Life after prostate cancer

Insights to help you live life restored

Hope. Recovery. Support.

Every year, more than 1.1 million men are diagnosed with prostate cancer globally. It is the second most commonly diagnosed cancer in men worldwide.[1] If detected early, prostate cancer is usually curable.

Like many men, you have undergone surgical treatment for your prostate cancer. Advances in surgical techniques have allowed surgeons to successfully operate on a growing number of patients, and surgery offers the greatest chance for cure for localised prostate cancer.[2]

On the following pages you will find important information about what to expect after your surgery. You can refer to these tools to track your progress and learn about support resources as you move through recovery.

Prostate cancer is a journey. Now it's your time to be in the driver's seat with your recovery.

Recovering bladder control and erections

In order to remove the cancer, the nerves or muscles in your body that help control your urine flow and enable you to get an erection may have been damaged. Most men are understandably concerned about their ability to regain bladder control and erections following their prostate surgery.

While men often leak urine (experience incontinence) immediately following surgery, the leakage usually tapers off within several weeks or months.[3] When incontinence persists beyond six to twelve months, you should consult your doctor.

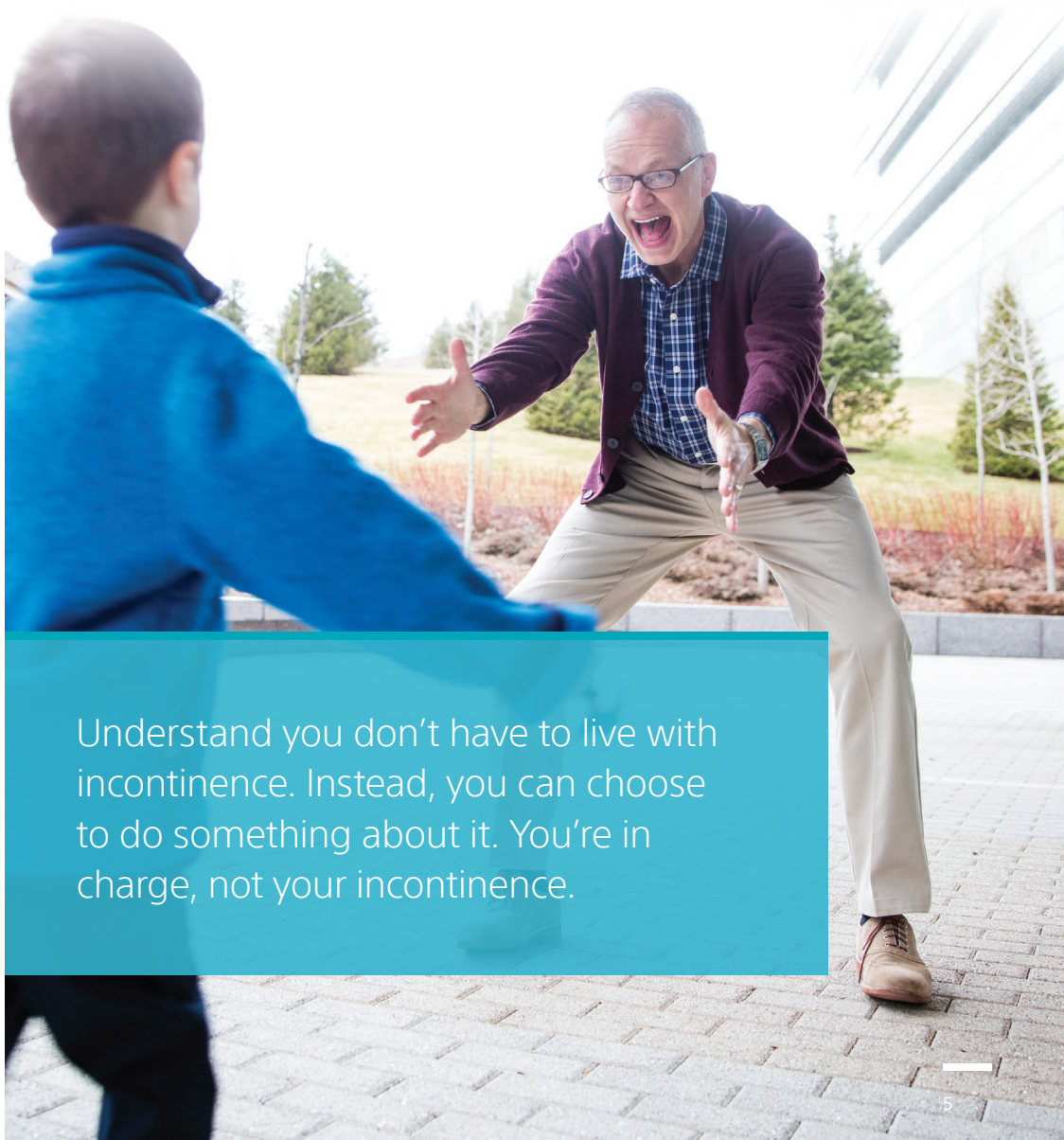
The same is true for erectile dysfunction (ED). ED is known to be a potential complication following prostate cancer treatment. With the advent of nerve-sparing procedures, some men may regain their existing erectile function. The journey is different for every man, and some may not recover their ability to have a natural erection.

