

## Resources

**REMEMBER, YOU ARE NOT ALONE.** Here is a list of organizations that are here to support you and your loved ones.

Name	Services	Website	Phone Number
American Bar Association	Legal helpline	<a href="http://www.americanbar.org">www.americanbar.org</a>	1-800-285-2221
Association of Oncology Social Work	Resource list for patients and caregivers	<a href="http://bit.ly/AOSWResources">bit.ly/AOSWResources</a>	847-686-2233
CancerCare	Support groups, counseling, financial aid, helpline	<a href="http://www.cancercare.org">www.cancercare.org</a>	1-800-813-4673
CaringInfo	Advance directives, palliative and hospice care information, helpline	<a href="http://www.caringinfo.org">www.caringinfo.org</a>	1-800-658-8898
GLMA: Health Professionals Advancing LGBT Equality	LGBTQI-friendly clinical directory	<a href="http://www.glma.org">www.glma.org</a>	202-600-8037
Lambda Legal	Advance directives, LGBTQI health care rights information	<a href="http://www.lambdalegal.org">www.lambdalegal.org</a>	212-809-8585
LGBT Cancer Project	Support groups, online forums, clinical directory	<a href="http://www.lgbtcancer.org">www.lgbtcancer.org</a>	
Malecare	Gay and bisexual prostate cancer support groups, clinical research information, online forums	<a href="http://www.malecare.org">www.malecare.org</a>	212-673-4920
National Cancer Institute	Information about prostate cancer treatments, side effects and support	<a href="http://bit.ly/NCIPrCa">bit.ly/NCIPrCa</a>	1-800-422-6237
National LGBT Cancer Network	LGBTQI-friendly clinical directory and support groups	<a href="http://www.cancer-network.org">www.cancer-network.org</a>	212-675-2633
The Patient Advocate Foundation	Financial aid, helpline	<a href="http://www.patientadvocate.org">www.patientadvocate.org</a>	1-800-532-5274
The Prostate Cancer Research Institute	Cancer treatment and clinical research information, helpline	<a href="http://www.pcri.org">www.pcri.org</a>	424-261-3727
Zero: The End of Prostate Cancer	Free testing center directory, screening and treatment information, financial aid	<a href="http://www.zerocancer.org">www.zerocancer.org</a>	1-844-244-1309

# Living with Prostate Cancer

## Resources to take charge of your health



For more information, contact:

This project is made possible through a grant from the Association of Oncology Social Work (AOSW). The GW Cancer Center is committed to improving care for the diverse people that make up the LGBTQI rainbow. If you have feedback on this fact sheet, email us at [cancercenter@gwu.edu](mailto:cancercenter@gwu.edu).

Gay and bisexual men have health care needs that are often not talked about. This fact sheet is for men who have sex with men and have been diagnosed with prostate cancer.

This fact sheet is only a starting point. It can help you work with your health care team and help you manage the effects of treatment. The resources list on the back has more information for you and your partner(s).

## About Prostate Cancer

### WHAT IS THE PROSTATE?

The prostate is a gland in your body that is located between your bladder and penis. It gives many men pleasure during anal sex.

### WHO GETS PROSTATE CANCER?

All people with a prostate can get cancer.<sup>1</sup> People who are Black or African American or those with a family history of prostate cancer are more at risk.<sup>2</sup>

### WHAT IS THE STAGE OF MY PROSTATE CANCER?

Stage is how far your cancer has spread to other parts of your body. Ask your doctor about the stage of your cancer and what it means for your care.

## Working with Your Health Care Team

### HOW DO I CHOOSE MY HEALTH CARE TEAM?

It helps to choose a doctor and health care team that you feel comfortable talking and working with. Here are some tips to help you choose:

- Visit the GLMA website to find LGBT-friendly doctors
- Call your local LGBT community center
- Reach out to a local or national prostate cancer support group
- Trust your instincts

### DO I GET A SECOND OPINION?

A second opinion can help confirm your diagnosis or treatment plan. Many people with cancer get a second opinion.



## Talk with your partner about...



**YOUR CARE:** When your partner knows what you want, they can help you talk with your health care team. They can also provide support throughout your care.



**YOUR EMOTIONS:** Talk about what makes you sad, anxious, or fearful. Your partner may feel similarly. Try to work together to find ways to get support for both of you.



**YOUR BODY:** During sex, your partner may worry about hurting you. They may be unsure about how treatment has affected your body. Try to be open about what has changed. Talk about how you can enjoy sex together.

