After Penile Cancer Treatment

Living as a Cancer Survivor

For many people, cancer treatment often raises questions about next steps as a survivor.

- What Happens After Treatment for Penile Cancer?
- Lifestyle Changes After Having Penile Cancer
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Cancer Concerns After Treatment

Treatment may remove or destroy the cancer, but it is very common to have questions about cancer coming back or treatment no longer working.

- Long-Term Side Effects of Penile Cancer Treatment
- Seeing a New Doctor After Treatment for Penile Cancer
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What Happens After Treatment for Penile Cancer?

For many men with penile cancer, treatment can remove or destroy the cancer. Completing treatment can be both stressful and exciting. You may be relieved to finish treatment, but find it hard not to worry about the cancer coming back. (When cancer comes back after treatment, it is called a recurrence.) This is a very common concern in people who have had cancer.

It may take a while before your fears lessen. But it may help to know that many cancer survivors have learned to accept this uncertainty and are living full lives. For more
For other men, the cancer may never go away completely. These men may get regular treatments with chemotherapy, radiation therapy, or other therapies to try to help keep the cancer under control and help relieve symptoms from it. Learning to live with cancer that does not go away can be difficult and very stressful. It has its own type of uncertainty. Read Managing Cancer as a Chronic Condition for more about this.

**Follow-up care**

If you have completed treatment, your doctors will still want to watch you closely. It's very important to go to all of your follow-up appointments. During these visits, your doctors will ask about any problems you are having and may do exams and lab tests or imaging tests (such as CT scans) to look for signs of cancer or treatment side effects. Almost any cancer treatment can have side effects. Some may last for a few weeks to months, but others can last the rest of your life. This is the time for you to talk to your cancer care team about any changes or problems you notice and any questions or concerns you have.

After your treatment is finished, you will probably need to still see your cancer doctor for many years. Doctor visits and exams will be more frequent at first (typically every few months), but the time between visits can often get longer over time. Ask what kind of follow-up schedule you can expect.

It’s also very important to keep your health insurance. Tests and doctor visits cost a lot, and even though no one wants to think of their cancer coming back, this could happen.

Should your cancer come back, further treatment will depend on where the cancer is, what treatments you’ve had before, and your health. For more on dealing with a recurrence, see Coping With Cancer Recurrence.

- **References**

  See all references for Penile Cancer

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Long-Term Side Effects of Penile Cancer Treatment

Penile cancer and its treatment can sometimes lead to long-term side effects.

Effects on urination

Most men can still control the start and stop of urine flow after surgery. They are still continent. But if the surgery removes part of the penis (partial penectomy) or the entire penis (total penectomy), how a man urinates can be affected. In some cases, a partial penectomy leaves enough of the penis to allow relatively normal urination. But men who have had a total penectomy often must sit to urinate.

Effects on sexuality

If cancer of the penis is diagnosed early, treatments other than penectomy can often be used. Conservative techniques such as circumcision, local therapy other than surgery (laser ablation, topical chemotherapy), or Mohs surgery may have little effect on sexual pleasure and intercourse once you have fully recovered.

Removing all or part of the penis can have a huge effect on a man’s self-image and ability to have sexual intercourse. You and your sexual partner may wish to consider counseling to help understand the impact of treatment for penile cancer and to explore other approaches to sexual satisfaction.

Satisfying intercourse is possible for many, but not all men after partial penectomy. The remaining shaft of the penis can still become erect with arousal. It usually gains enough length to achieve penetration. Although the most sensitive area of the penis (the glans, or “head”) is gone, a man can still reach orgasm and ejaculate normally. His partner should also still be able to enjoy intercourse and often reach orgasm.

Normal intercourse is not possible after total penectomy. Some men give up sex after the surgery. Since cancer of the penis is most common in elderly men, some are already unable to have intercourse because of other health problems. If a man is willing to put some effort into his sex life, however, pleasure is possible after total penectomy. He can learn to reach orgasm when sensitive areas such as the scrotum, skin behind the scrotum, and the area surrounding the surgical scars are caressed. Having a sexual fantasy or looking at erotic pictures or stories can also increase excitement.
A man can help his partner reach orgasm by caressing the genitals, by oral sex, or by stimulation with a sexual aid such as a vibrator. The activity some couples enjoy after total penectomy can give hope to those coping with fewer changes in their sex lives.

After total penectomy, surgical reconstruction of the penis might be possible in some cases. If you are interested in this, ask your doctor if this might be an option for you.

Removing all or part of the penis can also have a devastating effect on a man’s self-image. Some men might feel stressed or depressed, or might not feel “whole” after the operation. These are valid and understandable feelings, but they can often be helped with counseling or talking with others. For more on this, see How Might Having Penile Cancer Affect Your Emotional Health?

For more information on sexuality after cancer, see Sexuality for the Man with Cancer.

Lymphedema

The lymph nodes in the groin area normally help excess fluid drain out of the lower part of the body and back into the bloodstream. If the groin lymph nodes are removed or treated with radiation, it can sometimes lead to problems with fluid drainage in the legs or scrotum, causing abnormal swelling. This condition is called lymphedema.

