For Prostate Cancer Recurrence, Rising PSA, and Advanced Disease

The Prostate Cancer Playbook

Strategies for Building Teams, Optimizing Treatment, and Living Well

Made possible through a charitable contribution from the Abbott Fund
Knowledge is Power

Are you or someone you love facing:

- A recurrence of prostate cancer
- A rising PSA, or
- Cancer that is no longer responding to treatment or has spread?

If so, this presentation and its accompanying booklet – *The Prostate Cancer Playbook* – have been developed to educate and empower you and your family.
Playbook Objectives
for You and Your Loved Ones

✓ Become more effective and confident in your decision making
✓ Better cope with the continuing impact of cancer on your lives
✓ Provide strength to one another
✓ Discover new meaning in life as you deal with prostate cancer.

Let’s get started!
Goals

- How to interact to your loved ones
- What to expect from your medical team
- How to stay positive during this time
- Where to go for additional support
- Why it is important to eat well and exercise
- How to address special concerns
In team sports, the home team has a significant advantage – their fans who cheer, root and energize them to go the extra yard and score winning points.

In prostate cancer, you also have a home team advantage – supportive family and friends!

While your doctors may change, your home team always will be with you.
Selecting Your Home Team

- With the powerful advantage that a home team offers, have you asked your loved ones:
  1. To join your home team?
  2. To take a more active role in understanding your disease?
  3. To partner with you to better manage your disease for the best possible outcome?

- When thinking about who to ask, think of those who are the most knowledgeable, capable and supportive.

- Your team should be uniquely suited to treat and care for you!
The Role of the Home Team

• What does a home team do?
  ✓ Go to doctor’s appointments
  ✓ Learn about the latest treatments
  ✓ Act as your own medical advocate
  ✓ Share the burden of this disease
  ✓ Cheer you up when you are feeling low
  ✓ Enjoy life’s many positive moments

• Remember, with a home team, you do not need to go through this disease alone.
Getting Started:
Become Informed

- Speak with other patients
- Ask your librarian for books/articles
- Join an Us TOO Support Group
- Go online/Internet
- Read the Us TOO booklet called, “What Now”
Getting Started:
Explore Your Options

• With your home team, become experts on:
  – Your stage of disease
  – New treatment options
  – Available pain medications (if needed)
  – Clinical study possibilities
  – Health and fitness regimens
  – Beneficial foods/a healthy diet
  – Stress management techniques
  – And more…
Getting Started:
Working with Your Medical Team

- Attend medical appointments with someone from your home team
- Ask questions – lots of questions, and have your team member write down the answers
- Bring a tape recorder
- Talk to your doctor about all of your concerns
- Become your own self-advocate – speak up!
Getting Started:
Find the Best Treatment Plan

• **Review** what you have learned with your home team
• **Share** your thoughts and concerns with each other
• **Consult** with your medical team and with your home team
• **Determine** the best course of action **for you.**
Getting Started:
It Takes Team Work

Studies show that families who communicate during stressful events report feeling better and less distressed.

During this time, openly share your feelings/concerns with your loved ones.

Thank them for their support.

Work together to share news of your disease and treatment with family and friends.

Listen to your loved ones’ feelings.
Assembling Your Medical Team

• Up until this point, you may have primarily been treated by your urologist.

• Now is the time to assemble a team of specialists to determine the best courses of action moving forward for you.

• This will include:
  – Your urologist
  – A radiation oncologist
  – A medical oncologist
Assembling Your Medical Team

- When selecting these specialists, talk to other cancer patients and your urologist
- Look for the very best and assess their experience (e.g., training/education, number of years practicing, amount of experience with your type of cancer)
- Equally important: identify physicians who are team players, and can work well with you, your home team and your other physicians
1. Get a full explanation of your diagnosis and treatment options
2. Seek second opinions from other specialists
3. Keep copies of all of your medical records
4. Prepare a list of questions before each medical appointment
5. Look for new treatment scenarios that are beginning to emerge
• Fluctuations and rate of change of your PSA value can reveal certain patterns or cycles
• Regular monitoring of your PSA levels is critically important and provides helpful information to your medical team and you for making future treatment decisions.
• Using the provided worksheet, track your PSA level, testosterone, DHT and timing of treatment and medication changes
• Note your actual numbers!
• Monitoring your Gleason score also can be beneficial
Sample tracking page, found in the Us TOO Playbook.

