

**male
care**

**PROSTATE CANCER
WHILE BLACK**





**I was born as a man
I will die as a man
Prostate cancer does
not change that.**

Prostate cancer is a crisis in our community. Every year, thousands of our men die from prostate cancer, and tens of thousands suffer harm to their quality of life from prostate cancer treatments.



Prostate cancer might seem like a plot against our community

- Prostate cancer kills our men at more than twice the rate as white men.
- Our men are more likely to be diagnosed with an advanced-stage disease than white men.
- Prostate cancer treatment can make our men impotent.
- Prostate cancer treatment can cause our men to urinate or defecate in their pants or on their bedsheets.
- Prostate cancer treatment can make our men feel like eunuchs by reducing their testosterone.
- Clinical trials have few African American participants, so we don't know for sure if drugs and treatments will work for our community.

Prostate Cancer While Black is our guide for managing some of those changes and challenges. We've gathered the wisdom of community elders, spouses, partners, sons, and daughters—all of whom are either diagnosed with prostate cancer or love someone who is diagnosed. We have not covered everything, but we hope the skills we highlight in this booklet will carry over into all aspects of your experience with having prostate cancer while black.

Racism in the Doctor's Office

White patients don't have to acknowledge that they are white.

White patients don't have to wonder if the prescribed drug will work on them.

Black patients are likely to wonder if their doctor will show them respect.

Black patients are often treated as if they can't understand healthcare terminology or may not have the ability to pay their bills.

Racism in medicine masquerades as color-blindness. Non-black doctors who say, "I treat all my patients equally," really mean that they treat white patients the same way, with little insight into histories, disparities, and cultures of their non-white patients.

Black men have a history of being closed out from active and meaningful participation in their health care. Some doctors wear their long white coats and suit and tie with the same authority as a police uniform. That has to change. Both you and your doctor must have some level of trust, rapport, and respect.

When you meet your doctor, listen to your gut and decide if this is the doctor for you.

Non-black doctors might feel intimidated or uncomfortable when you ask questions about prostate cancer and its potential impact on your life, particularly around the more common sexual side effects and urinary incontinence. Ask anyway. You might even suggest that your doctor should say, "I don't know," rather than fumble with a less than helpful response. Your doctor is supposed to work for you. You are the boss.

Your doctor is your new partner in the business of killing your cancer while maintaining your quality of life. Doctors can't fix what they don't know. If you don't feel the two of you can have open and stress-free conversations, then consider finding a new doctor with whom you can establish a better relationship. Your best shot at treating prostate cancer is with a doctor who listens to you and does not rush you into decisions you are not ready to make.

When your choices are limited, then you might have to compromise. Your cancer cells don't care what your doctor looks like. Your cancer cells only fear the doctor with the best skillset and the most effective therapies to kill them.

Unfortunately, the best doctor that you may have access to may not be the doctor with whom you feel most comfortable. Think about this. These doctors are not going to become your best friends and will rarely become your health advocate. Your doctor is your employee, hired to make you healthier. Choose the doctor you feel can do the best job for you.

It's okay to wonder if your doctor offers you the same treatment recommendations as he or she might provide to a white man. You may feel that a black doctor will be more concerned about you than a white doctor. Or you may think that white doctors are better educated. In truth, there are brilliant black doctors and caring white doctors. Let's hope you are blessed to have access to a great doctor, no matter what they look like.

Feeling comfortable and confident in your choice of doctors is essential. But it's not okay to delay treatments repeatedly or for long periods. Don't turn away from a great doctor, just for the sake of comfort or to make a social or political statement.



*You didn't
create racism,
nor did you create
discomfort with
white doctors.*

*Prostate
cancer is
the bad guy,
not you.*

White Women

Most doctors are clueless about how black men feel about getting told what to do by white women. You may find yourself in treatment with a white female doctor, nurse, or social worker. She may even assist you in using a penile injection to help you get an erection. Our history of white women telling our men what to do creates feelings that few people outside of our community can understand. You are not alone in this experience.

Talking to Doctors About Impotence and Incontinence

You may feel uncomfortable talking to a white doctor about sexual issues like impotence. We get that. Unfortunately, there are very few doctors in our community that specialize in sexual matters. Your doctor may suggest an erectile dysfunction medication that you inject into your penis. Yes, you read that right. Believe it or not, you'll barely feel the needle. And the injection usually works. We mention this because your doctor may ask their nurse to demonstrate this on you.