This problem was more common in the past because more lymph nodes were removed to see if the cancer had spread. Now fewer lymph nodes are usually removed, which lowers the risk of lymphedema. But lymphedema can still occur even with less treatment. For more on this, see Lymphedema.

- References
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At some point after your treatment, you may be seeing a new doctor who doesn’t know anything about your medical history. It’s important to be able to give your new doctor the details of your diagnosis and treatment. Gathering these details soon after treatment may be easier than trying to get them at some point in the future. Make sure you have this information handy (and always keep copies for yourself):

- A copy of your pathology report(s) from any biopsies or surgeries
- Copies of imaging tests (such as x-rays or CT or MRI scans), which can usually be stored digitally (on a DVD, etc.)
- If you had surgery, a copy of your operative report(s)
- If you stayed in the hospital, a copy of the discharge summary that the doctor wrote when you were sent home
- If you had radiation therapy, a copy of the treatment summary
- If you had chemotherapy or other medicines, a list of your drugs, drug doses, and when you took them
- The names and contact information of the doctors who treated your cancer

References
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Lifestyle Changes After Having Penile Cancer

You can't change the fact that you have had cancer. What you can change is how you live the rest of your life – making choices to help you stay healthy and feel as well as you can. This can be a time to look at your life in new ways. Maybe you are thinking about how to improve your health over the long term. Some people even start during cancer treatment.

Making healthier choices
For many people, a diagnosis of cancer helps them focus on their health in ways they may not have thought much about in the past. Are there things you could do that might make you healthier? Maybe you could try to eat better or get more exercise. Maybe you could cut down on alcohol, or give up tobacco. Even things like keeping your stress level under control may help. Now is a good time to think about making changes that can have positive effects for the rest of your life. You will feel better and you will also be healthier.

You can start by working on those things that worry you most. Get help with those that are harder for you. For instance, if you are thinking about quitting smoking and need help, call the American Cancer Society for information and support.

**Eating better**

Eating right can be hard for anyone, but it can get even tougher during and after cancer treatment. Treatment may change your sense of taste. Nausea can be a problem. You may not feel like eating and lose weight when you don’t want to. Or you may have gained weight that you can’t seem to lose. All of these things can be very frustrating.

If treatment causes weight changes or eating or taste problems, do the best you can and keep in mind that these problems usually get better over time. You might find it helps to eat small meals every 2 to 3 hours until you feel better. You might also want to ask your cancer team about seeing a dietitian, an expert in nutrition who can give you ideas on how to deal with these treatment side effects.

One of the best things you can do after cancer treatment is to start healthy eating habits. You may be surprised at the long-term benefits of some simple changes, like increasing the variety of healthy foods you eat. Getting to and staying at a healthy weight, eating a healthy diet, and limiting your alcohol intake may lower your risk for a number of types of cancer, as well as having many other health benefits.

**Rest, fatigue, and exercise**

Extreme tiredness, called fatigue, is very common in people treated for cancer. This is not a normal tiredness, but a bone-weary exhaustion that often doesn’t get better with rest. For some people, fatigue lasts a long time after treatment, and can make it hard for them to be active and do other things they want to do. But exercise can help reduce fatigue. Studies have shown that patients who follow an exercise program tailored to their personal needs feel better physically and emotionally and can cope better, too.

If you were sick and not very active during treatment, it’s normal for your fitness,
endurance, and muscle strength to decline. Any physical activity plan should fit your situation. If you haven’t been active in a few years, you will have to start slowly, maybe just by taking short walks.

Talk with your health care team before starting anything. Get their opinion about your exercise plans. Then, try to find an exercise buddy so you’re not doing it alone. Having family or friends involved when starting a new activity program can give you that extra boost of support to keep you going when the push just isn’t there.

If you are very tired, you will need to learn to balance activity with rest. It’s OK to rest when you need to. Sometimes it’s really hard for people to allow themselves to rest when they are used to working all day or taking care of a household, but this is not the time to push yourself too hard. Listen to your body and rest when you need to. (For more on dealing with fatigue, see Fatigue in People With Cancer and Anemia in People With Cancer.)

Keep in mind exercise can improve your physical and emotional health.

- It improves your cardiovascular (heart and circulation) fitness.
- Along with a good diet, it can help you get to and stay at a healthy weight.
- It makes your muscles stronger.
- It reduces fatigue and helps you have more energy.
- It can help lower anxiety and depression.
- It can make you feel happier.
- It helps you feel better about yourself.

Getting regular physical activity also plays a role in helping to lower the risk of some cancers, as well as having other health benefits.

**Can I lower my risk of the cancer progressing or coming back?**

Most people want to know if there are lifestyle changes they can make to reduce their risk of cancer growing or coming back. Unfortunately, for most cancers there isn’t much solid evidence to guide people. This doesn’t mean that nothing will help — it’s just that for the most part this is an area that hasn’t been well studied. Most studies have looked at lifestyle changes as ways of preventing cancer in the first place, not slowing it down or preventing it from coming back.