Suggestions: Make several photo copies and use the copied for on-going record keeping.
Examining Your Strategies: Assessment

- Prostate cancer is an ever-evolving challenge, particularly when you experience:
  - Recurrence
  - Advanced disease
  - Cancer that is not responding to treatment
- Before making any treatment decisions, you and your medical team will need to re-assess your cancer
- **Assessment tools** that may be used include:
  - Imaging tools (bone scan, CT, MRI, PET Scan, etc.)
  - Biopsies
• If cancer spreads to your bones, you may experience pain.
• However, various pain medications and treatments are available.
• If you are experiencing pain, speak to your doctor immediately.
• If your doctor is unable to help you, consult with a pain specialist.
• **You do not need to experience pain**, if medication can help.
Making the Best Treatment Choices

• You have taken many important steps up until this point, now is the time to carefully consider your best treatment plan.
• You do not have to rush this process.
• It is critical that you make a careful and informed decision.
• Your treatment options will vary, depending on your situation.
# Treatment Options

<table>
<thead>
<tr>
<th>Treatment Option</th>
<th>What It Does</th>
<th>How It Works</th>
</tr>
</thead>
<tbody>
<tr>
<td>External Beam Radiation Therapy (EBRT)</td>
<td>High energy-rays are administered by a machine outside the body through daily treatment for a period of several weeks.</td>
<td>High energy-rays are aimed through a single beam at cancer cells.</td>
</tr>
<tr>
<td>3D Conformal Radiation Therapy (3D-CRT)</td>
<td>High energy-rays are administered by a machine outside the body, allowing the body to be shaped to the contour of the cancer. Treatment takes place for a period of several weeks.</td>
<td>High energy-rays are aimed through three beams at different angles to concentrate intensity of radiation at the cancer cells.</td>
</tr>
<tr>
<td>Intensity Modulated Radiation Therapy (IMRT)</td>
<td>High energy-rays are administered by a machine outside the body through daily treatment for a period of several weeks.</td>
<td>Multiple beams of rays are aimed at the cancer cells, allowing the intensity of the radiation to conform to the shape of the prostate.</td>
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<tr>
<td>Proton Beam Therapy (PBT)</td>
<td>A beam of protons is aimed at the cancer cells by an external machine during daily sessions for 1 to 7 weeks.</td>
<td>Protons more precisely target cancer cells, allowing for reduced damage to healthy tissue. Performed in few locations in the United States.</td>
</tr>
<tr>
<td>LHRH Therapy</td>
<td>Inhibits stimulating hormone-releasing hormone.</td>
<td>Causes a drop in testosterone levels.</td>
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<tr>
<td>Antiandrogen Therapy</td>
<td>Administration of a drug, antiandrogen.</td>
<td>Actions of male hormones, including testosterone and androgens released by the adrenal glands, are blocked.</td>
</tr>
<tr>
<td>Estrogen Therapy</td>
<td>Administration of estrogen hormones.</td>
<td>Lowers testosterone production and may destroy both androgen-dependent and androgen-independent prostate cancer cells.</td>
</tr>
<tr>
<td>PSA Enzyme Inhibitors</td>
<td>Involved in hormone synthesis, including testosterone, that stimulates prostate cancer cell growth.</td>
<td>Can decrease levels of testosterone and adrenal androgens and slow the growth of prostate cancer cells.</td>
</tr>
<tr>
<td>Cryosurgery (frozen therapy)</td>
<td>Technique uses liquid nitrogen, or a similar cold agent, to freeze and destroy cancer cells.</td>
<td>Similar to radiation. Can be combined with hormone therapy to reduce the size of the tumor before freezing. Long-term effectiveness is still being evaluated.</td>
</tr>
<tr>
<td>High Intensity Focused Ultrasound (HIFU) Medical device placed by a transrectal ultrasound probe.</td>
<td>Ultrasound waves heat localized prostate cancer (increasing the temperature to 140°F) inside the prostate.</td>
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</tr>
<tr>
<td>Chemotherapy</td>
<td>The administration of powerful task drugs, usually by mouth, intravenously or intramuscularly.</td>
<td>Two drugs circulate throughout the body to kill growing cancer cells. Taxotere® (docetaxel) in combination with prednisone is indicated for the treatment of patients with androgen-independent (formally referred to as metastatic) prostate cancer.</td>
</tr>
</tbody>
</table>
Clinical Studies

- A clinical trial is a **research study** that is conducted with permission of the FDA to **investigate a possible new drug** for a disease/condition.