The good news is that there are multiple treatment options for incontinence and ED.

Regaining continence

Prostate cancer surgery may cause weakness in the pelvic floor muscles and the urinary sphincter that normally control urine flow. Once the catheter is removed after your surgery, you may experience symptoms ranging from light urine leakage (a few drops when you exercise, cough or sneeze) all the way to a complete inability to control your urination.

Continence tends to improve over time. While every man's situation is different, many find they are continent within six to twelve months after surgery. Recovery can be impacted by factors such as your age, your general physical health, and the degree to which you had full bladder control before the surgery. If after six to twelve months the symptoms persist, consider contacting your doctor.[4]



Understand you don't have to live with incontinence. Instead, you can choose to do something about it. You're in charge, not your incontinence.

Short-term solutions

Until urinary control returns, using absorbent pads or special absorbent underwear can help. Your doctor will also likely encourage you to perform regular pelvic floor/Kegel exercises. These isolate and strengthen the pelvic floor muscles and can help men regain bladder control following prostate surgery.[5]

It is important to do the exercises correctly and regularly. It may help to work with a nurse or physical therapist on the exercises to ensure you are doing them properly and often enough. Some men use collection devices such as external or condom catheters or urine collection pouches to avoid accidental leakage. In the weeks and months following your surgery, talk to your doctor about your treatment options and your progress in regaining continence.

Long-term solutions

For those men who experience long-term incontinence, it's important to remember that there are effective solutions available that can restore your confidence, control and quality of life.

Injections – Injecting bulk-producing agents, such as collagen into the bladder neck, can help keep the urethra and bladder opening closed and may help prevent small leaks. Even if successful, repeated injections over time may be required to maintain continence.[6]

Male sling – The AdVance™ XP Male Sling System from Boston Scientific is positioned in the body with a minimally invasive,[7] surgical procedure for correcting stress urinary incontinence. A small "sling" made of synthetic mesh is placed inside the body through three small incisions. The sling supports the urethra, restoring normal bladder control.[8] Most patients are continent immediately following the procedure.[9]

Artificial urinary sphincter – The AMS 800™ Urinary Control System is the "Gold Standard Treatment" for incontinence.[10,11] This implantable device mimics the function of a healthy urinary sphincter, closing off the urethra in order to stop the flow of urine.[12] The procedure involves implanting an inflatable cuff around the urethra, which is inflated by a fluid-filled balloon that is placed behind the pelvic bone.[13] A pump inside the scrotum allows the man to deflate the cuff when he needs to urinate. It will automatically re-inflate, firmly closing off the urethra, preventing leakage.[13]

Incontinence: Stress urinary incontinence (SUI) quiz

This short quiz helps evaluate your level of incontinence and can be a useful tool in discussing your progress with your doctor.

1. How long ago did you complete your prostate cancer treatment?

   Years Months

2. What prostate cancer treatment did you (or the person you care for) receive?

   - ☐ Radical prostatectomy
   - ☐ Radiation therapy
   - ☐ Combination therapy (i.e., Radiation and surgery)
   - ☐ Medication
   - ☐ Other

3. How often do you (or the person you care for) leak urine?

Never	About once a week or less	Two or three times a week	About once a day	Several times a day	All the time
0	1	2	3	4	5

4. How much urine do you think (or the person you care for thinks) usually leaks (whether protection is worn or not)?

None	A small amount	A moderate amount	A large amount
0	2	4	6

5. Overall, how much does leaking urine interfere with your (or the person you care for's) everyday life?

Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

6. When do you (or the person you care for) leak urine? (select all that apply)

   - ☐ Never
   - ☐ Leaks before I can get to the toilet
   - ☐ Leaks when I cough or sneeze
   - ☐ Leaks when I am sleeping
   - ☐ Leaks when I am physically active/ exercising
   - ☐ Leaks when I have finished urinating and am dressed
   - ☐ Leaks for no obvious reason
   - ☐ Leaks all the time