White female clinicians teaching you about Kegel (pelvic floor) exercises for urinary incontinence may equally cause some men discomfort. Speak up if you have any concerns about any demonstrations or interventions. You can say that you want a man to demonstrate a treatment or exercise. We don't want you to be distracted from learning how to do things that assist in your healthcare.

Waiting Rooms

You will spend a lot of time in doctor's waiting rooms. There are magazines and certain kinds of pictures and portraits on the walls that might make you feel like an outsider. There's not much you can do about a setting that's not inclusive and welcoming. Consider bringing reading material or a mobile device and headphones. And hope that your doctor will see you soon.



The Myth of Cure and Truth of Recurrence

Many doctors use the word “cure” or describe their treatments as “curative.” We all hope and pray that is true. We know that for many men, it will not be true.

Approximately one-third of all men who have primary treatment will see a recurrence of their prostate cancer. For black men, the recurrence rate might be higher, but we don’t know why. We do know that more of our men get diagnosed with an advanced stage of prostate cancer at a younger age and more frequently than white men.

Consider thinking of your prostate cancer as a chronic disease to manage with a variety of treatments, one after the next, as needed. By monitoring yourself with blood tests and an occasional scan, you’ll be ready to jump on the next treatment at an advantageous time if your cancer progresses. By thinking of your prostate cancer as a chronic disease, you’ll be less likely to feel disappointment, depression, and anxiety if you need additional treatments.

Prostate cancer is rarely the type of cancer that kills people quickly. Your doctor will probably say that you have weeks or months before it becomes critical to make a treatment choice. Take time to consider options. Get a second opinion on your biopsy slides, read a few online articles, meet with two or more doctors, and connect in online or in-person support groups with other men who have been diagnosed with prostate cancer.

Cover all your bases so you'll feel confident that you've done everything to make the best possible treatment choices. Most men reconcile

themselves to the fact that the cancer cells are not going to go away by themselves. Whichever doctor and treatment you choose, the simple act of deciding and following through on treatment is empowering. You'll feel much better and less afraid once you make a choice.

Prostate cancer kills our men at a higher rate than for other ethnicities. But if your diagnosis is low-grade cancer, active surveillance can be a treatment choice for you. Active surveillance is a way to avoid treatment and its side effects while keeping a close eye on your disease's

progress. Active surveillance means developing a testing schedule, such as having PSA blood tests every three to six months or an MRI every year, so that you can get a jump on your disease with more potent treatment, should the need ever arise.

Under active surveillance, your goal is to live a long life with minimal impact on your quality of life and die from something else. Doctors seem to discuss active surveillance less often with black men than with other men. Bring it up. It may be the best option for you.

Join a prostate cancer support group at www.malecare.org

Online support groups are great places to get information. You don't have to go anywhere or meet anyone. You don't need to use your real name. No one knows how you look or what you are wearing. You can log off whenever you want. The Malecare online prostate cancer support communities have brilliant people from our community and thousands of helpful posts. There are prostate cancer groups for gay men and men on the down-low, too.

Hope

Hope is a feeling of optimism that gives us motivation and energy to get past obstacles and reach our goals. Hope is different for our community than for others. Our ideas and feelings about hope have been fertilized by decades of despair and dehumanization. Don't waste time going in the weeds when white cancer survivors tell you how "hope" has brought them to better health. For us, hope is an all-day effort about everything we want to change for the better.



Prostate cancer may not be your only health concern

Diabetes and hypertension (high blood pressure) are a plague in our community. Moderate activities for physical wellness (e.g., walking) and a healthy, more balanced diet (e.g., more vegetables, vitamins, supplements, fewer soft drinks, less caffeine) are helpful for your overall health, including prostate cancer. Keep yourself active and smart. Don't let prostate cancer keep you from fixing other health problems.

Prostate cancer isn't the only thing that makes us more likely to die than white men.

We know what it's like to be more at risk and more likely to die.

