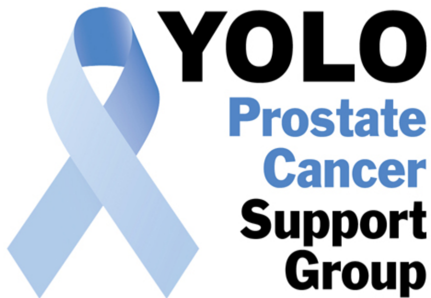
PROSTATE CANCER

An Informative Guide for the Patient You



Hello

If you are a new prostate cancer patient, we welcome you to a new world of friends who are here to extend a helping hand, if it is your wish. Each man is different before and after treatment, and the path ahead will also be different for you. Information is **key** to reducing fear, thus become a student of the disease, and feel free to ask questions.

Objective

This booklet is NOT a text book, but is to serve as a guide of snapshots of published information and where you may find the full text of the references. The **key** is for **you** to get a copy of the reference(s) for an in-depth study that will help you to crystallize your concerns.

En Española

Pacientes con cáncer de próstata que deseen tener más información en española, que tienen está enfermedad y el tratamiento, podemos ayudar.

Compiled and made available by the"
Yolo Prostate Cancer Support Group July 2019
Printing was by the courtesy of :
Senior Center, Woodland, CA with our sincere "Thanks"

All rights reserved : July 2019

Contents

Page #

Chapter 1 - the Yolo Prostate Cancer Support Group 4
Here to Help,
Chapter 2 - the Disease & - Early Detection 7
Better Early than Never . .
Chapter 3 - Inform Yourself - Help is Here 13
You are NOT alone .
Chapter 4 - Questions to Ask My Doctor 19
Answers are needed
Chapter 5 - DNA Genetic testing 23

Chapter 6 - Tests and Testing - Get Answers . . . 26
Numbers and Pictures . . . . .
Chapter 7 - Treatment Options - Which One 29
Get the Facts,
Chapter 8 - ED 1 vs ED 2 - To get up 32
Keep or Restore
Chapter 9 - Incontinence - Urine leakage 41
Stop the drip
Chapter 10 - Recurrence - If it comes back . . . 43
How best to deal .
Chapter 11 - Advanced Prostate Cancer 46

Chapter 12 - Fatigue, - Very tired 49
It may happen . .
Chapter 13 - Communication need to talk 51
Make it easy
Chapter 14 - Plant Based Diet 53

Chapter 15- Peer Navigators - Help, if needed . .. 54
A Friend's aid
Chapter 16- Educational Resources 55

For YOU Your record - a Worksheet 57
Your record
Last page 59

Chapter 1 - the Yolo Prostate Cancer Support Group

The Yolo Prostate Cancer Support Group provides a discussion forum for men who are dealing with prostate cancer issues. At group meetings men have an opportunity to raise questions, share concerns and exchange personal experiences. By fostering communication the support group hopes to provide encouragement, dispel myths, and offer useful prostate cancer information

Who Should Attend ?

Men who find themselves with any one of the following needs, and women who have concerns about their men:

1. seeking early detection procedures,
2. contemplating treatment options,
3. comparing treatment results,
4. learning more about therapy to manage side affects,
5. undergoing active surveillance,
6. experiencing recurrent disease,
7. sharing their personal experience to help other men,

Why Should You Attend ?

As the result of clinical studies and ongoing research, there is a constant flow of new and updated findings for the treatment and prevention of prostate cancer. Attending meetings can help men sort through the maze of information. As a result men ultimately learn more about the disease and are able to make better informed decisions. Many of the support group meetings feature presentations by medical professionals and specialists.

As the subject for many men is a very private matter, we have one cardinal rule, "What is said in the meetings stays within"; thus you are assured we will keep private your concerns.

When and Where ?

When: second Monday evening of each month at 7:00 p.m.

Where:

Odd numbered months	**Even** numbered months
Woodland Senior Center	Yolo Library, Davis Branch
2001 East St. Woodland, CA	312 East 14th St., Davis, CA

visit our **website:** www.yoloprostate.net

join our email list to receive news and meeting notices.

Additional Information ?

For additional information about the Yolo Prostate Cancer Support Group, you may call any of the following men:

Harold 530-756-9153, Joe 530-758-8322, Ray 530-756-6408

or Gil 530-661-6449 Paul 530-758-1616 Art 530-756-5768

Other Support Groups in Sacramento

Mercy San Juan Medial Center

This group meets at: Mercy Physicians Plaza
6555 Coyle Ave., Rm 150 Carmichael, CA 95608
1:30–3:30 p.m. the third Thursday of **Odd**-numbered months.

UC-Davis Medical Center

This group meets at: UC Davis Cancer Center Auditorium
4501 X St., Sacramento, CA 95817
1:30–3:30 p.m. the third Thursday of **Even**-numbered months.

For additional information about the two above groups,
contact: Beverly Nicholson, R.N. 916-537-5237 or
e-mail: beverlynicholson@comcast.net

Other Support Groups in California

Visit website: www.prostatecalif.org or
Or e-mail: Bill Doss, wdoss@surewest.net
Stan Rosenfeld : vegstan2@ix.netcom.com

The Story of Yolo Prostate Cancer Support Group

In early 2007, some Davis, CA men were at a Sacramento PC-SG meeting, and thus met for a cup-of-coffee in Davis to visit and exchange views of common concerns. This became to creation of the Davis PC-SG on March 2007, with a core of 7 men, meeting at the *Caffe' Italia for a morning cup-of-coffee.* More PCa patients started coming and each with a story of his journey.

In March 2008 the group moved to the Davis Senior Center with an evening meeting on a set monthly date and time. This lasted till May 10, 2010 when the group was offered the conference room at Sutter-Davis Medical. We were there for 2 years, when Sutter informed us they were remodeling and thus we were out. Luck was with us to find the welcome hand of the Woodland Senior Center and held our meeting there on April 9, 2012 Also we received an offer from the Yolo Public Library in Davis, and met there in July 2012. To serve the men in the area, the Group decided to meet on even months in Davis, and odd months in Woodland. Our sincere 'thanks' to each. The group changed our name from Davis PC-SG to **Yolo PC-SG.**

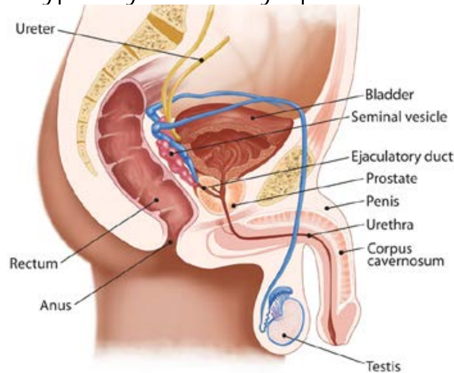
The group always elected to be a technical group with speakers with a message related to the subject, and some time for attendees to ask questions. During the past 12 years, we know from the attendance sheets that over 212 men have attended our meetings. The group has functioned by a core of men who volunteer their time, to whom each has our "sincere **Thanks**.

Each year during September, PC Awareness Month, we receive *Proclamation for Awareness* from the City of Davis, the City of Woodland, and the Yolo County Board of Supervisors. Also we have had a display table at the Farmer's Market on each Saturday in September in Davis. For Health Fairs, the group participates with a display table. Out- reach to men is a primary goal of the group to spread the word "We are here to assist you".

"There is Hope".

Chapter 2 The Disease

The prostate is part of the male reproductive system. Located below the bladder and just in from of the rectum, this walnut size gland make fluid for semen. Cancer is a disease that cell form tumors, which can spread to other parts of the body if left untreated. The majority of newly diagnosed prostate cancer is localized, the tumor is still within the prostate. Prostate cancer in its early stages typically has NO symptoms.



September is Prostate Cancer Awareness month. To raise the awareness, many local governmental entities grant proclamations as a symbol of participation. Most of these proclamations provide factual information regarding the disease. Let's review some of the facts:

1. In California the estimated number of men who will be diagnosed with prostate cancer during the year 2018 is 15,190, and in 2019 is **24,550**.
2. In California the estimated number of men who may die of the disease during the year 2018 is 3,490, and in 2019 is: **4,470.**
3. The survival rate approaches 100% when prostate cancer is diagnosed and treated early, but drops to 28% when the disease spreads to other parts of the body.
4. Little is known about the causes of prostate cancer and most prostate cancer cases are detected as a result of a PSA screening test followed by other tests to confirm the present of prostate cancer.
5. In the Yolo Prostate Cancer Support Group, the youngest man to come for help was 36 years of age, and the youngest man to die of the disease was 53 years of age.
6. Thus there are good reasons for men in their early forties to be concerned, and to become **informed** about the disease.

September may be the time for you to take stock of your health, and to seek information by checking at the local library for any of the available books, or attend a Support Group meeting. Then a leisure cup-of-coffee with a survivor who may open the door for you, please remember it is "**Better Early than Never"**

Early Detection

Most men will eventually develop prostate cancer if they live long enough. Typically, the disease is slow growing, and many men live for years with prostate cancer and die from other causes. However, in some men, the cancer appears earlier in life, grows more rapidly and, if left untreated becomes life-threatening. Prostate cancer will affect one in six men, and one in thirty will die from it. It is the second leading cause of cancer deaths in men. There are no clear cut symptoms in the early stages of the disease, and at present, the earliest indicator is an abnormal Prostate Specific Antigen (PSA) blood test.

A PSA test is a simple blood test and the result is only a number. So, what is the risk and /or harm in testing? There is no real risk from the test itself. A single PSA test is nearly worthless, because a series of tests over time is needed to know if the result is increasing and at what rate. The PSA test does NOT indicate cancer, but only means that other tests may or may not be required, including a digital rectal exam (DRE) and, if indicated, a prostate biopsy. Only the biopsy will provide the data that cancer is present. Unlike other forms of cancer that do NOT have an early detection marker, changes in the PSA level are important signs that a patient should be referred to a urologist or an oncologist for further examination.

Dr. Stephen Jones (Reference 2, as listed below p. 193):
"+PSA is the best tumor marker ever identified. However, it is still only a tool to predict the likelihood of cancer.
+The normal PSA rises with aging, but most men should have a PSA below 2.5. A level higher than that doesn't necessarily require a biopsy, but you should discuss with your physician.
+ Early detection suggest that mortality is decreased substantially in populations aggressively screened.
+No one ever died of PSA. The concern is not its level, the concern is why it is elevated."

Dr. Peter Scardino (Reference 3, as listed below page 143):
"I'd urge you to make sure you're fully informed before deciding to forgo screening for prostate cancer. Blinders are poor defense against a lethal disease. You don't want to undergo unnecessary invasive treatment, but neither would you wish to die unnecessary from a disease that is highly treatable, if detected in time. Detecting a cancer does not mean you're compelled to have it treated."

Those who advocate for PSA screening believe early detection is important and does save lives, because without such testing, some men will surely die prematurely. An annual PSA test establishes the baseline level for each man, from which any change can be measured and timed. Testing empowers the patient with knowledge of his annual PSA levels, and if, at a later date, he finds his PSA has a much higher value, then what ? He can move forward with a rigid program of re-checking test data, obtaining additional tests, and taking time to become 'informed'. If a biopsy is positive for prostate cancer, decisions about which treatment, if any, are the subjects for separate and may be fully presented in **current** published literature, which may be on the shelf of your local library.