7. What solutions have you (or the person you care for) tried to cope with your bladder leakage? (select all that apply)

   - ☐ Lifestyle modifications (decrease liquid consumption, diet changes)
   - ☐ Bladder muscle exercise regime (Kegels)
   - ☐ Pads or diapers
   - ☐ Urinary catheter
   - ☐ Other

8. How would you (or the person you care for) feel if you (they) were to spend the rest of your life with your (their) current urinary condition the way it is now?

   - ☐ Delighted
   - ☐ Pleased
   - ☐ Undecided, don't know
   - ☐ Unhappy
   - ☐ Terrible

Add the corresponding numbers from Questions 3, 4, and 5.

Bladder Leakage Score: _____

Score Breakdown:[31,32]

1-5: Slight
6-12: Moderate
13-18: Severe
19-21: Very Severe

How common is incontinence following prostate cancer surgery?

Male patients who undergo a prostatectomy, the surgical removal of the prostate gland, may experience stress urinary incontinence (SUI) after their procedure. Studies indicate that as many as 50% of men report leakage due to SUI in the first few weeks following prostate surgery after removal of the catheter.[14] Data suggests a range of 8%–63% of men will report some degree of SUI to be a significant problem one year after their prostatectomy.[15,16]

Incontinence: Pad usage – weekly journal

Use this journal page to keep track of your pad usage. It will help you and your doctor evaluate your return to continence, and help to determine the best solutions for you.

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Restoring your sexual health

Many men find that it takes months or over a year to regain their ability to have an erection, and some men find that their ability to have an erection does not return.[17] Should the ED persist, there are both short-term and long-term solutions that can be considered, and you will want to discuss which solution may be right for you.

Penile rehabilitation[18]

A penile rehabilitation programme refers to a course of action designed to help the nerves responsible for erections recover after surgery, while maintaining the health of the penile tissue.

There are several factors that play a role in erection problems after prostate surgery. First of all, nerve damage can lead to erectile dysfunction. Even though your surgeon may have performed a "nerve sparing" operation, the techniques that are used to protect the erectile nerves may temporarily cause the nerves to be damaged and it may be more than a year before they recover.

Rehabilitation works for three reasons:

1. Gets more oxygen to the penis,
2. Keeps blood vessels healthy, and
3. Keeps muscles healthy.

Among 301 doctors from 41 countries, 84% performed or prescribed some form of penile rehabilitation. Your doctor will discuss the specifics of penile rehabilitation with you.

"The penile implant changed my life in such a way that confidence is abundant. I do not have to worry about whether or not I'm going to be able to satisfy my partner."

Treatment options

There are multiple treatment options available for ED. For some men, oral medications don't work,[19-21] so it's important to know all of your options. Find a solution to regain the confidence, control and wholeness you seek with an active, satisfying sex life.