Sleep and Rest

Thinking about death, pain, and suffering from prostate cancer treatment may trigger difficulty falling asleep, waking up in the middle of the night, and nightmares. Lack of sleep won't change your prostate cancer as much as it will cut down your enjoyment of life.

Incontinence and urinary urges will wake you. Don't try holding it in. You'll just keep yourself awake. Use the toilet and get back to bed. Learn to use the bathroom without turning on a light or use a nightlight. Staying in darkness will help you fall back to sleep. And don't go to the kitchen. A break in sleep time is not the time for eating.

Some prostate cancer treatments cause hot flashes, a minute or two where you will feel warm and sweat a lot. Hot flashes will interfere with your sleep. Use disposable dry mattress pads (like those used for babies) to protect your bed. Keep a towel and dry shirt by your bedside. If your sheets become moist from a hot flash, continue your sleep on the dry towel. Change your sheets in the morning. Don't try to sleep in wet clothes after a hot flash. Change into dry clothes and go back to sleep. Do your best to get a sleep that leaves you well-rested. It's hard to enjoy a day after little sleep.

Making Babies

Don't let the myth that prostate cancer is an attack on our community and our ability to reproduce become a reality. Few doctors will talk with you about sperm banking. Doctors think men in their fifties or sixties or older don't want babies. Some doctors don't want to start discussions about sperm banking because then they have to spend time talking about how radiation and surgery destroys your ability to ejaculate and that you should expect to have dry orgasms. Don't wait for your doctor to discuss fertility. Ask.

Consider banking your sperm...at least for the first year or two after your treatment. You don't know what life has in store for you.

Is Anyone Listening?

We know you'll hear someone say, "Men don't talk." Well, you know, and we know that you do talk. Men don't talk when we feel no one is listening or when we think that we are being judged. Black men know that we are being judged and tested and suspected every day. It's not that black men don't talk; it's that we are not listened to, and we are endlessly judged about what we say and how we say it.

Fortunately, there are online support groups where we can connect on an equal playing field and share and ask questions and offer support to our new brothers in prostate cancer. Go to www.malecare.org and join one of our online prostate cancer support groups.

Are you living with someone you love and who loves you?

You'll likely share fears and concerns, but at different times. You may feel one thing while your partner or spouse may feel something else. It's okay to say to your spouse or partner, "there are things I'm not ready to discuss." Most spouses and partners understand that sharing takes time. You may feel uncertain regarding your spouse or partner's ability to care and give you the emotional support that men with prostate cancer need.

Many of our men feel they are protecting their spouse or partner by not talking about prostate cancer. You may think that you have to ease your family's concerns about prostate cancer by repressing your feelings, avoiding "the talk" to keep cancer anxiety and stress out of your relationship. Keeping quiet might work for a short time. Eventually, though, you'll notice that your spouse or partner is not comfortable about you being silent about your cancer. You can start by talking about the cost of treatment, the taste of the medications and contrast agents (some might leave a metallic feel in your mouth), and work your way towards talking about treatment side effects, pain, and mortality.

Listen to your spouse or partner, too. They will likely have health and emotional problems of their own, maybe even cancer. They may fear the time when they lose you is sooner rather than later. Sharing your thoughts and opening your ears is helpful for both of you.

Racism affects both of you

Discuss what it's like for both of you to bring a white person's opinions into your lives. African American women and African American gay men have experienced a lifetime of racism, sexism, and sexually based discrimination. The woman or man in your life is sharing some of your prostate cancer experience. Even if your spouse or partner is not African American, they will try to empathize with the barriers that you face. They are going to wonder what to say or not say, what life will be like if you are impotent or incontinent, or if you die. Be as understanding as you can if you have a spouse or partner who is struggling with your prostate cancer as much as you are. Share your concerns and listen to theirs.

Are you living with someone with whom you no longer feel close?

Some folks are married or partnered for reasons other than love. We know that you may have grown to dislike or distrust the person with whom you are living. That happens to many couples. And now, you have prostate cancer. The prostate cancer isn't going to improve things between you...it may even be the excuse for breaking apart and moving on. That may be a good thing. Getting out of a stressful relationship makes life better and creates mental and emotional space for taking care of things and moving forward in ways you can't yet imagine.