In Summary

Early Detection is necessary if a man wishes to ward off problems associated with prostate cancer before it has spread to other parts of the body. Thus E A R L Y is the key.

E - is for Early detection,
A - is for Awareness, to become acquainted with test results and the significance of the changes.
R - is for Reliance, on yourself to increase your learning curve by becoming a student of the subject.
L - is for Life, to live a longer life by taking charge.
Y- is for Yearly, obtain your annual PSA and DRE is a MUST.

Now go back and re-read item 5 on the first page of this Chapter, which bring reality back into life versus medical options. The PSA debate is **OVER**, and the conclusion is "It is better to be tested and know the results of the blood test, and then make decisions regarding your own life.

Prostate Cancer Screening Guidelines

These screening guidelines apply to all men who have concerns of their health, and wish to know some basic information regarding bodies. The information has been collected from PCa survivors of the Yolo Prostate Cancer Support Group of which there has been over 200 men.

Yes, there are some Screening guideline that state as age increases PSA testing may be omitted till later in life, but this misses the point, the sooner PCa is discovered the chances it can be treated, as the treatment for cancer within the prostate is far better than treatment after it has spread outside of the prostate – in short it is then metastasized .

Let's review the PSA test values, there are two types; (1) normal, which reports to the nearest 0.1 or <0.1, and (2) ultrasensitive, which reports to the nearest 0.01, which is used when PCa is being monitored for tracking the increase of PSA.

Now let's review PSA testing for men who have been treated for Prostate cancer, and are survivors, they in order to discover if cancer has returned, if so refer to Chapter 9 – Recurrence.

There is another option for men who may wish to determine if they are likely to become a candidate for prostate cancer and that option is to obtain a DNA genetic test. See Chapter 5 for information.

<u>Men ages 40 to End-of-Life</u>

a. Should have a baseline PSA test taken annually

b. If the PSA level is less than 1 ng/mL, men should continue with annual tests.

c. If the PSA level is between 1 and 3 ng/mL, men should see their doctor for taking PSA tests every six months to determine if there is an increase in the level PSA over a period of time. .

d If the PSA level is 3 ng/mL or higher, men should talk with their doctor about having a biopsy of the prostate, as the Gleason score will provide the rate of aggressive growth.

Note: ng/mL is an abbreviation for Nano-grams per milliliter. This is a lab test measurement to identify the amount of a specific protein in a donor's blood sample.

Reference:
https://www.mskcc.org/cancer-care/types/prostate/screening/screening-guidelines-prostate .
Memorial Sloan Kettering Cancer Center

It is a MUST

1. Obtain a PSA test and a DRE exam yearly starting at age 40
2. It there appears to be an abnormal DRE, and/or a much higher PSA test result than previous tests, then there is reason to conduct further tests to determine if prostate cancer is present.
3. If prostate cancer is present, then it is time for the patient to seek a second opinion, and to conduct an in-depth study of current literature regarding various treatment options.
4. Men, become informed, and get your annual PSA **tests.** Do not be overcome by fear of the word, "cancer", it can be treated, if needed.
5. Should you be diagnosed with prostate cancer and elected Active Surveillance (AS), then STAY with the protocol prescribed for you. A recent study reports that in Los Angeles, about 50% of men on AS have become LOST for some reason, but denial is NOT the Nile river, the water continues to flow and your cancer will continue to grow. Ref: UsTOO "Hot Sheet" April 2017

Be Aware, there are some items that may cause a false PSA result to be higher. During a 48-hour period of time before the blood test, you should avoid doing items, such as: (1) bicycle riding, (2) sexual activity, (3) a DRE conducted just before, and (4) some medications. Talk to your Doctor about just these considers.

Your Public Library,
Visit your public library for current books about prostate cancer, which will provide you the information about the disease, and the many options of testing, treatments, side effects, and the new technology.

Support Groups
Prostate cancer support groups do not give medical advice nor come between a doctor and his patient, but do seek to offer emotional support and provide presentations, discussion sessions, and published literature; plus the social events of survivors who voice their experiences.

A new Blood test approved :

FDA approved on June 25, 2012, the Prostate Health Index (phi), a simple, non-invasive blood test that is 2.5 time more specific in detecting prostate cancer than PSA, in the range of 4-10 ng/mL range, and thus reduces the need for biopsies. Ref: **www. uspreventiveservcerstaskforce.org/prostatecancerscreening.htm.** Beckman Coulter, U.S. Prostate Cancer Pivotal Study Report

Resources

American Urological Association, AUA,
1000 Corporate Blvd, Linthicum, MD 21090
website: http://www.UrologyHealth.org or www.auanet.org

Prostate Cancer Foundation, Inc 1250 Fourth St., Santa Monica, CA 90401, 1-310-570-4705 1-800-757-2873
http://prostatecancerfoundation.org

California Prostate Cancer Coalition (CPCC) 7825 Fay Ave., Ste. 200, La Jolla, CA 92037 1-707-786-7009
website: http://www.prostatecalif.org

Us TOO International, Inc 2720 S. River Rd. Ste 1112
Des Plains, IL, 60018 telephone help# 1-800-808-7866 or 1-630-795-1002 website: http://www.ustoo.org

References regarding PSA tests, please obtain and read.

1. *Mayo Clinic Essential Guide to Prostate Health*, by Lance A Mynderse, M.D., 2015 pub. Mayo Clinic
2. *The Complete Prostate Book* by J. Stephen Jones M.D. 2005 pub. Prometheus Books, (at Davis Public Library)
3. D*r. Peter Scardino's Prostate Book* by Peter T. Scardino M.D. Judit Kelman, 2010, pub. Penguin Group. (at Davis Library)
4. *The Prostate Health Program, A Guide to Preventing and Controlling Prostate Cancer* by Daniel W. Nixon M.D. and Max Gomez PhD 2004 pub Free Press (at Davis Library)
5. *The Davis Enterprise* issue dated, September 18, 2012 "Inform Yourself About Prostate Cancer" regarding the PSA Debate.

Chapter 3 - Inform Yourself

Get Information

You have been diagnosed with **prostate cancer** and are filled with fear about your future. **Now what ??** Yes, most survivors have been there and have walked the same path. Talking to a fellow survivor can help reduce your fears, help you better understand your prospects, and give you suggestions about available resources. Most prostrate cancer cases are not urgent, so you can take some time to learn the about the disease and various treatments. Each man is different, emotionally as well as physically. Thus what works for one man may not work for another.

Step 1. Obtain a medical book, such as listed on **book list # 1**. This will give you a basic understanding of prostate cancer and of various treatments. You have now learned the terminology on which to build more detailed information.

Step 2. Find a Prostate Cancer Support Group. Hearing the experiences of other men is reassuring and will make the printed words more meaningful and relevant to you. If you have a computer and can access the Internet, try some of the **websites** listed below in **List 4 - websites.**

Step 3. Obtain a book that goes into more depth such as a book(s) on the **book list #2** Every time you read it, you will discover an item over-looked before. and so you are now becoming 'informed'.

Step 4. What has your Medical Team told you about the "Stage" of your cancer?. Stage is a term used to describe "**aggressive"**. How fast is your cancer growing, slow, intermediate, or fast ? This is the most important question to be answered NOW!!

Step 5. Get a second opinion. One opportunity for a second opinion is to consider a panel of medical specialists, called **The Second Opinion,** a 501(c)3 non-profit agency in San Francisco. They will review your medical records and offer a medical opinion free of charge.

For info: call **The Second Opinion**
Telephone # 415-775-9956 or visit http://thesecondopinion.org
to obtain basic information and an application.

Step 6. The selection of treatment depends upon your personal situation. What is your age? What are the potential side effects? Can you live with them ?. Is your partner on-board? The decision about which treatment is **yours** to make. Thus, take the time to satisfy yourself of facts about the treatment you have selected.

Step 7. Have you considered consultations with other more focused specialists such as: urological oncologist, radiation oncologists, and to learn more about specialized imaging, other medical clinics, diagnostic laboratories, robotic surgery devices, and special radiation equipment that are available?

Step 8. Select a treatment plan, and proceed knowing the post-treatment may be different from your expectations. Remain an attendee with the prostate cancer support group. Sharing your experience will help you progress through recovery and to cope with any side affects. The relationship with other survivors is vital to restoring your quality of life.

Become INFORMED

Because prostate cancer is a complex disease, and there are many options for treatment; patients are being given the advice to become "informed". The problem is "To become informed about, "WHAT and by WHOM". There are two sides to this coin, on one side is the patient and his needs, on the other side is the Doctor and what is expected from him.

First the patient himself is responsible to become knowledgeable of the disease and the treatment options as all decisions are HIS to make.

Second the physician providing care is responsible to inform the patient of the values of each options and of the tests required to obtain the data needed to support the decisions.

Items for the Patient

1. Importance of Family members !

There is sufficient medical records that link risk of the disease to some degree of being "inherited", especially between father, uncle, brother, or son; and also some ethnic groups have a higher risk factor.

2. At any time should the PSA test result shows an increase, what steps should be undertaken to determine if it is significant? If so repeat the PSA test. Ref to: http:/tinyurl.com/caprisk.

3. How does the patient determine if the cancer is 'aggressive'? This question must be determined by the physician, and the answer may dictates its relevant to treatment options.

4. If early detection does NOT discover aggressive cancer, what are the risk?
Then in time when it is found, it depends on how far the cancer has developed, and will be difficult to impossible to treat, leaving only to manage it.

5. It is well known that to obtain factual data regarding the cancer, a biopsy is needed, thus is there any risk?
Yes, there may be in minor cases, some bleeding, or an infection, but these are very minor and are worth the risk to obtain the data which is a MUST for further decisions to be made.

6. If the biopsy reveals cancer, what is the next step ahead?
First, because ALL decisions ahead are made based upon the results of the biopsy, it is a MUST to have an independent Second Option of the biopsy. Then one can determine a Treatment option.

7. Should my first PSA be undertaken after some symptoms have developed? Prostate cancer has NO symptoms, and if one waits for any symptoms, then it is too late for treatment leaving only various ways to manage the spread and the pain.

8. After obtaining the facts of biopsy(s), and of treatments, and the side effects, are the decisions his to make?
The decision to obtain PSA tests are yours to make, the decisions regarding further tests, treatment options are best to be made after a joint discussion with your physician.

Items for the Physician

The USPSTF has provided the standard for informed decisions between the clinician and the patient.

1. Having a relative who has had the disease, double the risk factor of the patient. Other items that increase the risk are prostatitis, obesity, diet of red meat, and lack of exercise.

2. Should there be an increase in the PSA result, a repeat test must be taken, then consider if a biopsy is necessary. (Journal of Urology Vol. 185, issue 5, p. 1650-1655, May 2011)

3. Early screening created a 40% decline in prostate cancer mortality, due to treatment of the disease. Currently there are about 20 various treatment options. (ref: UsTOO pamphlet "Pathways")

4. Various trials found contradictive results regarding PSA screening, but have concluded that there should be no doubt about the fact that screening does save lives.

