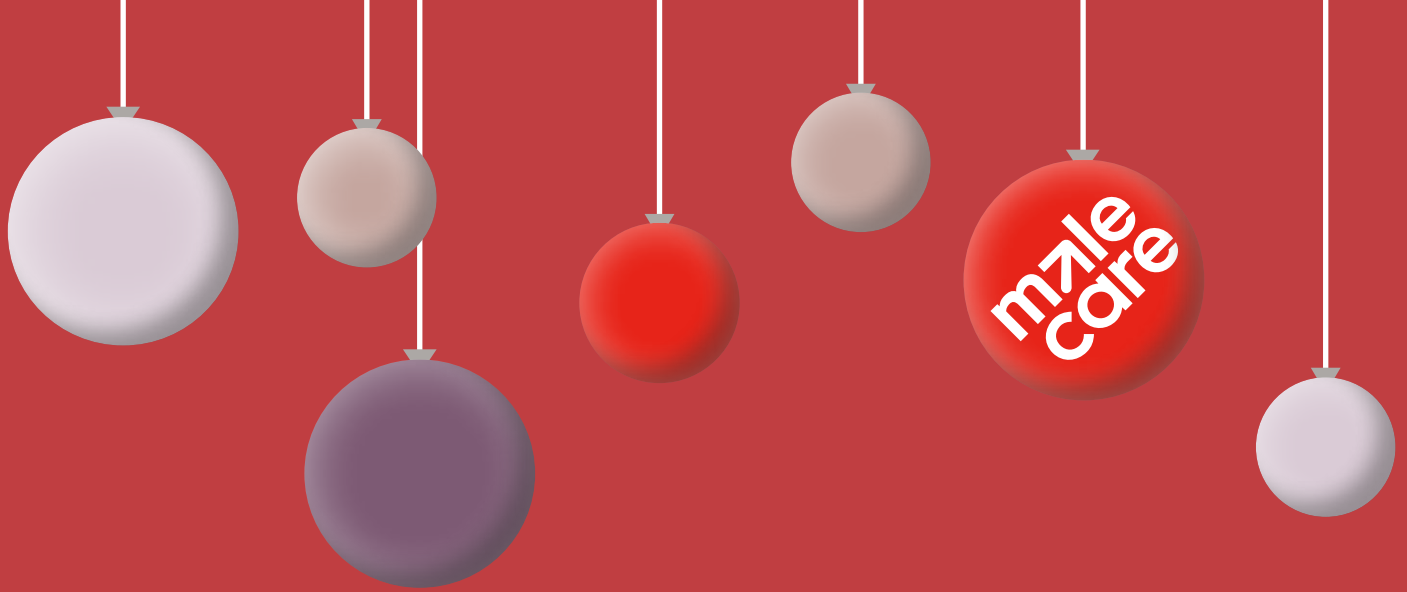


Your life is more than prostate cancer. Stay active, involved, and focus on giving to others.



Prostate Cancer is not just a "you" disease. It is an "us" disease. Many of the treatment options can have profound impacts on you and your partner's intimacy. Your relationship may be your most helpful resource.

Help Men Live Longer and Happier Lives.
Donate at www.malecare.org/donate



The day I had the catheter removed, we were so hungry, we went out to eat lunch. I had to go pee. Good thing, the doc gave me a pad in place before we left. I was dribbling out like a water fountain. This was a little funny at first until I realized I had no control over it.

I immediately started doing the Kegel exercises. It is essential to know that before surgery, you have three valves to control your urine. You now only have one at the urethra. Prior there was one at the prostate, one at the bladder and one at the urethra. You now only have the one at urethra from what I have read. Make the most of what you have left.



I started masturbating about a week after the catheter removal. You can still have an orgasm and enjoy your penis. Use lots of lube; some nicely scented ones look like cum and feel nice. Be patient and have a towel nearby.



Masturbate like no one is looking. No one can hear your thoughts, either. Train your penis to orgasm without an erection by imagining (and wearing and doing) whatever you want.