Don't Act Out

It's tough to predict or prepare for your post-treatment emotions and behaviors. You might be keeping it all together in front of your friends, workmates, or doctors, but act differently at home. You might feel sad or depressed or agitated and argumentative. Demanding things. Ignoring things. You might withdraw and keep to yourself. You might be verbally abusive. All of your feelings are valid. You are human, and you are making difficult choices with unpredictable outcomes. Your feelings are yours, and the actions of your feelings must remain with you. Do not act out on others. If you feel like you are or about to act out, find a safe place to work out your feelings.



Racism, historically in this society, sends a message that you are 'less than.' We feel we have to compensate by exaggerating stereotypical ways men are supposed to act. And that's a trap.



- Barack Obama

Do You Live Alone?

Living alone doesn't mean that you are alone. Storeowners and clerks at your pharmacy, food take-out, supermarket, barbershop, and other stores probably have seen you several times a month. They may not know your name or your life story, but they know what medications you take, what you like to eat, and how you want your hair cut. They're people just like you. Maybe now is the time to strike up a conversation. Say something like, "Hey, do you know anyone with prostate cancer?" You might start a talk, which might lead to a connection that might lead to having someone who could come with you to your next doctor's appointment or drive you home after a scan or procedure. You get the idea. You have people in your life that are just waiting for you to say, "hi."

Roles and Relationship

Prostate cancer does not change your position as a husband or worker or leader. You will likely need a few personal days here and there to take care of your health. Some of the treatment side effects may impact your ability to perform, but for the most part, you are still the husband, worker, or leader that you were before prostate cancer.

Your spouse or partner was probably attracted to you at first by your looks or smarts or smile but stays with you because of the man that you are. Even if you are dealing with impotence, incontinence, hot flashes, body fat, and other kinds of side effects from treatment or pain from advanced-stage disease, you are part of your family, our community, and our Malecare community. You have our support. Nothing about prostate cancer changes that.

I'm Gay, and I'm Black

You're not alone. There are thousands of black men in the United States who enjoy sex with other men and have prostate cancer. You may be out as a gay man, on the down-low, or may not even think of yourself as being unique in any way from heterosexual men. There is no need to worry about that. Prostate cancer will interfere with your quality of life in ways that heterosexual men don't experience. It's worth your time to ask your doctor to discuss how anal receptive and insertive sex, rimming, and other kinds of lovemaking and sex-play may change by the various treatments you may undergo. We can tell you there is absolutely no cause and effect regarding man to man sex and prostate cancer.

You're not alone.

There are thousands of black men in the United States who enjoy sex with other men and have prostate cancer.



**The most frequent question you are going to hear:
How are you feeling?**

*The most helpful personality trait you have is self-worth.
Like your own body, trust your instincts, value your time, and expect
respect from others.*

There's no point in saying, "I'm fine." Few people will believe you. And it won't stop the person from asking again. Instead, consider saying, "Well, I have cancer, but I try to keep enjoying life."

Or, "I am not enjoying life as much as I want to, but I am doing the best I can. Thanks for asking."

Both of these answers will be truthful without revealing much detail or provoking more questions.

Also, when people tell you to do things, like try different treatments or see different doctors, you can reply, "Thank you for sharing. I'll let you know what I decide."

Control

Prostate cancer is not an envelope that protects you from racism or bigotry.

Our community has a long history of distrust of physicians and the health care system. Many people cite the syphilis experiments conducted at Tuskegee Institute as the reason our men have suspicion and profound fear about doctors and for research participation.

The truth is, our men have an appropriate and self-protective suspicion of almost all aspects of American society. Distrust and fear are strong deterrents for our men to engage the healthcare system. Our community's experiences with the larger society disrupts trust.

We don't have a choice. The health care system is where the best prostate cancer treatment opportunities are. Each of us might have to swallow more than we would like to get the best treatment for our prostate cancer.

You Are Not Crazy

We all need to process our thoughts and emotions when we hear that we have cancer. Sometimes, we feel sad, confused, scared, or more profound states of mind like feeling depressed or anxious. However, the characterizations and treatment approaches to mental health issues vary by where you and the people who raised you are from. People from Afro-Caribbean, African, Afro-Creole, and other cultures may have different ideas about treating depression or anxiety.