5. The risk factors related to obtaining a biopsy are minimized when proper clinical procedures are used.

6. If the biopsy indicates cancer is present, then it is a MUST to determine "How aggressive is the cancer?" Low-risk cancer can be addressed with Active Surveillance (AS). However if the cancer is moderate-risk, then other treatment options should be discussed including the side-effects of each.

7. Should be biopsy indicate the cancer has spread to other parts of the body, then it is no longer curable, and treatments to manage the cancer must be discussed. **???** A scan is required to confirm that cancer has spread to other parts of the body.

8 A factual discussion must be undertaken to review ALL the facts of the disease, the desires of the patients, the treatment options that best meets the patient's desires, and long-term quality of life.

Reference:

Calif. Prostate Cancer Coalition, Guideline "Prostate Cancer – Informed Decision Making for Men 40 and Over", 2014

BOOKS and/or BOOKLETS

List # 1. - Books with basic information

1. *100 Questions and Answers About Prostate Cancer* 3rd Ed. (2013) Pamela Ellsworth M.D., pub. by Jones and Bartlett,
2. *What You Need to Know About Prostate Cancer* (Sept. 2008) by US Dept of HHS, and National Institute of Health, pub. No. 08-1576, 54 p.

List # 2. - Books with in-depth information

3. *Guide to Surviving Prostate Cancer, 3rd Ed.* (2012) Patrick Walsh, MD, Warner Books, Davis Public Library
4. *Mayo Clinic, Essential Guide to Prostate Health* (2015) Lance A. Mynderse M.D., Mayo Clinic, Rochester, MN
5. *Dr. Peter Scardino's Prostate Book* (2010) Peter T. Scardino M.D. and Judith Kelman, Penguin Group. 565p. (Davis Public Library)
6. *The Johns Hopkins Medical Guide to Health After 50* (2002), Medical Editor Simeon Margolis, M.D., Ph.D. 441 p.
7. *Patients' Guide to Prostate Cancer* (2010) by John Hopkins Medicine, Jones and Bartlett, 137 p.
8, *The Complete Prostate Book* (2005), J. Stephen Jones M.D. Prometheus Books, 425 p. (Davis Public Library)

List # 3. Books with general and/or recovery information

9. *Promoting Wellness for Prostate Cancer Patients* 2nd Ed, by Mark A Moyad MD, MPH, 2013 Spry Pub. p.288
10. *Prostate Cancer, A Patient's Guide to Treatment (2004)* Arthur Centeno, M.D., Gary Onik, M.D., and Jack Allen Kusler, Addicus Books, 145 p.
11. *The Supplement Handbook.* by Mark A. Moyad MD. Pub by: Rodale Pub. 2014 p 500+/-
12. *Brachytherapy and IMRT* (2007) Michael J. Dattoli, MD, Jennifer Cash, and Don Kolten Bach by. Dattoli Cancer Foundation, 61p.
13. *Surviving Prostate Cancer Without Surgery (2005)* by Michael J. Dattoli, Jennifer Cash, and Don Kalten Bach, Seneca House Press. 268 p.
14. *Surviving Prostate Cancer Without Surgery* (2005) Bradley Hennenfent, M.D. Roseville Books, 322p.
15. *The Prostate Health Program, A Guide to Preventing and Controlling Prostate Cancer* by Daniel W Nixon MD, and Max Gomez PhD, 2004 pub. Free Press (copy at Davis Public Lib.)

List 4 - Websites

The following websites are available for information regarding Prostate Cancer, treatment options, side effects, wellness, nutrition, recurrence, and other related topics.

1. http:// www (of Yolo-Prostate Cancer Support Group
2. www.cancer.gov National Cancer Institute
3. www.prostatecancerfoundation.org Prostate Cancer Foundation [www.pcf.org]
4. www.ustoo.com UsTOO Prostate Cancer Education and Support , newsletter Hot Sheets
5. www.cancercare.org Cancer Care
6. www.mayoclinic.org The Mayo Clinic
7. www.pcri.org and www. prostate-cancer.org Prostate Cancer Research Institute, Insights; Sponsors of the September Prostate Cancer conference in Los Angeles, Calif.
8. www.paactusa.org Patient Advocate for Advanced Cancer Treatments, they issues a quarterly newsletter with updates by Dr. Mark Moyad.
9. www.prostatecancerinfolink.net a daily blog update on news related to prostate cancer, wide range of resource and education material, discussion section for sharing information with other PCa patients.
10. www.prostatecalif.org Calif. Prostate Cancer Coalition

Chapter 4 - Questions to Ask my Doctor

A. When were you informed, “you have prostate cancer “:

1. What is my PSA level ? What is the significance?
2. Exactly what type of prostate cancer do I have ?
3. How do I get copy of my Pathology report ?
4. What is my Gleason score? Its significance is?
5. What is the cancer's clinical stage and grade ?
   How aggressive is the growth rate of my cancer ?
6. Has the cancer spread beyond my prostate ?
7. What are my chances of survival, and for how long?
   (with and without treatment)
8. How much experience do you have treating my cancer?
9. Will I need other tests before we decide on treatment ?
10. What are my treatment choices ?
11. What treatment do you recommend and why?
12. Is active surveillance an option for me?
13. If I have surgery, will the nerve bundles be spared?
    Will the surgery be open or robot-assisted?
14. If I have radiation, will it be external beam or by
    implanted seeds?
15. What are pros and cons of each type treatment ?
16. Should I get a "second opinion"?, and from where?

B. When deciding on a Treatment :

1. Will the cancer return after being treated?
2. Will I be able to have children after treatment?

3. When & Where will treatment be conducted ?

4. Will the treatment cause incontinence or ED?

5. Are there other side affects, and how are they treated ?

6. How will my daily life change, can I keep working?

7. Will there be any pain during treatment or recovery?

8. Will I have any physical scars ?

9. What literature is available for treatment details?

10. What will be my out-of-pocket costs, and will the Insurance company cover the major portion?

11. May I obtain a name of a PC survivor who has had the same treatment ?

12. Should I consider taking part in a clinical trial?

C. Before treatment :

1. What can I do to get ready for the treatment ?

2. Will I need a blood transfusion ?

3. Do I have all tests necessary before treatment ? What is my current PSA, and testosterone ?

4. Should I change what I'm eating or make any lifestyle changes ?

5. If you have decided for a treatment that involves Radiation, you should review info about Space OAR to add some protection for adjacent organs. www.spaceoar.com ph 781-895-3235 or 781-902-1623

D. During treatment :

1. How will we know if the treatment is working ?
2. What can I do to manage side affects ?
3. What symptoms should I inform you of, ASAP ?
4. What is your contact info to reach you if needed ?
5. Are there any limits on any physical activity ? or any exercises I should do or not do ?
6. Should I need a mental health professional, from whom do you suggest I seek assistance ?
7. Will I need follow-up tests, such as imaging scans or blood tests, and how often ?

E. After treatment :

1. Do I need a special diet after treatment ?
2. Are there any limits on what I can do ?
3. Do I need to seek professional assistance from an Oncologist for problems of side effects?
4. What kind of exercises should I do now ?
5. What type of follow-up care will I need ?
6. How often will follow-up exams and tests be needed, Including PSA blood tests ?
7. If my PSA is detectable, at what level should I become concerned about recurrence ?
8. What are the options should cancer return ?
9. What medical journals or literature do you suggest ?

F. Tips for talking to your Doctor.

Refer to Chapter 13- Communication p. 48-49
for various item to improve your skills for talking to the Dr.

G. Other questions. I need answered

Make notes of other questions you have been advised from friends, relatives, or survivors to ask; and list these below for your convenience.

Video websites:

Here are two video websites that may assist you in learning about PCa, and also may answer some of your questions, try them.

https://www.youtube.com/watch?v=kQ4im2WQ75E, or
https://www.youtube.com/results?search_query=Univ.+of+Calif.+/San+Francisco+Prostate+Ca

Chapter 5 - Genetic Testing

Genetic testing can play an important role for patients with prostate cancer, as well as help inform preventative care for family members who may be at risk of developing cancer.

What types of genetic testing are used in cancer care?
There are two types of genetic tests, and they each have a different purpose. The first type of test is called **tumor profiling** (also called somatic testing or molecular profiling). This involves taking a small amount of tissue from a prostate tumor (part of the biopsy) and analyzing dozens of genes for DNA errors. This is genetic testing of the tumor itself, and the purpose of this test is to guide treatment decisions. Certain genetic alterations are known to respond to specific treatments, so your doctor would use this information when determining your treatment plan. These types of genetic changes are usually confined to the tumor (not inherited) and not present in the rest of body.

The second type of test is called **germline genetic testing** which is done to see if a patient has a hereditary predisposition to cancer. This test involves getting a blood or saliva sample to analyze genes such as BRCA1, BRCA2, and genes associated with a condition called Lynch syndrome. The purpose of this test is to learn whether there is a hereditary link to prostate cancer, because this information can also guide treatment decisions. Men who test positive for certain inherited genes may be candidates for targeted treatments. For example, a man who tests positive for a Lynch syndrome gene may receive immunotherapy, as recent studies have shown this to be an effective treatment.

Who should consider genetic testing for hereditary conditions?
Current guidelines recommend testing all men with metastatic prostate cancer as well as men with high-risk disease. It is also recommended for men with a family history suggestive of a hereditary cancer condition. If a family member (male or female) has any of the following, consider talking to a genetic counselor:

- Breast cancer diagnosed at < 50 years, or multiple breast cancers
- Ovarian cancer (diagnosed at any age)
- Pancreatic cancer (diagnosed at any age)
- Prostate cancer diagnosed at 60 years or younger

- Colon cancer diagnosed <50 years, or multiple colon cancers
- Uterine cancer diagnosed at <50 years, or uterine and colon cancers in same family
- Ashkenazi Jewish ancestry (ethnic group with increased risk)

Which hereditary conditions are linked to prostate cancer?
So far, studies have shown that at least 14 different genes are associated with increased risk of prostate cancer.

NAME	GENES	POSSIBLE FAMILY HISTORY	NOTES:
Hereditary Breast and Ovarian Cancer (HBOC) syndrome	BRCA1, BRCA2	Breast cancer, ovarian cancer pancreatic cancer, prostate cancer, melanoma	BRCA2 is the most common gene in men with aggressive prostate cancer
Lynch syndrome	MLH1, MSH2, MSH6, PMS2, EPCAM	Colorectal cancer, uterine cancer, brain cancer, and other types	Lynch syndrome is common, occurring in 1/300 people
Hereditary Prostate Cancer (HPC) syndrome	HOXB13	Three or more men with prostate cancer, especially at early ages	Rare, but may explain a family history of prostate cancer
OTHER	NBN, ATM, PALB2, RAD51D, TP53, CHEK2	Varies	Many newer genes are under investigation

How much does genetic testing cost?
The cost of testing has come down considerably in recent years, particularly for germline genetic testing. Most patients are covered by their insurance if they meet testing criteria, or they may have a maximum out-of-pocket of $100. For men who don't meet testing criteria, the cost can be as low as $249 for a comprehensive, multi-gene panel.

How can genetic testing help family members?
Some families are very worried about cancer because they have seen their loved ones impacted by a cancer diagnosis. Germline genetic testing can be used to keep family members healthy by implementing early detection and prevention strategies.