At this time, not enough is known about penile cancer to say for sure if there are things you can do that will be helpful. Adopting healthy behaviors such as not smoking, eating well, and staying at a healthy weight might help, but no one knows for sure. However, we do know that these types of changes can have positive effects on your health that
can extend beyond your risk of cancer.

So far, no dietary supplements have been shown to clearly help lower the risk of penile cancer progressing or coming back. Again, this doesn’t mean that none will help, but it’s important to know that none have been proven to do so.

- References
  See all references for Penile Cancer

How Might Having Penile Cancer Affect Your Emotional Health?

For any man, dealing with cancer of the penis can be a frightening prospect. Partially or completely removing the penis is often the most effective way to cure penile cancer, but for many men this cure seems worse than the disease.

It’s natural for a man facing treatment for penile cancer to be distressed (or even depressed) and to have feelings of grief or despair. You might want to ask your health care team for a referral to a counselor, who can help you sort through your feelings and adjust to your new body.

When treatment ends, you may find yourself overcome with many different emotions. This happens to a lot of people. You may find yourself thinking about death and dying. Or maybe you’re more aware of the effect the cancer has on your family, friends, and career. You may take a new look at your relationships with those around you. Unexpected issues may also cause concern. For instance, you might be stressed by financial concerns resulting from your treatment. You might also see your health care team less often and have more time on your hands. These changes can make some people anxious.

Almost everyone who has been through cancer can benefit from getting some type of support. You need people you can turn to for strength and comfort. Support can come in
many forms: family, friends, cancer support groups, religious or spiritual groups, online support communities, or one-on-one counselors. What’s best for you depends on your situation and personality. Some people feel safe in peer-support groups or education groups. Others would rather talk in an informal setting, such as church. Others may feel more at ease talking one-on-one with a trusted friend or counselor. Whatever your source of strength or comfort, make sure you have a place to go with your concerns.

The cancer journey can feel very lonely. It’s not necessary or good for you to try to deal with everything on your own. And your friends and family may feel shut out if you don’t include them. Let them in, and let in anyone else who you feel may help. If you aren’t sure who can help, call your American Cancer Society at 1-800-227-2345 and we can put you in touch with a group or resource that may work for you. You can also learn more Distress in People With Cancer or in the Coping With Cancer section of our website.

- References
See all references for Penile Cancer

If Treatment for Penile Cancer Stops Working

If penile cancer keeps growing or comes back after one kind of treatment, it’s possible that another treatment plan might still cure the cancer, or at least keep it under control enough to help you live longer and feel better. Clinical trials also might offer chances to try newer treatments that could be helpful. But when a person has tried many different treatments and the cancer is still growing, even newer treatments might no longer be helpful. If this happens, it’s important to weigh the possible limited benefits of a new treatment against the possible downsides, including treatment side effects. Everyone has their own way of looking at this.

This is likely to be the hardest part of your battle with cancer – when you have been through many treatments and nothing’s working anymore. Your doctor might offer you
new options, but at some point you may need to consider that treatment is not likely to improve your health or change your outcome or survival.

If you want to continue to get treatment for as long as you can, you need to think about the odds of treatment having any benefit and how this compares to the possible risks and side effects. Your doctor can estimate how likely it is the cancer will respond to treatment you’re considering. For instance, the doctor may say that more treatment might have about a 1 in 100 chance of working. Some people are still tempted to try this. But it’s important to have realistic expectations if you do choose this plan.

**Palliative care**

No matter what you decide to do, it’s important that you feel as good as you can. Make sure you are asking for and getting treatment for any symptoms you might have, such as nausea or pain. This type of treatment is called palliative care.

Palliative care helps relieve symptoms, but it’s not expected to cure the disease. It can be given along with cancer treatment, or can even be cancer treatment. The difference is its purpose – the main goal of palliative care is to improve the quality of your life, or help you feel as good as you can for as long as you can. Sometimes this means using drugs to help with symptoms like pain or nausea. Sometimes, though, the treatments used to control your symptoms are the same as those used to treat cancer. For instance, radiation might be used to help relieve pain caused by a large tumor. Or chemo might be used to help shrink a tumor and keep it from blocking the bowels. But this is not the same as treatment to try to cure the cancer.

**Hospice care**

At some point, you may benefit from hospice care. This is special care that treats the person rather than the disease; it focuses on quality rather than length of life. Most of the time, it is given at home. Your cancer may be causing problems that need to be managed, and hospice focuses on your comfort. You should know that while getting hospice care often means the end of treatments such as chemo and radiation, it doesn’t mean you can’t have treatment for the problems caused by your cancer or other health conditions. In hospice the focus of your care is on living life as fully as possible and feeling as well as you can at this difficult time. You can learn more in Hospice Care.

Staying hopeful is important, too. Your hope for a cure may not be as bright, but there is still hope for good times with family and friends, times that are filled with happiness and meaning. Pausing at this time in your cancer treatment gives you a chance to refocus on the most important things in your life. Now is the time to do some things you’ve
always wanted to do and to stop doing the things you no longer want to do. Though the cancer may be beyond your control, there are still choices you can make.

You can learn more about the changes that occur when curative treatment stops working, and about planning ahead for yourself and your family, in *Nearing the End of Life* and *Advance Directives*.

- References
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