Institutionalized racism has caused doctors to assign our men more severe mental

health diagnoses than might be appropriate. Moods and emotions are entirely human and usually healthy responses to being diagnosed with a life-threatening disease. It's hard to know when you need extra help with your emotional state. Prostate cancer challenges your vitality and disrupts your conception of yourself as a healthy man. Get a second opinion if someone diagnoses you with a mental illness or condition after you hear that you have prostate cancer.

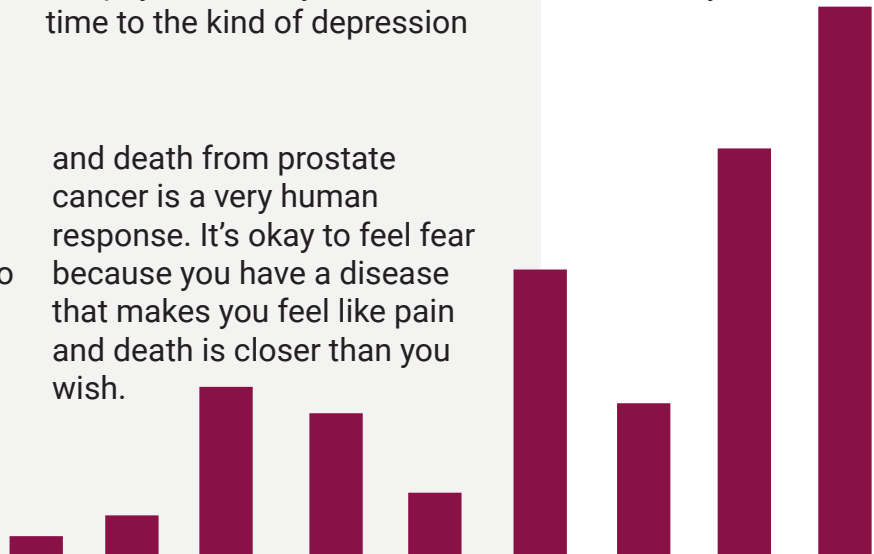
For most of us, death will come many years after a prostate cancer diagnosis. It is a pity to lose any of that time to the kind of depression

or anxiety that is treatable. Some men in our community genuinely have a treatable form of depression or anxiety. Professional help is usually helpful, at least as a first step. Seeking psychological help does not mean you are weak or have a feeble mind. And if you do not care for your psychologist, counselor, therapist, or psychiatrist, you are more than welcome to search for a new one. Mental healthcare is based on positive, trusting relationships, just like physical healthcare. Your behavioral healthcare provider (e.g., a psychologist or counselor) is your employee and works for you.

Fear

Men from our community have many reasons to feel fear every day. Fear tells us something is up, something to run away from or to confront. Prostate cancer creates different reasons for fear. For example, fear of treatments

and death from prostate cancer is a very human response. It's okay to feel fear because you have a disease that makes you feel like pain and death is closer than you wish.



Moods

Moods are temporary states of mind or feelings, such as happy, sad, frustrated, relaxed, cranky, surprised, and angry—just to name a few. Moods last from several minutes to many days. Mood

swings can be caused by hearing good or bad news from your doctor, seeing changes in attitudes in the people around you, money problems, or side effects from your medication. Crankiness is expected.

Once you complete a particular treatment like surgery or radiation, there is a “what’s next” feeling, which is scary and elevates moodiness or, for some men, a short depression.

Anxiety

Anxiety is more than the usual feelings of nervousness, such as when anticipating a new experience or something unexpected or the unknown.

Anxiety is an overwhelming and intense feeling of nervousness, fear, tension, powerlessness, and apprehension. It can reach a peak, so there are moments of panic where one's heart may be pounding or beating quickly. Hyperventilating or difficulty breathing can be symptoms of anxiety at its peak, as well. You might also experience sweating and trembling. Sometimes it can be so intense that you might have trouble concentrating or thinking, leaving the house, or difficulty being around other people. The fear can be severe, and you might feel like there is some impending danger when no danger actually exists.

Depression

Depression is more than feelings of sadness, such as following some disappointment.