If you have a family history that concerns you, speak to your doctor about getting a genetic counseling referral.

Questions and Answers:
1. Is it true that a prostate cancer gene may come from your mother as well as your father? Ans: Yes, a gene can be passed down from either parent. Using BRCA2 as an example, a man can inherit this gene from his mother (she would be at increased risk of breast and ovarian cancer), and his risk for prostate cancer would be higher than average.
2. How is a prostate cancer gene inherited? Ans. If a man's genetic test result is positive, there is a 50/50 chance he will pass the genetic alteration onto a child.
3. What does a negative genetic test mean? Ans: Genetic testing provides information about the level of risk (average vs. higher risk), not whether a person has cancer or will get cancer.

How do you find a genetic counselor?
Speak to your doctor or go to www.nsgc.org to find a genetics specialist in your area.

Local Genetic Counseling Services:
Dignity Health Cancer Institute in Sacramento 916-962-8967
Northbay Cancer Center in Vacaville, CA 707-624-8000
Sutter Cancer Center in Sacramento 916-453-5884
UC Davis Comprehensive Cancer Center in Sacramento
800-362-5566

Reference:
Https://www. urologyhealth.org/patient-magazine-Fall 2018
" Genetic Testing for Prostate Cancer: What You Should Know"

Chapter 6 - Tests and Testing

Now is NOT the time to be self-sacrificing, or withdrawn, you must become very active in learning the facts regarding the cancer within you. The question is, "**How aggressive is MY cancer ?"** The answer comes by test results. Your doctors are better equipped to provide "the best" health care when test results are available from which decisions are made for a specific treatment .

Tests for Grading and Staging

1. Prostate Specific Antigen PSA, a protein in blood that is an indicator of abnormal activity in prostate gland
2. Digital Rectal Exam DRE - to feel for abnormalities of the prostate gland.
3. PSA Free, PSA-f - is used to determine if more testing is needed, specifically a biopsy.
4. Testosterone & Dihydrotestosterone DHT - taken before treatment to determine food supply to cancer cells, and after treatment to determine if treatment was adequate.
5. PCA3 - Urine Test - is a marker found in urine, and is used to double check if a biopsy is needed.
6. Color Doppler - Ultra-sound Monitoring - is a test that can provide a sharper image of the location of the cancer cells within the prostate gland, and thus can guide the needle to obtain tissue samples during a biopsy.
7. Biopsy - tissue samples are taken, a pathologist determines the degree of cancer cells, gives Gleason score
8. Cellular & Molecular Analysis - (Px*+) provide info about the aggressiveness of cancer cells.
9. Trans-rectal Ultrasound - TRUS is used for placement of needles to obtain tissue samples.
10. Computerized Tomography CT-Scan - imaging used to evaluate the pelvis and abdomen for cancer cells.
11. Magnetic Resonance Imaging / Spectroscopy MRI/MRS are used for evaluating the prostate for any local spread beyond the prostate gland, staging, and treatments.
12. Monoclonal Antibody Scan - ProstaScint used with CT or MRI to evaluate your lymph nodes.
13. Bone Scan - is used to check for cancer spreading from the prostate to bones, which is common for metastasis cancer.

14. Lymph Node Dissection - used to detect prostate cancer spread to the most common pelvic region.
15. Oncogene - is a genetic makeup of the cancer tissue that reveals the aggressiveness of the active cancer tumor.
16. The 4-K Score, a blood test for data of aggressive cancer.

The details of these tests are clearly outlined in reference 1 , listed below. You should obtain a copy, before making any decision regarding the type of prostate cancer treatment.

The Gleason Score

The Gleason score is very important and is the second most asked question when talking about your cancer. What is your Gleason Score? The Gleason score is a combination of two numbers, such as: 3 + 4 = 7, or 4 + 4 = 8 . The first number is the number predominant type of cancer cells of the samples and the second number is the second most common type of tumor in the cells of the samples. These numbers are called "grades" which reflect the appearance of cancers cells, and collected equal the "Score".

What the Gleason Score means:

2 to 4 = very low in aggressive growth
5 to 6 = mildly aggressive
7 = moderately aggressive
8 to 10 = highly aggressive

Published literature may use other 'terms' to describe the nature of the cancer cells, such as: , 'stages', and 'risks'.

Be aware: Your Gleason score has great significances regarding the rate of growth of your cancer; you should request a 'second opinion" of a pathologist's determination of your biopsy slides.

References that are recommended for your study.

1. Us TOO pamphlet *Signposts* 2011, ph: 1-630-795-1002 UsTOO International, 1003 Fairview Ave, Downers Grove, IL 605155286 www.ustoo.org
2. *Promoting Wellness for Prostate Cancer Patients, 2013* by Mark A Moyad, MD, pub. Spry Publishing ,p.79-99
3. *Color Doppler Trans-rectal Ultra-Sound Monitoring*, PCRI, Feb. 2007 by Duke Bahn MD, Ventura, CA
4. *Invasion of Prostate Snatchers* by Mark Scholz MD and Ralph Blum MD, Jan 26, 2014 website.

Some New Testing Available:

Treatment for prostate cancer first is dependent upon knowing the location of the cancer cells within the prostate or the adjacent area. The primary problem is that standard imaging techniques such as bone scan, CT scans, and MRI are usually unable to detect small tumors. This has become important to obtain better imaging systems for patients with recurrence.

There has been two such Molecular Imaging procedures developed, these are:

1. Carbon-11 Acetate PET/CT Imaging for Prostate Cancer.
C-11-Acetate is able to visualize the metabolic process and can detect and localize recurrent prostate cancer.
For information regarding this procedure, contact:
Phoenix Molecular Imaging, 4540 E. Cotton Gin Loon Ste. 150
Phoenix, AR 85040, ph: 602-368-3055 or visit their website:
www.phxmi.com

2. Axumin™ (fluciclovine F-18) is a novel molecular imaging agent indicated for use with PET for patients affected with prostate cancer recurrence based on elevated blood levels PSA. The Axumin PET scan now offers doctors the ability to accurately determine where prostate cancer has recurred.
For information regarding this procedure, contact:
Northern California PET Imaging Center, 3195 Folsom Bvld,
Sacramento, CA 95816 ph: 916-737-3211
www.NorCalScans.org

Terminology
PET = Positron Emission Tomography
CT = Cardiac Triggering
MRI = Magnetic Resonance Imaging

Chapter 7 - Treatments

Prostate Cancer Support Groups do NOT give medical advice nor come between a patient and his doctor, but do provide copies of published literature, and emotional support. Refer to Chapter 4 for questions to ask your Doctor. As a patient, you should obtain for yourself copies of the US TOO bulletins (listed below) which provide the basic factual data that will assist you in "decision making" of a treatment.

Treatment Options

To wait

1. Watchful Waiting - do nothing, only an annual PSA test
2. Active Surveillance - An active plan of regular monitored testing, and allowing the results to guide decisions.

Surgery

3. Prostatectomy, Open — Surgically removal of prostate
4. Laparoscopy — Prostate removal by 4-5 1"incisions
5. Robotic (deVinci) — Like laparoscopy, but robot assisted

Radiation

6. External Beam (EBRT) — High X-ray single beam
7. 3D Conformal — High X-rays, 3-beams
8. Intensity Modulated (IMRT) — Multiple X-rays beams
9. Proton Beam (PBT) — Protons target cancer cells
10. Internal (Brachytherapy) — Seeds are inserted in prostate
11. High Dose Rate (HDRT) — Seeds are inserted for 1 hour
12. Image Guided Radiation (IGRT) allows for precise radiation during treatment while movement of body.

Hormone

13. Luteinizing Hormone Releasing Hormone LHRH
14. Anti-androgen Therapy
15. Estrogen Therapy
16. P450 Enzyme inhibitors
17. Orchiectomy — castration, testicles removed, and replaced with cosmetic implants

Other

18. Cryosurgery — Freezing
19. High Intensity Focused — Ultrasound treats localized cancer by increasing the temperature to 85° C inside the prostate.
20. Chemotherapy — drugs into the bloodstream

New Treatment Options & Lab. Tests

Triple Androgen Blockade

New treatment options for prostate cancer are being studied every day and one of these is TAB-FM as presented herein.

Terminology

American Society of Clinical Oncology	ASCO
Triple Androgen Blockage	TAB
Finasteride Maintenance	FM
Clinically Localized Prostate Cancer	CL-PC
3T-Multi-Parametric Imaging	3T-MP @ UCSF
Prostate specific membrane antigen	PSM A@ UCSF
Agonist, antiandrogen, finasteride	LHRH

Background: ASCO 2005 report and 2011 abstract e15198. 199 men were treated with 13 months TAB consisting of an LHRH agonist, antiandrogen, and finasteride with subsequent FM. The group of men's ages range 44 to 88, median 67 yrs; baseline PSA range 0.39 to 59.8, median 11.1 ng/ml; Gleason score range 4 to 10, median 7; testosterone (T) baseline 407 ng/dl.

Treatment: Lupron: A shot every 4 weeks, Casodex, 3 pills 50mg = 150mg per day; Proscar (finasteride) 5mg per day, start I day after the shot, 99% of patients also use Celebrex, 200mg twice a day; Patients stay on this therapy for 13 months, then stop Lupron & Casodex, but stay on Proscar. If Casodex is cost prohibitive, use Eulexin (flutamide) 2 pills every8 hours =6 pills per day.

Conclusion: A single 13 month cycle of TAB-FM provides excellent long-term control and management of CL-PC, including men with high risk CL-PC. For most men ADT toxicity reverses. Any form of radical local therapy has serious and often permanent impact on potency or urinary/fecal continence. We suggest further exploration of TAB-FM for CL-PC as a safe and viable alternative to surgery or radiotherapy.

Authors: J.N. Roundy, J. S. Turner, R.L. Leibowitz,
Compassionate Oncology Medical Group, Los Angeles, CA
Reference: Compassionateoncology.org

PSMA –Clinical trials.
It uses a radioactively-labeled (Gallium 68) antibody which binds specifically to prostate cancer cells any where in the body. Cancer locations are visualized by PET/CT scanning. The advantage over C11 Choline/Acetate PET scans is that the

antibody does not label any other organs unless there is PC present and can detect PC with PSA <2.0 ng/ml. The Ga68 isotope is also much easier to synthesize.

Ref**: https://www.ncbi.nim.nih.gov/pmc/articles/PMC5439210 https://www.cancer.gov/about-cancer-treatment/clinical-trials/intervention/gallium-ga-68-labeled-psma-11**

SBRT (Stereotactic whole body radiation therapy) is a precisely-targeted treatment for tumors anywhere in the body. The Cyberknife machine creates a 3D map of the body from PET/CT images to target tumors with minimal effects on (normal) tissues.

Post Treatment - Recovery

There are two recoveries, which are:

1. the first recovery is from the treatment itself which varies greatly with the various treatment options, and
2. the second recovery is from side effects of treatment itself.

Each treatment option has its own associated typical side effects, which will also be different in each patient.
Side affects are separate issues which should be completely discussed with your prostate cancer care team. Two of these side effects are briefly discussed in Chapters 8 and 9 of this booklet.