- Clinical trials are an **important treatment option** for you to understand and consider.
  - Cutting-edge therapies are being evaluated by cancer researchers

- To **learn more** about clinical studies:
  - Speak to your doctor
  - Ask other cancer patients
  - Visit [www.clinicaltrials.gov](http://www.clinicaltrials.gov)
  - Learn more at [www.ustoo.org](http://www.ustoo.org)
Worries, concerns, distress and frustrations can directly impact your physical and emotional well-being.

If you are focusing on the negatives, stop and look at the positives – get your head in the game.

Easier said than done?

Try some positive-thought boosters
Positive-Thought Boosters

- Avoid violent or depressing movies, books or TV shows
- Go on a “news fast”
- Associate with calm, positive people
- Release any grudges
- Appreciate nature’s beauty and wonder

- Say positive affirmations
- List your gratitudes
- Volunteer your time
- Renew your commitment to purposeful activities
- Show some love to your home team!
Studies have shown that patients who regularly attend support groups tend to live longer than those cancer patients who do not. Us TOO has over 320 peer-to-peer chapter support groups worldwide that hold regular free meetings for:

- men living with prostate cancer
- their family and friends
- health professionals interested in this disease.

Go to www.ustoo.org
Caring for Your Caregiver

• While your caregiver may not have prostate cancer, they are having a very real experience with prostate cancer

• It is critical that your caregivers also care for themselves, and for you to remind them to:
  – Manage for their own health (eat well, sleep, exercise)
  – Receive emotional support from family, friends, support groups
  – Continue to enjoy their favorite activities and hobbies
Common Concerns

- Two of the most common concerns are:
  - Incontinence (urine leakage)
  - Impotence (erectile dysfunction)
- If this is happening to you, talk to your doctor and visit www.ustoo.org for more information.
- Treatment options are available.
Getting Additional Help

• Your family and you are carrying many burdens at this stage, and this is no time to “go it alone”
• Assistance is available for many different needs:
  – Understanding health insurance coverage
  – Information gathering and discerning
  – In-home care
  – Light housekeeping/house repairs
  – Transportation
  – Caregiver support
  – Equipment/adaptive aid services

• Talk to an expert in your area and learn what is available to your family and you
An All-Star Fitness Plan

• Your body is experiencing enormous stress in its battle against cancer.

• You can **help your body** fight cancer by:
  – Eat a healthy well-balanced diet
  – **Condition your body** with exercise
Conditioning
Your Body

- Walking
- Weight resistance exercises
- Yoga/Pilates
- Stretching
- Tai chi
- Meditation
- Trampoline (small rebounder)
- Exercise bike
- Treadmill
- Rowing
- In-line skating
- Elliptical trainer
Keeping Your Bones Healthy

- **Hormone therapy** sometimes can lead to bone fractures, hospitalization and reduced mobility.
- **Maintaining your bone health** is an important part of your prostate cancer management.
- **Things you should do are:**
  - Measure your pre-treatment bone height
  - Demand a bone density test
  - Get your daily requirements of calcium and vitamin D
  - See your doctor if you have pain for more than 7 days
  - Do weight bearing exercises to strengthen your bones
• While we always hope for long-term survival, there may come a time when this is no longer the case.

• If you have reached this phase of your life, you still have options.

• A discussion with your doctor about your quality of life can lead you to local palliative and hospice care resources.
An interdisciplinary hospice team includes:

- your doctor
- hospice nurse
- home health aide
- social worker
- Respite care volunteers
- others
Several major resources to support you & your loved ones, include:

- Managing the patient’s pain and symptoms
- Assisting with the patient’s emotional, psychosocial and spiritual needs
- Providing needed drugs, medical supplies, and equipment.
- Coaching the family on how to care for the patient.
- Delivering special services, like speech and physical therapy, when needed.
- Making short-term in-patient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time.
- Providing bereavement care and counseling to surviving family and friends.
Hospice and Palliative Care

Call the National Hospice & Palliative Care Organization Helpline at 1-800-658-8898 or visit www.nphco.org
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