Depression can be characterized by having a low mood or can be as severe as an overwhelming feeling of intense sadness. It can include feeling helpless, hopeless, and worthless. It can sometimes be expressed through angry outbursts, as well as bursting into tears. There can also be a loss of appetite or an increase in appetite. There can also be difficulty sleeping or oversleeping. Also, there can be a loss of interest in things you ordinarily might enjoy. Depression might cause you to isolate yourself from friends, family, and society and might even cause you to neglect your physical hygiene. You might feel this way for days or weeks.

Reducing Stress

Most hospitals and cancer booklets suggest yoga and meditation for relaxation. That's all well and good, but don't feel like you have to relax the way a brochure or a nurse tells you to. Do whatever it is that you like to do, from extreme exercise to sitting in a chair watching the clouds go by. Travel to the next town over or visit the motherland. Get someone to rub your back or feet. Maybe take a kitchen spoon and scratch your back. Some folks throw caution to the wind and attempt something opposite from what they usually do. You'll find your way to relax, but the point here is to be intentional about it. Relaxation is about turning your mind away from thinking about cancer and towards living.

You did not cause your prostate cancer by doing evil, eating bad foods, or having sex with lots of different partners.

Stress from Doctors

It can be challenging to be persistent and assertive with your doctors, nurses, and medical staffers. We know you don't want to appear pushy or entitled, but this is cancer. Now is not the time to be unassuming or self-protective. Tell your doctor everything. Write everything down and hand it to your doctor. Use symptom lists and mobile apps like Cancergraph to share your everyday quality of life experience with your doctor. Stress is our enemy, and unanswered questions might cause you to worry. Don't wait until your next appointment if you have a concern or aren't feeling quite right about something. If you have a question, relieve your stress and call your doctor.

Prostate Cancer is My Punishment

Some cultures continue to stigmatize cancer patients as bad people. Of course, we should respect the ideas of our elders and kin. However, know this as truth: cancer is not punishment for the life you have led.

You did not cause your prostate cancer by doing evil, eating bad foods, or having sex with lots of different partners. Anal sex doesn't cause prostate cancer. Licentious thoughts do not cause prostate cancer. Cancer is a disease, worse than a headache, more mysterious than the common cold, but something all men might get. No one knows how to prevent prostate cancer, and no one knows why some men get prostate cancer, and some don't.

You are a man going through life, getting older, and contracting the diseases that many men get. Having prostate cancer means you are a human being; nothing more, nothing less.

Religiosity and Spiritual Well Being

It's okay to seek meaning by exploring or questioning religion and faith. You are human. God has not abandoned you. Most theologians believe God doesn't punish you with something you can't handle. God may have given you something to help you find and develop your inner strength. Prostate cancer may be God's classroom for you to learn to be resilient, how to ask questions, and move forward for yourself and others.

Our churches are foundations of civil rights movements, food and clothing programs, and political and education advocacy and activism. Your church will positively stand up and support you as a man and support your health while going through prostate cancer treatments.

Faith is the spine of many people. Prostate cancer won't change your thoughts about religion and belief. Take comfort where you feel faith leads you, and don't worry if you think that your faith fails to support you. Comfort can be found outside of religion, as well as within it.

Alternatives to Western Medicine

You might wonder if the hundreds of years of treatment from the motherland are more effective than the treatments tested mostly on Europeans and Americans? Unfortunately, there is no clear or certain answer. We need more evidence-based trials that include a large percentage of men from our community. Which is why we need more researchers who care. For now, be very careful and skeptical of lay people who say they have cured cancer. It's probably not true, and if it were, we would all know about it.

Thanks for Reading!

Being diagnosed with prostate cancer is a life-changing event. But isn't every day filled with little things and big things that are life-changing events? Being human means, we have the opportunity to have a variety of emotions about those changes. You know yourself better than anyone else. Keep enjoying life—you deserve to enjoy your life.

Please let us know if this booklet has been helpful. Send an email with your comments and suggestions for the next edition to prostatecancerwhileblack@malecare.org

Malecare is a national nonprofit organization dedicated to helping men live longer and happier lives.

We do this by:

Supporting men, and their friends and families affected by prostate cancer through information and resources and support groups.

Developing helpful and innovative research.

Promoting awareness and advocacy about disparities and the needs of underserved communities.

Fighting for what's right and decrying what's wrong.

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We wish you a long and happy life.