References, which are on the MUST list for study:

1. US TOO International Prostate Cancer Education & Support Network, 5003 Fairview Ave., Downers Grove, IL 60515-5286 telephone No. 630-795-1002 www.ustoo.org
Prostate Cancer Help Line: 1-800-808-7866

1, One very good pamphlet for a brief view of treatment options is *PATHWAYS* for new Prostate Cancer Patients. pub 2010 Understanding "What it is" and "What Happens"

2. *100 Questions & Answers About Prostate Cancer (2013)* by Pamela Ellsworth MD pub by. Jones and Bartlett

3, National Comprehensive Cancer Network, NCCN, their new book: " Prostate Cancer Patient Guidelines" 2015, use their website, or call 215-690-0300

4. Harvard Medical School, "2015 Annual Report – Prostate Diseases: www.health.,harvard.edu. 877-649-9457

5. UCSF Medical Center: http://urology,cusf.edu "Radical Prostatectomy" FAQ

Get a Good Health Care Team

Chapter 8 Erectile Dysfunction Impotence

Yes, erectile dysfunction, ED, is a common problem with any man as he ages, and is also a side effect of several prostate cancer treatments. When a man seeks medical assistance, he will find that ED can be confusing and also very complex. So let's start at the beginning of the subject to understand the male body, its parts and their function, and general health issues.

A brief background - man and who he is!

1. Culture of Man - when it come to his private parts, the culture of man is simple: No talk, No see, No touch is engrained at childhood and each of us know it, and act according.
2. Comfort Zone - again for a man, his comfort zone about his private parts may extend to his partner, and his doctor; and that is the limit. However a man with ED problems, is eager to learn about treatments to restore his Quality of Life.
3. Men of all ages (18, 28, 38, 48, 58, and +) have one item in common which is: 3 to 5 erections per night. Let's use 4 per night times (x) 7 = 28 erections per week, none of which are for penetration, so what are they for and why ? These nocturnal erections are nature's way of exercising the penis to maintain elongation, elasticity, and rigidity.
4. The cause(s) for most men with bedroom performance problems are vastly different than for men who have been treated for prostate cancer, thus the expression: ED-1 vs. ED-2.

ED-1 For the average John Doe

John, like many men, may encounter a problem during mid-life (age 50+/- yrs.) of being unable to achieve an erection with sufficient rigidity for penetration. So off to the Doctor's office, where he is told "its due to aging" and is given a prescription for "the pill". WHY is there a problem ? Some of the most common causes for why are:

Some causes are internal, such as:

1. obesity/overweight - body mass index BMI>25
2. cholesterol / plaque
3. enlarged prostate, aka BPH
4. high blood pressure
5. diabetes

Other causes are external, such as:

1. stress: at work, and/or at home
2. depression
3. low-desire for sex
4. cold partner
5. pills, Rx, prescription drugs for any other illnesses. There are currently more than 200 medications that can seriously reduce erections and sexual performance. You should double check this item with your pharmacist.

Treatment for ED-1

The most common treatment prescribed by doctors is one of the pills, Viagra, Cialis, or Levitra, which will provide the rigidity needed for penetration. It is like a man with a car that will not start, so he uses a set of 'jumper cables" and then the motor runs like a clock. The 'pill' will not provide physical therapy (PT) needed to regain the number "#" of night-time erections which are necessary to restore, elasticity, elongation and flexibility so that the pill will remain effective. These pills are packaged in various dosages, such as:

Viagra, -	sildenafil citrate		25 mg	50 mg	100 mg
Cialis -	tadalafil	2.5 mg	5 mg	10 mg	20 mg
Levitra -	vardenafil	2.5 mg	5 mg	10 mg	20 mg

Alternative remedies:

Over-the-counter male enhancement supplements, such as:

Triverex, . or

Zyrexin™, , or reZerect™ , and Naturomeds, "Maxman"

Other alternative remedies,

1. DHEA - dehydroepiandrosterone
2. Folic Acid, or Horny Goat Weed, or Ginsong,
3. Ginkgo - a herbal remedy to improve blood flow
4. Zinc Supplement, or L-Arginine

The above supplements MUST be taken with caution, so review the literature first. Then if you wish to try, do it, if it fails, you will only lose the money it cost; but if it work, then good for you. Be Aware that some otc products may to harm to your liver.

Internet websites: There are many sites that offer a wide range of information for erectile dysfunction, **but** be careful.

Summary of ED-1, For some men, the pill may be a GREAT helper to achieve an erection needed for penetration but the pill does not restore the number of nocturnal erections. If you feel that you are still young at heart, and "aging" is not an acceptable excuse for ED, then you need to examine the causes: WHY. But be on guard not to allow a continuous 6 o'clock low 24/7 to be status quo. Attention should be directed to finding and treating the cause(s) which will then result in a better quality of life.

ED-2 Post prostate cancer treatment

For every 10 men who undergo treatment of prostate cancer, and at least 5 will suffer the side effects of ED. We know the cause which is the nerves and tissues of the pelvic area have been damaged. Some men will recover, but others do not and are told by the medical professionals that it may take up to two (2) years for the nerves to grow back. What is not told during this period of time is that men are left with a 6 o-clock low for 24/7, and this is paralyses. The nerves stop working, causing no oxygen-rich blood to flow into the penis. So what treatments are available for ED-2? Once again the cause is NOT treated, but other methods are found to provide some comfort to the patients.

Treatments for ED-2
Let's examine the conditions; there are two cases:

1. to obtain rigidity for penetration,
2. the health of the penis itself.

For case #1; to achieve an erection, most Doctors will stay with the 'approved' practices. Finding the method that will provide the best results for an individual is **not a given, and** thus he may need to begin a 'trial and error' of many of the 'approved' practices before finding one that is the most satisfying.

The current methods are prescription drugs from retail pharmacies

1. the pills - try all 3, Viagra, Cialis, Levitra and all doses as listed above for treatment of ED-1
2. dilators, there are two:
   a. pellets, MUSE - alprostadil- all doses, 250, 500, 1000
   b. injection, Caverject- alprostadil - all doses, 5, 10, 15, 20, and 40

Other methods, there are three,

1. an injection - a Tri-mix. (aka Double P or Triple P) Select an MD, who is an ED specialist, for a prescription mix [papaverine, phentolamine, prostaglandin]. A compounding pharmacy is needed to provide the medication.

2. vacuum pump - for both therapy and penetration

3. implants - obtain the DVD, "Straight Talk about ED" by Coloplast, provider of the Titan and the Alpha Inflatable Penile Prosthesis. It demonstrates the device, and its components.

For case # 2 - health of the penis: Recall the number 28, the nocturnal erections, they had a purpose to create blood flow. For some men to regain nerve function may take two years or more, and during this time period the lack of oxygen-rich blood to the penis will result in loss of tissue mass. Waiting alone will not get erectile function back. One can accept the status quo and do nothing for reasons due to age and/or life style, or seek help.

Another choice may be to start with **Penile Rehabilitation (PR)** .
The vacuum device is the only treatment that preserves both length and girth of the penis, while drawing oxygen-rich blood into, and allowing it to flow out. The device should be used without a cockring, as the exercise is for therapy to re-build tissue mass. The procedure is to insert the penis into the chamber and fit firmly next to the body with the lower side of penis resting on the lower curve of the chamber. Pump for 5 seconds, hold for 5 second, release and hold for 5 seconds, then repeat for 5 minutes. Continue the drill for 15 minutes, and when a full erection has been attained hold for 5 minutes. Be alert to signs of painful stress within the penis, stop pumping and release, before repeating the drill.

The pump may NOT work the first time because of a failure to obtain seal due to a heavy forest of pubic hair. It may take several sessions with the pump to find the right rhythm and it may a month or two before you start seeing a change One should engage in therapy sessions at least four times per week, and over a period of time the effort will be rewarded!

Post Treatment Therapy

"The nerve bundles that run along the prostate are the nerves that control erections. If any of these nerves are injured, there is less of a stimulus for the blood flowing to the penis. The results is a reduction in activity of the penis to become erect, thus with no elongation or elasticity over a period of time, will cause a reduction in the length and girth of the penis. This change is called 'atrophy' .

A patient should engage in penile rehabilitation (PR) to maintain nerve stimulation and to restore elasticity, elongation, and rigidity. Remember what you had when you were at 28 years of age., and what you have now? You cannot run the marathon if you cannot walk! Expand you comfort zone to include PR (to exercise the tissues) which will restore elasticity, elongation, and rigidity. Like the lungs of an athlete, to expand his lungs for more air capacity for the endurance required of a sport's event.

Summary of ED-2 Which treatment is right for you??
Each man is different, and you must first recognize that the problem is treatable. Finding the right treatment takes time. One item that is known, if a patient had any nerve damage during treatment, then the "pill" will have little to no effect.

Yes, there will be attempts that result in embarrassment and frustration, which requires the very best of the spousal support.
Each man must walk through the maze of various treatments to find the one that fits his needs. You see it is like the man with the car, but now the 'jumper cables' do not work, as there are no spark plug wires !

To find the best treatment, one may need to expand one's comfort zone, talk to a friend, engage in therapy, and find a good medical reference, such as number 1, or 2 as listed below.

Other lectures and/or presentations
Other professionals will speak about "How to engage in sex with ED" and/or "the Art of Making Love without Penetration". These topics are needed and helpful; and they have their place in helping men live with ED. There are several books available on this approach to the intimacy of life with partners.

Seeking the services of a sex counselor may open the door. The first session will be difficult as that is when a commitment is made from both partners to make a change from the status-quo.

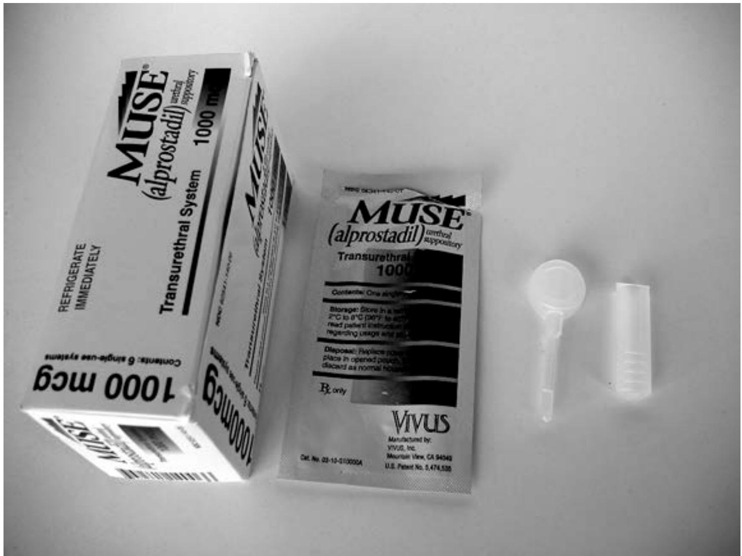


Figure 1 ED, dilator, MUSE

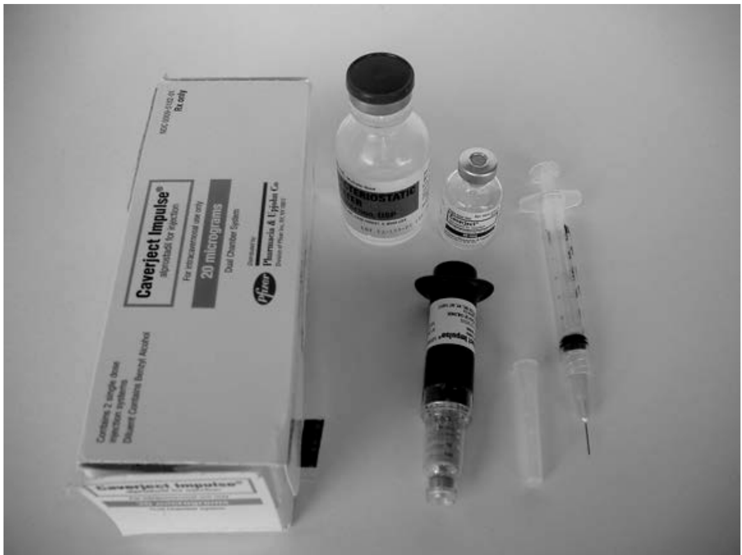


Figure 2, ED, dilator, Caverject

Figure 3, ED, dilator, Tri-Mix

Figure 4, ED, vacuum pump,

Summary

Are you discouraged, and are you going to surrender to "aging"? You can take action to experiment with various treatments to find a method that is right for you even if you endure some embarrassment & frustration. Erectile dysfunction, ED, is treatable. Expand your comfort zone, and strive to change the number from 0 to 7 erections, which is not 28, but will maintain elongation, elasticity, and rigidity. Your self esteem will then be restored. ED-1 and ED-2 are the same in daily life - a 6 o'clock low, but are very different in cause, and in treatment.