I enrolled in the RESTORE study, Malecare's NIH funded clinical trial collaboration with the University of Minnesota. It is for gay men with prostate cancer. It has really taught me that by using the penis pump, Masturbating, cock rings, or whatever other toys turn you on, there is hope and also fun to be a little kinky.

I have a husband of 20 years, who is supportive and loves me. That has been my safety net while struggling with all of this.

Be kind to yourself, buy some sexy tight underwear, and enjoy what it feels like to have your package propped up and feeling good.



While getting ADT treatment, hot flashes were unbearable. I couldn't sleep. My massage therapist gave me great advice. Wearing a simple athletic cooling towel around my neck could be a big help. Just a quick rinse with water and squeeze, shaking it 4-5 times and putting it around my neck delivered a comforting chill beyond belief that slowed, stopped, or prevented these flashes from hell.



These cooling athletic towels can be purchased online or at a sporting goods store for as little as \$10-\$12 for a 4-pack that comes in different colors and that I could wear at work or in public. Another hot-flash stopper is a gel icepack on my neck around the carotid artery, back of the neck, temples, cheeks, or lips. This often stopped a flash dead in its tracks and enabled me to recover and reorient to whatever I was doing. I took a frozen gel icepack to bed, put it in a baggie, and wrapped the whole thing around a small hand towel, which helps me get back to sleep after a hot flash.



Voice record all of your doctor meetings. Then send the mp3 file to a transcribing service (which you can find online...most are \$1/minute). Now, you will have an easy to read record of your doctor's advice and will note the questions you need to ask during your next meeting or phone call.

I told the urologist, “get the thing out and throw it in the bin. I reported to the surgery ward at 7.30 am to get ready for the surgery. First thing to do was an enema. I rushed to the toilet stalls. I can still see the nurses grinning as I flew across the hospital ward. Now it was the time to get the blighter out. All most five hours later, I came around from anesthesia and was wheeled back to the ward. Everything went well. I was let home with no prostate but just 6 little scars and bruised all around my stomach, not painful at all.



I took my time walking out. It was tough to get my head around that 12 hours before I had been on the operation table. I had the catheter for the next week and actively used my pads and nappies.

One week later, out came the catheter, and still no pain. Then the worst part ... waiting six weeks for the surgeon’s appointment and PSA result, which came back 0.01.

I credit my doctor for choosing the right treatment for me, and the love and support of my family and closest friends. They tell me that my positive outlook, my proactive steps such as exercise, better eating, and a sense of humor, have helped. I am grateful.



Make sure to ask your surgeon to shave a patch of hair on your thigh if they are using a catheter lock. It will inevitably come loose from the skin and dangle by the hairs. Not fun.



You will leak for a long time after surgery...maybe even several years. Buy a case of puppy pads at your local discount store. These go on top of the sheets and maybe on your favorite chair.

Fabric stores sell a vinyl sheet with fabric on both sides. A half yard will give you an excellent protector on top of your mattress cover and for double protection, another one under your mattress cover. Mattress covers can be washed. Mattresses cannot.



Vinegar is handy for rinsing out the urine collection bag. I was told not to wash it out, but I think that is terrible advice. I know how to handle things to keep them clean. Vinegar is better than bleach, both as a cleanser and as an antiseptic.