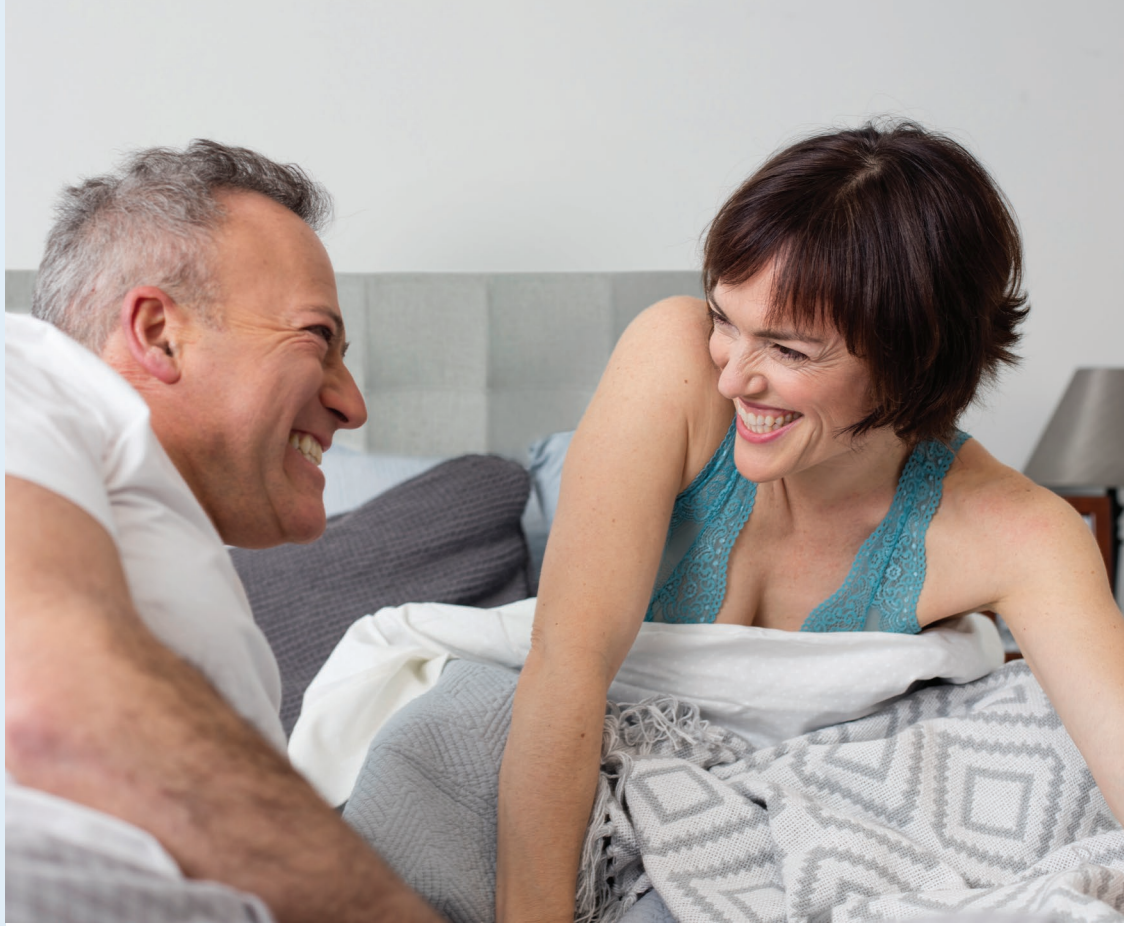
Oral medications – There are a number of prescription medications (for example, Viagra™, Cialis™ and Levitra™) available that may improve blood flow to the penis. Combined with sexual stimulation, this may produce an erection. Drug therapy is usually a first-line treatment option for most men experiencing ED, and may be used in conjunction with other methods as well.[22]

Injections and urethral suppositories – With injection therapy, a small needle is used to inject medication directly into the base of the penis.[22] The medication allows blood to flow into the penis, creating an erection. Many men find this method effective, but the idea of regular injections can be difficult to accept. Another option, MUSE™ is the same drug available in the form of a small pellet (suppository) that is inserted into the opening of the penis.[22]

Vacuum pumps – Pumps mechanically enhance the flow of blood into the penis. A plastic cylinder is placed over the penis, and a pump (either manual or battery operated) creates vacuum suction within the cylinder, drawing blood into the penis to create an erection. A stretchable tension band placed at the base of the penis can help maintain the erection.[22]

Penile implants – When drug treatments, injections and other non-surgical therapies are not successful or unsatisfactory in resolving ED, a penile implant may be a long-term, satisfying solution. An inflatable implant uses a pump surgically placed in the scrotum to inflate and deflate the penile implant. All components are completely concealed, and the implant allows for the ability to have an erection suitable for intercourse at any time.[22] Another type of penile implant is the positionable or malleable implant. It provides ease of positioning, cosmetic concealment and rigidity for sexual intercourse.[23]

An erection achieved with a penile implant can be safely maintained for as long as desired, which many men and their partners find adds to the quality of their sex life.



The journey to restored sexuality

For some men — and their partners — conservative treatments (vacuum pumps, injections, etc.) for ED may not be satisfying, and may affect the quality of their sex life. Surgical solutions provide more spontaneity. Whatever you are experiencing, it's important to maintain open lines of communication.

Involve your partner in the decision making, talk about what you are feeling, and experiment with new ways of being intimate together. The journey might be a challenging one, but working through it may actually strengthen your love life in unique ways.

Sexual health: Sexual health inventory for men (SHIM)[24]

This questionnaire is designed to help you and your doctor identify if you may be experiencing erectile dysfunction. If you are, you may choose to discuss treatment options with your doctor.