## References

1. National Cancer institute (2017a). *Prostate Cancer Screening (PDQ®) - Patient Version*. Retrieved from <https://www.cancer.gov/types/prostate/patient/prostate-screening-pdq>
2. National Cancer Institute (2017b). *Prostate Cancer - Patient Version*. Retrieved from <https://www.cancer.gov/types/prostate>
3. Chen, R.C., Clark, J.A., & Talcott, J.A. (2009). Individualizing Quality-of-Life Outcomes Reporting: How Localized Prostate Cancer Treatments Affect Patients with Different Levels of Baseline Urinary, Bowel, and Sexual Function. *Journal of Clinical Oncology*, 27(24), 3916-3922. doi: 10.1200/JCO.2008.18.6486

## What is Palliative Care?

It is supportive care to make patients feel more comfortable. Palliative care is not “giving up.” It includes care to relieve symptoms like pain and depression. Palliative care can be given at any time during and after treatment. Talk to your nurse or social worker to learn more.



## How can I be sure my wishes will be met?

There are ways to ensure your wishes will be met by your health care team and loved ones.

- **LIVING WILL:** It is a legal document. It instructs medical providers on certain treatments that you do or do not want to help you live longer. Treatments can include having a machine breathe for you or having a feeding tube.
- **MEDICAL POWER OF ATTORNEY:** You can assign medical power of attorney to any person outside of your health care team. This person will make health care decisions for you if you are not able to communicate.

These documents are also called **advance directives**. Talk to your doctor about how to set these documents up. You can also visit the Lambda Legal and the American Bar Association websites for information.



## SHOULD I COME OUT TO MY HEALTH CARE TEAM?

Your health care team is made up of everyone involved in your care. This includes doctors, nurses, oncology social workers as well as others.

Coming out to your health care team is very personal. It should be done on your own terms. You should not feel pressure to come out or hide your sexual identity. If you do come out to your team and don't feel your needs are being addressed, talk with them. If that doesn't work, consider choosing a different team.

Whether or not you are out to your providers, let your health care team know who your important caregiver(s) are. Tell them who you want in the room and when. Talk about who you want involved in decisions about your care.

## HOW DO I CHOOSE MY TREATMENT PLAN?

Before you visit your doctor, write down your thoughts or have someone help you do so. It can help to talk through your concerns and questions with others.

When you go to your doctor's visit, tell them what's important to you. Share your concerns. Ask what they recommend and why.

If you don't understand something, ask your doctor to explain it again. Nurses can also explain symptoms you should expect and steps you can take to manage them. A patient navigator or oncology social worker can answer questions about support services and logistics regarding your care.

*"Get as much information as you can. Bring a friend. You don't want to miss anything or miss questions you should have asked and didn't."*

SEAN, PROSTATE CANCER SURVIVOR



## Your Body

Most people find their bodies change after treatment, but each person's experience is different.

Consider finding a sex therapist or a local or online prostate cancer support group for gay and bisexual men if you experience any of the changes below.

### SEXUAL FUNCTION

Treatment for prostate cancer may change hormone levels, which can affect sexual function and desire. Changes may include:

- Not having an erection
- Not having an orgasm
- Not having semen
- Shrinkage of the penis<sup>3</sup>

If you experience changes, try to:

- Talk to your doctor about ways to help you keep an erection
- Use sex toys with your partner

### URINARY CONTROL

Some people find that after treatment they are unable to control when they urinate. People may also urinate when they orgasm. If this happens to you, try to:

- Use a bed cover
- Switch to a place where cleanup is easier
- See a pelvic floor specialist or discuss options with your doctor

### CHANGES TO ANAL SEX

People may also have pain when bottoming during anal sex. This can be caused by burns from radiation or other treatment effects.<sup>3</sup> Try to:

- Talk to your partner about switching roles
- Focus on oral sex or rimming

"In my recovery family, I asked, 'Any men in here have prostate cancer? If you have, please talk to me.' And a whole bunch of men came to me and my family's home and talked to us about what it was like for them. That helped me."

TONY, PROSTATE CANCER SURVIVOR

## Common Feelings

Everyone's experience is different. Some people may question their masculine identity, especially when dealing with the effects of treatment on their sex lives. Some people may worry about the cancer coming back. Others may think a lot about death and dying.

Emotional and mental stress is normal. You may feel:

- Angry
- Fearful
- Guilty
- Complexity around masculinity
- Lonely or isolated
- Overwhelmed
- Out of control
- Sad or depressed
- Shame or stigmatized
- Stressed or anxious

### DEALING WITH EMOTIONS

While you may be dealing with many emotions, there are steps you can take to help you feel in control. Be open about how you feel—good or bad. Remember that others want to support you. Reach out to family, friends, and your health care team for help. All of these people can be a part of your support network:

- Partner or spouse
- Family of origin and choice
- Doctors
- Nurses
- Oncology social workers
- Patient navigators
- Therapists
- Friends
- Neighbors
- Support groups
- LGBTQ community members

"I think one important thing is support groups. My doctor gave me a list of support groups even before I had surgery."

HOWARD, PROSTATE CANCER SURVIVOR