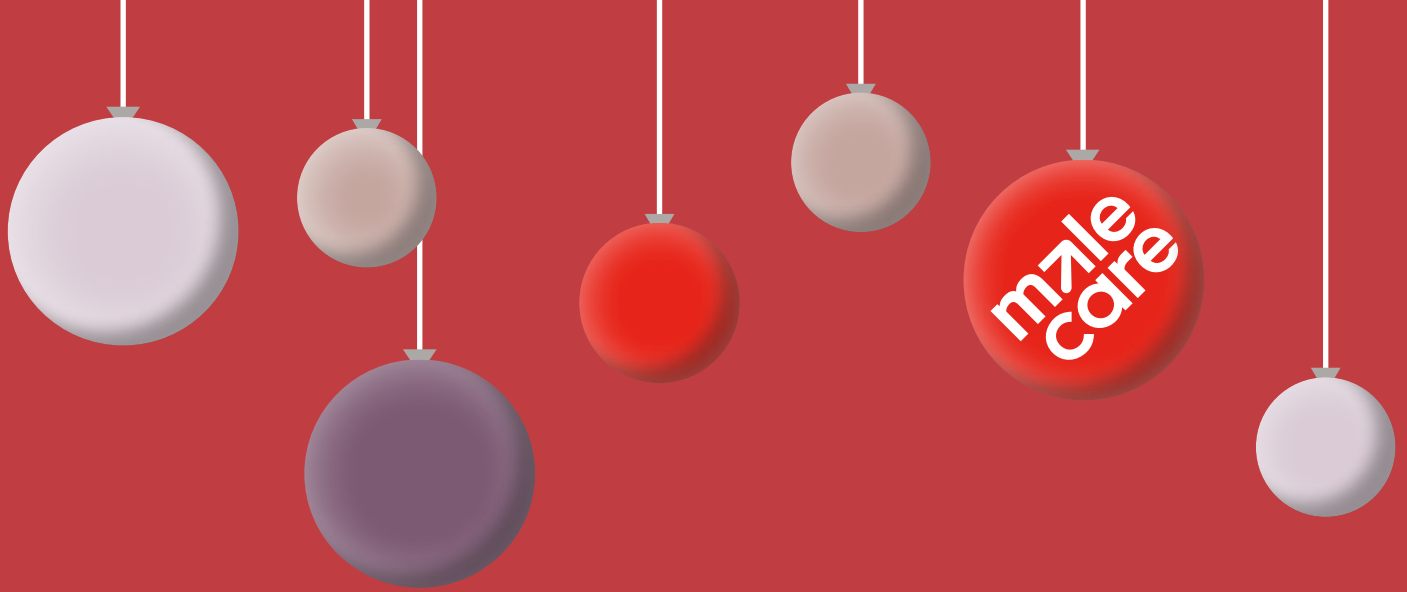
Alternate collection bags every day and hang the one in the shower to drain dry after a vinegar rinse.



Tube of Neosporin or triple antibiotic ointment. Put a tiny dollop where the tube enters your penis. This will help lubricate the tube and decrease irritation at the tip while reducing the risk of infection. Your medical team will tell you not to do this. I am a physician, and I think they are wrong about that. I understand their concerns about infection. Still, they have never worn a catheter for two weeks, and, again, I know how to do things cleanly.



I was diagnosed with prostate cancer when I was 40. I hadn't been feeling 100% for a few months and had lost around 10kg in weight. I saw my GP, had a full blood screen test and discovered my PSA was 4.9. After the CT and MRI scan, nothing showed up, so he suggested a prostate biopsy....and 6 of 10 cores came back as cancerous. I was given the news 2 days before my 41st birthday.... fast forward 11 years... I'm minus my prostate, my PSA reading is consistently 0.01. I'm continent, and the "old man" still works without ejaculate, but - in my opinion - that's a small trade for being alive.



Sperm bank before treatment. No matter what your age or situation, you don't know what the future will present. Peace of mind is priceless. You can always cancel your annual sperm bank contract whenever you want.



Even if you don't have a rock hard erection, oral sex can do the trick quite nicely, and it's a dry orgasm.



No matter where you are in your treatment, prostatectomy, radiation, ADT, etc., I have found the thing that minimizes the side effects of the therapy is... exercise. It helps fatigue, bone loss, muscle loss, and rejuvenates the mind and soul. It is not as easy to do as say, taking a pill, but I believe it is just as useful as other medications.



"Life isn't about waiting for the storm to pass. It's about learning how to dance in the rain."



Walking is exercise!

An early-morning walk is a blessing for the whole day.

I was diagnosed with prostate cancer (PSA 5.65/Gleason 6) on August 24, 2011, on a Monday. The urologist told me over the phone. I hung up, looked at my wife, and said, "I have cancer." I didn't know if I was going to die in one year or five. He didn't tell me.



I'm 76, I feel great, I am alive. I still have prostate cancer after 29 years, I haven't beat it, but I reached an accommodation.