The voice of Experience, Survivor # 37

I had prostate cancer and had surgery to remove it, followed by ED-2, which was a 6:00 o'clock 24/7, and shrinkage resulted. Talking to your doctor is the correct medical advice. I did and was told, "It's all part of the aging process, you are OK, go home and be happy". I did and lost ½ of what I had ! It took one year of PR with the vacuum pump (which was somewhat painful) to regain both length and size. Now after continued PR , I have a bit more. Penile re-habilitation is necessary to maintain good health of the penis, and to restore the Quality of Life. Life continues and so does 6:00 O'clock, 24/7, atrophy becomes reality, and all help vanishes.

Between thee Sheets

A question from a survivor, "I was treated two years ago, and since then, I have not had any erections. I expected this, but now my penis has almost disappeared. I can hardly find it when I need to urinate. Why has this happened, and what can I do about it

.

Ans: Dr. Anne Katz: Genital shrinkage is common and is a complex process due to lack of testosterone and lack of erections that limits blood flow to the penis, resulting in penile tissue is starved of oxygen and nutrients, and thus is scared and shrinks. Androgen deprivation also results in shrinkage of the testicles.
Help is to encourage flood flow to the tissues, and using a penile pump is helpful for this to offset shrinkage.

Local Helpful resources:

For patients who wish to obtain ED assistance for Tri-Mix; (this has been a difficult path), but services are available, and here are a few tips to try for help within our local area.

Prescription Rx for Tri-Mix.

1. Pharmacies : (sorry there is only one)
   a. Innovative Compounding Pharmacy 1-916-984-9292
      820 Wales Dr Ste 3 Folsom, CA 93630
   b. Pacific Compounding Pharmacy 209-474-7271
      (no longer fills Rx for Tri-Mix)
      312 Lincoln Ctr Stockton, CA 95207
2. Doctors
   a. Dr. Matthew Janiga 530-889-7488
      11795 Education St. #224 Auburn, CA 95603
   b. Dr. Bryan Golden 916-262-9386 op1
      or: 707-427-4900 of 4, op5 Sutter Medical Foundation
      8170 Laguna Blvd, Ste 303 Elk Grove, CA 95758
   c. Dr. Joshua B Jefferds 916-482-5200
      BioVital Men's Clinic
      3808 Auburn Blvd Ste 41 Sacramento, CA 95821
3. for Vacuum Device,
   Your Urologist should have the info for the sales rep as to how and when to make contact, if not: Timm Medical Technology, 2111 W.Wyatt Earp, Dodge City, KS 67801tele #800-438-8592
   www.timmmedical.com

References for Patients to Browse for in-depth information:

1. *100 Questions and Answers, About Erectile Dysfunction* 2nd Ed 2008 by Pamela Ellsworth MD.
2. *Managing Impotence*, UC-San Francisco Medical Center by Stan Rosenfeld and others www.ucsfhealth.org
3. Manufacturers' Literature of various products.
4. *Guide Surviving Prostate Cancer* by Patrick Walsh, MD, and Janet Farrar Worthington, 2012, 3rd ed, pub. Wellness General, Hachette Book Group, New York, NY
5. *Mayo Clinic Essential Guide to Prostate Cancer* by Lance A Mynderse M.D. 2015
6. *The John Hopkins Medical Guide to Health After 50* by Simeon Margolis, MD, PhD.
7. *Saving Your Sex Life* by John P Mulhall M.D. pub. 2008 Hilton Publishing Co. p.208
8. *Prostate Cancer, and the Man You Love*, by Anne Katz, RN PhD, 2012, pub. Rowman & Littlefield Pub. Inc.
9. *Penile Rehabilitation* by unk, pub. unk -abt 2013, abstracted from www.sexualityresources.com (11-2014),

Chapter 9 - Incontinence **urinary leakage**

Incontinence may vary from a drip to persistent leakage of urine, and it is one of major side affects of most prostate cancer treatments. If a man had an incontinence problem before becoming a prostate cancer patient, the problem will surely continue after treatment. The definition of "incontinence' varies. In medical terms, the word "means" any involuntary leakage, if more than a pad per day is needed. Fear of leakage may limit your social life, your self-esteem, and/or your quality of life. Incontinence is usually caused by damage of the sphincter which is the circular muscle that controls the flow of urine.

Mans' Anatomy

There are two sphincters, the first sphincter is located between the bladder and the prostate, the second sphincter is located between the prostate and the penis. The upper one, aka the 'interior' sphincter functions involuntarily when the bladder becomes full; whereas the lower one, aka the "exterior' sphincter functions voluntarily on demand to release urine from the body.

Types of leakage

First, you need to visit a specialist who can assist to determine the degree and type of incontinence. Usually there are three:

1. stress incontinence = intrinsic sphincter deficiency allowing leakage when coughing, sneezing, or exertion.
2. urge incontinence, is the loss of urine with an overwhelming urge to urinate and is related to an over-active bladder.
3. overflow incontinence, is the loss of urine related to incomplete emptying of the bladder

Treatment Options

After the type and severity of your incontinence has been determined, you can discuss treatment options with your doctor. Here again, it may be a trial-and-error path to find a treatment is right for you.

1. Food control, important to control intake of alcohol, caffeinated drinks, and acidic foods.
2. Prescriptions, anticholinergics are used to treat over-active bladder. But there are no medications to treat incontinence. Thus only absorbent pads and diapers are available.

3. Interior and exterior penile catheters of which there are many types. Obtain medical product suppliers' information
4. Pelvic floor muscle exercises, to strengthen the muscles within the pelvic floor, commonly known as " Kegel" exercises with a digital feedback to show correct and effective movements.
5. Penile clamp, an external device to compress the urethra to prevent the flow of urine. These are to be worn for brief periods of time and not for a full day.
6. Collagen injection, a chemical that is injected into the neck of the bladder causing the urethra come together.
7. Male slings, is the placement of a piece of tissue under the urethra. The tissue may be the patient's, a synthetic material, or from cadavers.
8. Artificial urinary sphincter, a three piece mechanical device placed within the body in the pelvic area to control the release of urine.

Finding informative material may also be difficult, so it becomes necessary to attend various seminars and/or lectures, and to visit medical specialists to assist you. By attending prostate cancer support group meetings, you may find another survivor and his experiences may be helpful to locate sources of information.

References for Patients to Browse to obtain in-depth information

1. *Mayo Clinic on Managing Incontinence,* by Mayo Clinic Pub. 2019, 222 pages, PO Box 3301 Big Sandy, TX 75755

2. *100 Questions & Answers about Overactive Bladder and Urinary Incontinence* 2005 by Pamela Ellsworth MD and David A. Gordon MD, pub. Jones & Bartlett

3. *100 Questions & Answers about Prostate Cancer, 3rd ed.* pub. 2013 by Pamela Ellsworth MD. pub Jones & Bartlett

4. *Answers for Men* with an accompanying DVD by American Medical Systems (AMS) 2013, also their website: www.AnericanMedicalSystems.com 1-800-328-3881.

5. Liberator Medical Supply, Inc www.liberatormedical.com 1-866-761-0534 This firm may now be BARD/Liberator

Chapter 10 - Recurrence its back

Generally about 30 to 40 % of PCa patients have recurrence, and the best way to deal with this condition within yourself is: "it MUST be detected." There are two types of recurrence:

(1) short term after an initial cancer treatment, and is mainly within the pelvic area.

(2) after a longer period of time when the cancer has spread to other parts of the body.

For type (1)

When PSA tests indicates an increase, during the follow-up tests for the initial treatment, this alerts the trigger for action. One method is for Ultra Sensitive PSA tests every 12-weeks , and if there is an increase in the PSA, the next tests should be on a 4-week basis. If there is a consistent increase, then remedial action should be taken, the most common is **salvage** radiation. The remedial treatment should begin before the PSA reaches 0.40 ng/dL which may have a > 50% probability of being cured.

For type (2) – When several years has lapsed from initial treatment

Should the PSA test reflect any number, after several year of the PSA test was "nil", then a value appears, even if very small, such as 0.01, and then may increase to 0.02, there is cause for ALARM, as cancer is present somewhere. Specialized imaging if necessary, see page 28 for a suggestion.

Basically, there are four options of treatment, which are:

1. Hormone management,
2. radiation,
3. immunotherapy,
4. chemotherapy.

A new patient is encouraged to attend a prostate cancer support group to visit with other men who are also walking the same path. We who are survivors advise you to: "Become Informed", which will greatly lower your **fears** and restore HOPE.

Voice of Experience, Survivor # 6

I was informed I had prostate cancer. I elected to be treated by surgery (prostatectomy) on June 12, 2007. My Gleason score prior to surgery (3+3), and after surgery (3+4), cancer cell were found on the margin. Regular PSA testing following surgery remained steady at less than< 0.1 until June 17, 2015, a lapse of 8 years, when PSA recorded at 0.1.

PSA remained stable at 0.1 until June 15, 2018, when PSA recorded at 0.15 an increase of 50% in a lapse of 3 years. Followup PSA on Sept.9, and Nov. 1, 2018 were 0.23, a 53% increase, indicating a rapidly rising PSA.

Several options were available, Watchful waiting, hormone therapy, radiation combined with hormone therapy. A radiation oncologist advised to have a "AXUMIN PET/CT SCAN. (Scan is able to isolate prostate cancer activity at PSA levels as low as 0.2. Result of scan-cancer activity found in right iliac chain lymph node. I elected the prescribed therapy of radiation/hormone therapy combined. On May 20, 2019 the first PSA test following treatment result was less than <.05. Hormone treatment to continue 12-18 months subject to further PSA test results.

Comments: What did we learn for this Survivor??