Each question has several possible responses. Circle the number of the response that best describes your own situation. Please be sure that you select one and only one response for each question. For an online version of the quiz, visit **www.edtreatments.com**

1. Over the past six months, how do you rate your confidence that you could get and keep an erection?

Very low	Low	Moderate	High	Very high
1	2	3	4	5

2. When you had erections with sexual stimulation, how often were your erections hard enough for penetration?

No sexual activity	Almost never or never	A few times	Sometimes	Most times	Almost always or always
0	1	2	3	4	5

3. During sexual intercourse, how often were you able to maintain your erection after you had penetrated your partner?

Did not attempt intercourse	Almost never or never	A few times	Sometimes	Most times	Almost always or always
0	1	2	3	4	5

4. During sexual intercourse, how difficult was it to maintain your erection to completion of intercourse?

Did not attempt intercourse	Extremely difficult	Very difficult	Difficult	Slightly difficult	Not difficult
0	1	2	3	4	5

5. When you attempted sexual intercourse, how often was it satisfactory for you?

Did not attempt intercourse	Almost never or never	A few times	Sometimes	Most times	Almost always or always
0	1	2	3	4	5

Total score: _____

The Sexual Health Inventory for Men (SHIM) classifies ED severity with the following breakpoints:

1–7: Severe ED 8–11: Moderate ED 12–16: Mild-moderate ED
17–21: Mild ED 22–25: No ED

6. Check any ED treatments you have tried:
   - ☐ Pills/Medication
   - ☐ Vacuum Device
   - ☐ Injection Therapy
   - ☐ MUSE™
   - ☐ Other

EDTreatments.com is a website sponsored by Boston Scientific Corporation.

Erectile dysfunction (ED) following major pelvic surgery is not uncommon. The nerves that control an erection lie very close to the prostate, and may be injured by being cut or separated from the prostate during surgery. This may cause temporary or permanent difficulty in achieving an erection, although sexual desire is not usually affected. After prostate cancer surgery, most men can still experience an orgasm (climax) but no ejaculation.[25,26]

Sexual health: Frequency of intimacy

Keeping track of your sexual experience post-surgery can be helpful for you and your doctor as you evaluate your erectile function. Use this journal page to make note of every attempt or occurrence of sexual activity (including intercourse as well as masturbation). Note whether attempts were unsuccessful (U) or successful (S) and/or the quality of your erections (bad/none=QB, poor/partial=QP, fair/full=QF or good/rigid=QG).

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Resources

Healing Well is a social network and support community. You'll find information, resources and support, plus access to helpful forums and chat rooms where you can ask questions to members of the prostate cancer community.
www.healingwell.com

Prostate Cancer Research Institute's mission is to improve the quality of men's lives by supporting research and disseminating information that educates and empowers patients, families and the medical community.
www.prostate-cancer.org

Us TOO International Prostate Cancer Education & Support Network is a grassroots organisation started in 1990 by prostate cancer survivors to serve prostate cancer survivors, their spouses/partners and families. This not-for-profit charitable organisation is dedicated to communicating timely and reliable information enabling informed choices regarding detection and treatment of prostate cancer. Ultimately, Us TOO strives to enhance the quality of life for all those affected by prostate cancer.
www.ustoo.org

For almost 40 years the **European Association of Urology** (EAU) has addressed the most pressing issues of urological care in Europe, through its scientific and educational initiatives, as well as its publications. The EAU delivers training, stimulates research, organises exchanges and broadcasts information. More than 16,000 professionals have joined the EAU and together they create and explore numerous opportunities for professional growth and knowledge-sharing.
www.uroweb.org

The **European Association of Urology Nurses** (EAUN) is the representative body for European Urology Nurses. Its aims and objectives are to facilitate the continued development of urology nursing in all its aspects, including patient advocacy.
nurses.uroweb.org

With more than 9,000 members, the **European Association for Cancer Research**, founded in 1968, is Europe's largest member society for cancer research. The association enjoys particularly strong links with other European cancer societies and is a founding member of the European CanCer Organisation (ECCO). EACR has always had one guiding aim: The advancement of cancer research.
www.eacr.org

The **International Continence Society** (ICS) is a registered charity with a global health focus, which strives to improve the quality of life for people affected by urinary, bowel and pelvic floor disorders by advancing basic and clinical science through education, research and advocacy.
www.ics.org