Second opinion? Not good enough. I needed to meet with seven doctors until I found the doctor who understood my specific type of Prostate Cancer. He recognized it as a variant subset that presented with Lymph node metastasis. He treated me more aggressively than the other doctors had proposed.



I lost my Dad three years after his initial diagnosis. He was diagnosed at 58. Too late for a prostatectomy because it had spread to the lymph nodes and bones. Attitude is everything because when my Dad gave up fighting, he was dead in 2 weeks.

The best piece of advice I received after my diagnosis was to talk about it freely. Many people are afraid of the word “cancer.” Friends, colleagues, and acquaintances will hear about your cancer. They may not know what to say and, unconsciously, they may distance themselves from you. If you take the initiative and talk about it openly, you “break the ice” and end up drawing people closer to you. You also help to educate people about prostate cancer, and that can only benefit everybody.



Carefully check the most common side effects of your medication. If fatigue is near the top, then take medicine at bedtime. As a pharmacy tech explained to me, the best time to be fatigued is when you’re going to sleep. You may still be tired in the early morning, but you will have much more energy during the day.

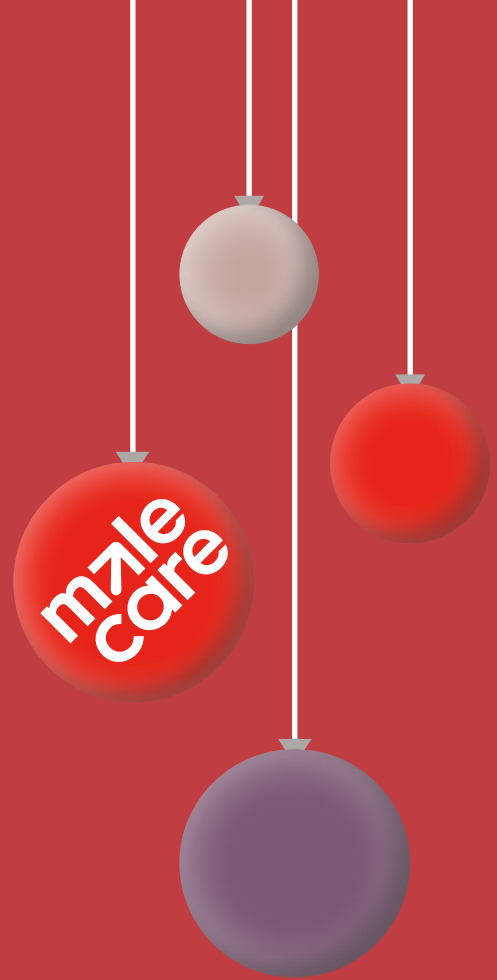


Part of my prostate cancer journey meant that I had to, in some ways, reinvent myself. This meant exploring sex in different ways. It also meant being upfront to potential sex partners. So, in addition to explaining my likes and dislikes, I also told potential lovers how my body functioned. The mechanics of sex changed me forever. I now accept and become comfortable with the changes. I have become a more sensitive lover.



I had never felt sick from the disease, only from the treatments.

In August of 2015, I was diagnosed with Gleason 8 advanced-stage prostate cancer. I'm a single father with full custody of a nine-year-old son. Can you imagine the freight, and devastation I faced hearing this news? After receiving multiple opinions, which I advise everyone to seek, I had robotic surgery. I live with ED, I live with annoying incontinence, but I'm alive. I'm able to hug my son, walk him to school, hold his hand, and I am here to fulfill the promise I made him at his birth, to see it through no matter what and never leave his side. Cancer is insidious, and it destroys everything. If you survive it, you're changed forever. My advice? Focus on the good things, you're alive, you won, revel in that because you let the darkness get you, then cancer wins. Every time I look at my son I realize how fortunate I am, I thank God for the day I have been given, and each night I ask him to please allow me the gift of another tomorrow.



Thank you for reading. Though you and I may not yet have met, I know that you and I are not alone. You are my brother or sister. I offer you the gifts of optimism and care. I wish you and all those whom you care about, near and far, a warm and love filled holiday season.

With my kindest regards,
Darryl

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