1. The lapse of time from initial PC treatment to the return of cancer.
2. The importance of monitoring PSA for many years after treatment.
3. The type of PSA testing needed to obtain the very low values.
4. The type of imaging needed to locate the source of cancer.

Voice of Experience, Survivor #76

The most important question after diagnosis is "is my cancer confined to the prostate gland, or has it spread to other organs?" This is very important since local treatment such as a radiation and surgery to the gland are not going to help if your PC has spread to other organs and primary treatments do come with serious side effects. The Gleason score can only tell you the likelihood the cancer has or will spread in the future, and not whether your PC has actually spread. Also, since a biopsy is a sampling procedure, tumors with high grade Gleason may be missed. Even so, some doctors will rule out primary treatment based on Gleason score alone. Fortunately, several new scans can now precisely locate sites of PC anywhere in the body at the time of diagnosis or after biochemical recurrence. (shown by rising PSA after primary treatment)

PSMA (Prostate-specific membrane antigen) scan is most sensitive PC scan to date. It uses a radioactively-labeled (Gallium 68) antibody which binds Specifically to prostate cancer cells anywhere in the body.

Cancer locations are visualized by PET/CT scanning. The advantage over C11 Choline/Acetate PET scans is that the antibody does not label any other organs unless there is PC present and can detect PC with PSSA <2.0 ng/ml. The Ga68 isotope is also much easier to synthesize.
Ref**: https://www.ncbi.nim.nih.gov/pmc/articles/PMC5439210**
https://www.cancer.gov/about-cancer-treatment/clinical-trials/intervention/gallium-ga-68-labeled-psma-11

SBRT (Stereotactic whole body radiation therapy) is a precisely-targeted treatment for tumors anywhere in the body. The Cyberknife machine creates a 3D map of the body from PET/CT images to target tumors with minimal effects on neighboring (normal) tissues.

Chapter 11 - Advanced Prostate Cancer

Men diagnosed with **metastatic prostate cancer** (their disease has already spread beyond the prostate by the time of diagnosis), will often not undergo local treatments of the primary prostate tumor, such as surgery or radiation. Instead, their therapeutic journey will start in a similar way to men who were diagnosed at an earlier stage and had subsequent disease progression.
The standard of treatment for metastatic prostate cancer was primary hormone therapy alone. However, recent clinical trials have found improvement if abiraterone or docetaxel chemo-therapy are started along with androgen deprivation therapy (ADT). Your treatment must be discussed with your doctor(s) to determine which is right for you.

Hormone therapy is designed to stop testosterone from being produced, which results in the side effects of hot flashes, loss of bone density, mood swings, weight gain, and ED. Follow up tests will include testosterone levels, liver, and kidney function.

Agonist LHRH is the most common hormone therapies used, and the drugs available are: leuprolide (Eligard, Lupron Depot, and Viadur), goserelin (Zoladex), and triptorelin (Trelstar) are given as shots, once a month.

When LHRH agonist is used for 6 to 12 months, during which time a low PSA level is maintained. If men reach a PSA below an agreed level, the hormone therapy can be stopped until the PSA rises to a second agreed to level, at which point the drug is restarted.

A patient-by-patient approach should be used based on response and tolerability to hormonal therapy.

For all men who are patients of Prostate Cancer Recurrence, and /or metastatic prostate cancer is advised to obtain the publication "***Prostate Cancer Patient Guide***" pub. by Prostate Cancer Foundation, 1250 4 St, Santa Monica, CA 90401. 1-800-757-2873 website: www.pct.org.

Other sources:

For patients whose tumors have been discovered after metastases have taken place, many of the techniques and treatments outlined by Dr. Crawford still have application, but are frequently applied in combination instead of individually. New techniques outlined by Dr. E. David Crawford in the website: http://www/cancernetwork.com/onology-journal/ small-steps-lead-leap-prostate-cancer-patients 08/15/14

Recent findings have shown that when androgen depravation therapy is followed by chemotherapy with docetaxel, will achieve better control of the tumor. Refer to the following websites: http://www.youtube.com/watch?v=nS17WkhbnyM, and http//www.uctv.tv/shows/Advanced-Prostate-Cancer-28498

Basically, there are four options of treatment, which are:

1. Hormone management,
2. radiation,
3. immunotherapy,
4. chemotherapy.

A new patient is encouraged to attend a prostate cancer support group to visit with other men who are also walking the same path. We who are survivors advise you to: "Become Informed", which will greatly lower your **fears** and restore HOPE.

Secondary Hormone Therapy

Abiraterone (Zytiga). To be used if Lupron has stopped working and cancer has metastasized.

Enzalutamide (Xtandi) Also used if Lupron has stopped working. Often used with Prednisone (a steroid).

Radium 223. Radium 223 is a mildly radioactive form of the metal radium. It's brand name is Xofigo (pronounced zoh-fee-go). You might Have radium 223 to treat cancers in the bone that \ began in the prostate.

Casodex (Bicalutamide) is a low-level form hormone therapy that helps to block the androgen receptor on PC cells. It does not affect circulating testosterone.

Recommended References for a patient to browse.

1. UsTOO pamphlet "*Advanced Prostate Cancer" pub 201 5003* Fairview Ave, Downers Grove, IL 60515 ph: 630-795-1002

This reference provides an outline of the scope of the disease and your health thorough knowledge and hope. It sets forth seven (7) Principles that are deeply presented to assist you to understand the scope

2. “Promoting Wellness – Beyond Homone Therapy” by
Mark A Moyad, MD, MPH. 2nd Ed 2013. By Spry Publishing 315 East Eisenhower Pkwy Ste. 2, Ann Arbor, MI 48108 Ph: 877-722d-2264 Dr. Moyad presents details of the various **drugs** used for the treatment and their side effects. This book will give you a wealth of knowledge to aid you in your health care as you move ahead.

3. “Androgen Deprivation Therapy” An Essential Guide for PCa Patients and their Loved Ones. By: Richard J. Wassersug, PhD, Lauren M Walker, PhD, and John W Robinson, PhD, pub. by **Demos** Medical Pub. LLC, 11 West 42d St, 15th Floor New York, NY 10036, ph: 1-800-532-8663 or 212-863-0072 158 pages
This book help patients and partners prepare and manage the changes in their lives associated with ADT, such as: What is ADT, Physical Side Effects, Exercise, Healthy Eating, Emotional Stress, Intimate Relationships, and Live Ahead. This book is a **MUST !**

4. http://www.cancernetwork.com/oncology-journal/small-steps-lead-prostate-cancer-patient
5. Texas Oncology, 1221 Merit Dr., Dallas, TX 75251
   telephone 1-888-864-4226, look for website.
6. *100 Questions & Answers, Prostate Cancer, 3rd Ed, 2013 by Pamela Ellsworth M.D. pub. Jones & Barlett, pgs, 156 to165.*

Abbreviations as used above.

AR = androgen receptor PCa = prostate cancer
CRPC = castration resistant prostate cancer
LHRH = luteinizing hormone releasing hormone
MO-CRPC = metastatic occurrence –CRPC

Men who have been treated for prostate cancer, may endure side affects of erectile dysfunction or incontinence. These events that occur during recovery may cause embarrassment and frustration which in turn may create depression, Depression, if not recognized, may deepen into a state of fatigue. Yes, some men will suffer from fatigue and thus it is better to be aware of the condition itself, and of the cause(s) in order to determine how to manage it.

Treatments.

Fatigue is more serious and is being one of the most common reported problems, Presently there are four methods being used to reduce the effects of fatigue; which are:

1. Lifestyle changes - physical exercises
2. Dietary supplements - see reference 2, listed below
3. Prescription Med's - there are a few, visit your doctor
4. Testosterone therapy -

Testosterone therapy requires awareness that most urologists will not prescribe this method because you are a prostate cancer patient. However, there are studies that show testosterone replacement is an acceptable treatment method (Ref. Nos. 4, and 5 listed below) To start a treatment program, the patient and doctor should establish a rigid testing schedule of PSA and T-level blood tests every three (3) months. The T-level range for a 40-60 year old man is from 300-900 ng/dL and will lower as a man ages to a range of 100-700 ng/dL. The goal will be to maintain a T-level somewhere in the mid-range, while at the same time with no significant increase in the PSA test results.

Methods

1. The patch, a skin patch (delivers 5 to 10 mg) is applied daily to one of muscle areas, such as: thighs, stomach, or shoulders. Skin irritations can be a problem for some men, which then requires a second method.

2. A gel (Testim or Androgel) or others; gels are available in various dosages (1.0%, 1.6%) and are applied daily to either the shoulder or thigh areas. It is necessary to apply to clean dry skin, and to wash hands thoroughly, or use rubber gloves.

3. Injections, an injection, either in the doctor's office or be trained to self-inject. The dosage and frequency are provided by the doctor. This method is the most common.

4. Pellets, There is one available (Testospel in 75 mg) which is administered in the doctor's office, and takes about 10 minutes. The pellet is placed just under the skin in the hip area, and will have a lasting effect for 3 to 6 months.

Summary

If you are feeling exhausted, and blood tests indicate a low-T, and if you are willing, GIVE it a try; you may be greatly amazed how your Quality-of-Life will be rewarded. Should the PSA level increase to a level causing a concern of risk, then terminate.

Conformation Study

website: MedScape Medical News Dec. 10, 2014 *"No Prostate Cancer Risk for Testosterone for Hypogonadism"* The study by Ahmad Haider MD, University Clinics, Muenster, Germany. pub. in *Journal of Urology*, January 2015. The findings with over 1000 men given T-therapy for 5 years showed low rates (less than 1%) of prostate cancer. Hypogonadism = a man whose body does not produce sufficient testosterone.

Recommended References for Patients to Browse:

1. *Beyond Hormone Therapy* by Mark A Moyad MD pub by: Spry Publishing 2011
2. *Promoting Wellness, 2ND Ed.* by Mark A Moyad MD pub by: Spry Publishing 2013
3, *Saving Your Sex Life* by John P Mulhall MD, pub by Hilton Publishing Co. 2008 p. 217
4. UsTOO *Newsletters* October 2013, p. 2; December 2014, p 3
5. Journal of Urology, Vol. 190, 2013. pp. 639-644

Chapter 13 Communications with ??

First each man must look at himself, is he mostly a private person and speaks to others in general terms about himself, or is he a free talker. Yes, communications is a topic that must be considered when the subject is **cancer**. Each man should become "Informed" about the disease so that he can feel comfortable in his own skin to speak about his condition with others.

Who are the persons with whom you need to freely talk about your condition and your plans ahead, such as your health care team, your spouse/partner, and other men with the same health issue.