Cancer.net provides timely, comprehensive, oncologist-approved information from the American Society of Clinical Oncology (ASCO), with support from the Conquer Cancer Foundation. Cancer.net brings the expertise and resources of ASCO to people living with cancer and those who care for and about them to help patients and families make informed healthcare decisions.
www.cancer.net/cancer-types/prostate-cancer

The **Spanish Association Against Cancer** (AECC) is the nationwide association fighting cancer by leading efforts towards reducing the impact caused by cancer and improving the lives of those affected by cancer. AECC integrates patients, families, volunteers and professionals who work together to prevent, raise awareness, accompany people and fund cancer research projects that will allow better diagnosis and treatment of cancer.
www.aecc.es

The **German Society of Urology** (DGU) is a scientific society with the mission to develop the scientific and clinical urology in Germany, to represent urology and urologists externally as well as the training and education of students and already trained urologists in their further education/training. The overall aim is to ensure a technically excellent and comprehensive urologic care for the population in Germany. This goal requires continuous learning and innovation in many areas of urology.
www.urologenportal.de

Bundesverband Prostatakrebs Selbsthilfe E.V., the German Association of Prostate Cancer, wants to understand the research and treatment options of prostate cancer to support the integration of the treatment into the clinical everyday work.
www.prostatakrebs-bps.de

Deutsche Kontinenz Gesellschaft E.V. is a medical-scientific society that has an interdisciplinary approach to support the prevention, diagnostic, treatment and care of urinary and fecal incontinence through training and educating doctors and patients.
www.kontinenz-gesellschaft.de

Frequently asked questions

How common is prostate cancer?[1]

Worldwide, more than 1.1 million men are diagnosed with prostate cancer every year, making it the second most common cancer in men. Two thirds of newly diagnosed prostate cancer cases are in the developed regions of the world.

Are some men more likely to be diagnosed with prostate cancer?

Older men, African heritage, and men with a family history of the disease all have an increased likelihood of being diagnosed with the disease. The common age for all men at prostate cancer diagnosis is 66 years old.[26]

How much does family history of prostate cancer increase my risk?

Men with a primary relative affected by prostate cancer (a brother or father) are more than two-fold as likely to develop the disease. Men with familial prostate cancer may develop the disease at an earlier age. They should begin testing with both the PSA blood test and the digital rectal examination at age 45 or even younger if they have multiple relatives with the disease.[27]

How curable is prostate cancer?

In general, the earlier the cancer is caught, the more likely it is for the patient to remain disease-free after treatment. Because approximately 90% of all prostate cancers are detected in the local and regional stages, the survival rate for prostate cancer is very high — nearly 99% after five years.[26,28]

What are the symptoms of prostate cancer?

If the cancer is caught at its earliest stages, most men will not experience any symptoms. Some men, however, will experience symptoms such as frequent, hesitant or burning urination, difficulty in having an erection, or pain or stiffness in the lower back, hips or upper thighs.[28]

What are some of the side effects from removing a prostate?

The two most feared side effects of radical prostatectomy are loss of erections and urinary incontinence. These side effects can occur but there are successful treatment options available. Also, after total removal of the prostate, there is no ejaculation, although there is the sensation of climax and orgasm.[25]

It's been a year since my prostatectomy and I still have no control of my bladder. What can I do?

Over the course of the first year following surgery, continence returns in the majority of men. However, 8%–63% of men will report some degree of SUI to be a significant problem one year after their prostatectomy.[15,16] After 12 months, if you are still suffering from SUI, you may want to seek out a urologist who specialises in restorative procedures.

Why don't all men recover erectile function after surgery?

Post-operative erectile dysfunction is compounded in some patients by pre-existing risk factors that include: older age, cardiovascular disease, diabetes, cigarette smoking, physical inactivity and certain medications such as anti-hypertensive drugs or psychotropic medications.[17]

When can a man resume sexual activity after a prostate cancer surgery?[17]

Sexual functioning can return after surgery — usually beginning within three to six months and then having continued improvement for two to three years. Erectile dysfunction can be treated with medication, vacuum erection devices, injections or with an implant.

Will I still be fertile after a radical prostatectomy?

There should be no seminal fluid after the prostatectomy, so you will no longer be fertile. Most men will still experience orgasm.[25]

What are penile implants?

Penile implants are a safe, surgical treatment option, have a high degree of patient satisfaction[29] and provide a natural feeling erection.[30] Ask your doctor to provide you with more information about this option.

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Notes

MH-715002-AA. Produced by Gosling.

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