With your spouse

a. Sharing the impact of the cancer diagnosis
 Yes, at first there is a fear factor that must be over-come, and and a plan to move ahead with testing and treatment.

b. Sharing in doctor's visits
 Your spouse being with you at the doctor's office is great for her to hear he answers to your questions and to take notes.

c. How well do you communicate with your spouse, and how well does she communicate with you, As you know this is a two-way street. Here are some questions?
 "What are the three words a wife needs most to hear?"
 _________ _________ ________ Ans. I love you
 " How often should you tell her these words?"
 _________ times per ________ Ans, more the better
 And it would be very nice to hear the words from HER.
 "What is best way to <u>show</u> her you value the words?"
 There are many ways, you know her likes, so do it.
 "What are your/her sexual desires?
 Yes this is a very private subject, but must be honestly discussed as it will be a major factor in treatment.
 Never use the words: "You never" or You always"
 What do you have the most trouble with in talking with your Spouse? It is time to start talking, maybe with "Help"

With your Doctor / Health care team

Your doctor who gave you the prostate cancer diagnosis, should also provide you the answers to your questions, unless you have obtain a specialist such as a urologist.

a. Get ready for your visit:
   i. Make a list of concerns/questions and then e-mail the to his office at least 5 days prior to the visit.
   ii. Consider bring your spouse to assist in making notes of the Doctor's response to questions.
   iii. Tell your Doctor what has changed since the last visit, such as: other Specialists, medications, weight, appetite, sleep, and energy.

b. Remembering what the Doctor said:
   i. Make notes, thus start a Note book to record all visits with Him and others, even Testing Labs.
   ii. Making notes will help you to be aware of effects, and to plan for the next step in your decision making.
   Iii Get a written record of your medical records, and any medical brochures for your condition. Get business cards from all medical personnel with whom you had have visited.
   iv. Keeping track of your medicines, Rx and otc
   Make a chart to record the drug Rx, what its for, date started, Dr. who ordered it, dosage, how often, etc.
   v. Making good use of time during the visit,
   Be honest, answer His questions with honesty
   What questions are the MOST important, and stick to the point. Should I visit a Specialist?
   vi. What results should I expect:
   Try to voice your feelings in a positive way. "I feel rushed, and wish more detail information".

With Others – Relatives, Friends, Support Groups

None of us are perfect, we all can take steps to communicate better – plan ahead to talk, set time and place.
We need to express our desires, and to listen to others, thus there may be surprises to be discussed and to gain an understanding of the other's point of view.
What troubles you most about your cancer ? Is it a lack of obtaining factual data, or living with unexplained side-effects?
Attending a Prostate Cancer Support Group may provide you with information from a man who is walking the same path as you and with the same frustrations or from a man who has been there and now has a better quality of life.
How has your family and friends reacted to you having cancer?
Have you provided them with information of the current status of the disease in order to lower their concerns for you and of the fear factor that they harbor.

Chapter 14 - Plant Based Diet

The one unifying diet found to best prevent and treat many diseases is a **whole-Food, plant based diet,** defined as eating unrefined plant foods, and discourages meats, dairy products, eggs, and processed foods. A diet that is a balance of plant foods to reap their nutritional benefits.
In lieu of treating the side effects of an illness with "pills", why not treat the cause of the root of the illness. Treating the cause is not only safer and cheaper but is can work better. Research has found there are ways to treat cancer by making a commitment of diet – the intake of 'which foods" provide the necessary nutritional balance needed for control of the body's requirements by healthy eating and active living.

Diet for Prostate Cancer.
Researchers have conducted studies for the affect of "drinking milk", of eating eggs, and for eating poultry. Men who regularly eat chicken and turkey had up to four time the risk of prostate cancer progression. (p. 216) There many other studies that have been conducted that reflect the results of cause and effect of red-meat and other animal-based foods. The blood of men on standard American diet slowed down the rate prostate cancer cell growth by 9%. Place men on a plant-based diet for one year, their bodies suppress cancer cell growth by 70%.

Recommendation
As a survivor, I recommend that prostate cancer patients read the references provided, so you may be informed as to "what may affect the decisions you are about to make.

References
1. "How Not to Die" by Michael Greger, M.D. with Gene Stone (copy at Davis Public Library, Davis, CA
2. on-line video, "Introduction to Whole Food Plant Based Diet, by Anthony Lim M.D. https:www.youtube.com/watch %3Fv%Du-u4YnfcTf0or: watch?v=4-u4YnfcTfo
Commentary: "Finally a physician has pulled together the latest studies on how to fight disease and prolong life. *How Not to Die* shows how the right nutrition prevents disease and transforms our genes so we can live healthier, longer. "Empowering, groundbreaking, transformative work." Kathy Freston, author

Chapter 15 Peer Navigator A Friend

Need Help, There are men who from time to time are in need of additional emotional support. In many cases when men do not have other people within the home to provide him with aid to understand the Doctors instructions or the means of travel to make the time and place of the medical appointments, they do need help. This help can be provided by a Peer Navigator. Please see contact information below.

Wish to Give Help, If you wish to share your journey with other men who are currently diagnosed with cancer, and need assistance to comprehend the scope of their conditions, your volunteer service will be very rewarding. Training will be provided to become a Volunteer Peer Navigator. See the contact information below.

To Obtain Help

There are currently two Peer Navigator Assistance Groups, both work to provide the services needed. Any man with prostate cancer, regardless of where he receives treatment, can request a "cancer coach" by contacting either group for Assistance Needed, or to be a Volunteer Peer Navigator.

Services from **Dignity Health,** Cancer Institute, Sacramento,
call: Michael Mair, RN, Oncology Nurse
916-962-8892 at Dignity Health. Mercy Cancer Center
6511 Coyle Ave, Carmichael, CA 95608
e-mail: Michael.muir@digniyhealth.org

Services from **UC Davis Cancer Center,** call:
Outreach Program, at US Davis Cancer Center,
4501 X St. Sacramento, CA 95817
Contract: Patricia Robinson 1-916-734-0823
patricia.robinson@ucdavis.edu.

Chapter 16 Educational Resources

American Cancer Society 250 Williams St. NW Atlanta, GA 30303 1-800-227-2345	ASC has information on all type of cancer, and is an excellent source of data of Prostate Cancer.
National Cancer Institute 9609 Medical Center Dr MSC 9760 Bethesda, MD 20892 1-800-422-6237	cancer.gov/types/prostate NCI has info for testing, treatments, clinical trials and other resources.
Prostate Health Education Network 500 Victory Rd, 4th Floor Quincy, MA 02171 1-617-481-4020	prostatehealthed.org Has educational materials and info of clinical trials and videos of PCa
Prostate Cancer Foundation 1250 Fourth St Santa Monica, CA 90401 1-800-757-2873	www.pcf.org Has a book "*Patient Guide*" 2019, A Great book Recommend as "**MUST**"
Prostate Cancer Research Inst. 5777 W. Century Blvd, Ste. 800 Los Angeles, CA 90045 1-310-743-2116	A patient is empowered to talk more effectively with doctors and obtain a better outcome. pcri.org
Prostate Conditions Education Co. 7009 So. Potomac St Ste. 125 Centennial, CO 80112 1-866-477-6788	prostateconditions.org Access to new information on biomarkers, genomic testing, and treatments
CURE 666 Plainsboro Rd, Bldg 300 Plainsboro, NJ 08536 1-800-210-2873	curetoday.com Visit the "Prostate Cancer" for extensive info of the needs for prostate cancer.
UsTOO Prostate Cancer 2720 So. River Rd Des Plaines, IL 60018 1-800-808-7866	ustoo.org Provide to 300 support groups with info monthly newsletter "HOT SHEET"

Prostate Advocates Aiding
Choices in Treatment
PO Box 45
Sparta, MI 49345
1-844-722-2848

paact.help
Help patients better understand their own PC and their own care.

Mayo Clinic Foundation
200 First St SW
Rochester, MN 55905
1-507-284-2511

Monthly Newsletter + books
"Mayo Clinic Health Letter"
P.O. Box 9342
Big Springs, TX 75755

Harvard Medical School
10 Shattuck St
Boston, MA 02115
1-617-432-1000

Has a good newsletter
Harvard Health Letter
P.O.Box 9306
Big Sandy, TX 75755

Cleveland Clinic
18099 Lorain Ave
Cleveland, OH 44111
1-806-320-4573

newsletter, and PCa books
"Men's Health Advisor"
P.O. Box 8545
Big Sandy, TX 75755

John Hopkins Medical
1800 Orleans St
Baltimore, MD 21287
410-955-5000

White Paper Records
P.O. Box 8540
Big Sandy, TX 75755
903-636-5355

NCCN
National Comprehensive
Cancer Network
275 Commerce Drive Ste 300
Ft. Washington, PA, 19034
1-215-690-0300

has a guide book,
version 1.2015

PAACT Inc
Prostate Advocates for
Advanced Cancer Treatments
11555 Iadon Ct NE
Sparta, MI 49345-8155
1-666-453-1477

has a quarterly magazine
very good.
www.paactusa.org

For YOU

A Second Opinion

In Chapter 3, step 5, information is provided for obtaining a second opinion. It is very important to obtain a second opinion by an independent source, as your decision for treatment is based on available information, which should be as correct, accurate, and complete as possible.

Yes, there is a place, the name, location, and contact info is:
"thesecondopinion".
They provide a free multi-disciplinary second opinion and related services to adults in California who have been diagnosed with new or recurring cancer. A referral from a physician is not required. All Consultations are provided at no charge. They are a 501(c)3 non-profit agency.

Contact info:
Telephone number: 415-775-9956, Fax: 415-346-8652
1200 Gough St, Suite 500 mezzanine level, San Francisco, CA 94109 e-mail: mail@thesecondopinion.org
Website: http://thesecondopinion.org/lf
If you elect to proceed, their Administrative Coordinator will send a detailed explanation and the forms, or you can save time by downloading the instruction sheet and three forms from the website. Their office hours are: 10:00 am - 3:00 pm

Please call first, it is important that they know who you are and what your needs are before sending your information.
To appear before the **Review Panel**, the following is:
1. Be present and stay two to three hours with them,
2. Have a diagnosis from your own physician,
3. Want clarity about the diagnosis or treatment options,
4. Your medical records to be available 7 days before.

The second opinion will obtain your medical records from your doctors to review your case. You will be the contacted for the scheduling date of a panel appearance. Lunch and Parking are also provided free of charge..

Your WORKSHEET

This worksheet is for you to record your medical data, which you will need at every step ahead. By law, you are entitled to copies of all medical records, including all lab work, pathology reports, special tests, and reports by specialists. If needed, ask your Health-care team for help.

Enter the appropriate information in the spaces provided:

PSA __________ng/ml Date ____________
PSA ___________ng/ml Date ____________
PSA __________ng/ml Date ____________
PSA,free ________% Date ___________

Gleason Score: Primary # _____ Secondary # _________

Biopsy cores: _____ # positive cores ___ Highest %_____

Clinical Stage [or T-score] __________
http:www.phoenix5.org/staging.html

Prostate volume _____ cc [40cc is average for 60-yr man]
Prostate density ____________ PSA / vol = _?_ [0.10 is normal]
Prostate velocity ________ ng/ml/y http://mskcc.org/application/ nomograms/Prostate/ PsaDoublingtime.aspx

Prostrate doubling time _________ yr. [same website above]
Your date of birth ___________ Your age _____

Do you have relatives diagnosed with prostate cancer ??
If so, list their relationship and age when diagnosed.

Please maintain a journal of your health care, date of doctor appointments, get their business cards, date of all tests and the results.

Attach the Business Cards of Your Medical Care Team

YES there is HELP.

compiled by:
Harold Honeyfield, a survivor, with
comments from survivors of the Yolo
Prostate Cancer Support Group
June 2019