



5905 Shamrock Road
Durham, NC 27713
919.321.0365
Email: info@pccnc.org
Website: www.pccnc.org

By working together the citizens of North Carolina will see a day when prostate cancer is no longer a threat to the families of our state.

Planning Workbook for Newly Diagnosed Men

Current as of September 2009.

This workbook is designed to assist prostate cancer patients in quickly understanding important prognostic markers that can help facilitate more informed discussions with their physicians. The information and opinions expressed in this workbook are not an endorsement or recommendation for any medical treatment, product, service or course of action by the Prostate Cancer Coalition of North Carolina or its officers and directors. For medical, legal or other advice, please consult appropriate professionals of your choice.



5905 Shamrock Road
Durham, NC 27713
919.321.0365
Email: info@pccnc.org
Website: www.pccnc.org

By working together the citizens of North Carolina will see a day when prostate cancer is no longer a threat to the families of our state.

Contents

Preliminary Considerations.....	3
Building your Team	7
Defining Goals and Objectives	10



5905 Shamrock Road
Durham, NC 27713
919.321.0365
Email: info@pccnc.org
Website: www.pccnc.org

By working together the citizens of North Carolina will see a day when prostate cancer is no longer a threat to the families of our state.

Preliminary Considerations

General Health

Age at diagnosis: _____

Current age: _____

Health conditions (check all that apply):

___ heart condition ___ diabetes ___ other cancer ___ other (list all):



Preliminary Considerations: Age & General Health

- Typically younger men have more aggressive cancer.
- Men under 65 may likely benefit from definitive action.
- If you have less than a 10 year life expectancy, aggressive treatment needs careful consideration.



5905 Shamrock Road
 Durham, NC 27713
 919.321.0365
 Email: info@pccnc.org
 Website: www.pccnc.org

By working together the citizens of North Carolina will see a day when prostate cancer is no longer a threat to the families of our state.

Preliminary Considerations

Information from your PSA blood test(s)

Date of diagnosis: _____

PSA at time of diagnosis: _____

Last 5 PSA results:

Date	Value



Preliminary Considerations: PSA & PSA doubling time

- Your PSA at diagnosis.
 - The absolute level of PSA at diagnosis is also of prognostic importance. A PSA 10 or greater is a higher risk cancer.
- Your PSA velocity.
 - The rate of change of PSA prior to diagnosis can be of prognostic value and help plan therapy.




5905 Shamrock Road
 Durham, NC 27713
 919.321.0365
 Email: info@pccnc.org
 Website: www.pccnc.org

By working together the citizens of North Carolina will see a day when prostate cancer is no longer a threat to the families of our state.

Preliminary Considerations

Information from your digital rectal exam (DRE) – and possibly other tests (if advanced disease is suspected).

Clinical stage: _____



Preliminary Considerations: Understanding Stages

T1: tumor present, but not detectable clinically or with imaging

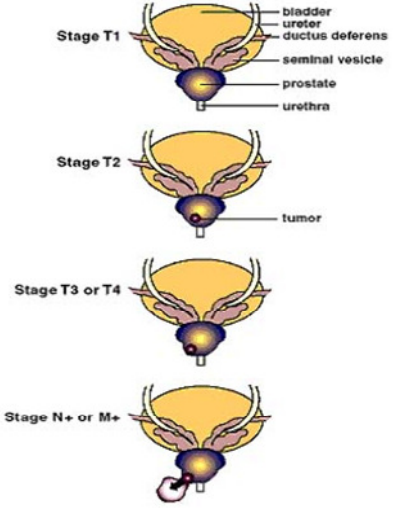
T2: the tumor can be felt (palpated) on examination, but has not spread outside the prostate

T3: the tumor has spread through the prostatic capsule (if it is only part-way through, it is still T2)

T4: the tumor has invaded other nearby structures

N+: cancer in regional lymph nodes

M+: distant metastasis



The diagram illustrates the progression of prostate cancer through four stages, shown as cross-sections of the prostate and surrounding pelvic region:

- Stage T1:** The tumor is confined within the prostate gland. Labels include: bladder, ureter, ductus deferens, seminal vesicle, prostate, and urethra.
- Stage T2:** The tumor is larger and more prominent within the prostate gland. Label: tumor.
- Stage T3 or T4:** The tumor has grown larger and is beginning to break through the prostatic capsule.
- Stage N+ or M+:** The tumor has spread beyond the prostate, with metastasis shown in the lymph nodes and distant organs.



5905 Shamrock Road
 Durham, NC 27713
 919.321.0365
 Email: info@pccnc.org
 Website: www.pccnc.org

By working together the citizens of North Carolina will see a day when prostate cancer is no longer a threat to the families of our state.

Preliminary Considerations


Information from your biopsy results

Number of cores sampled: _____ Number of cores positive: _____

% core involvement (per positive core): _____

Gleason Score

Primary: _____ Secondary: _____ Total: _____ Highest score found: _____

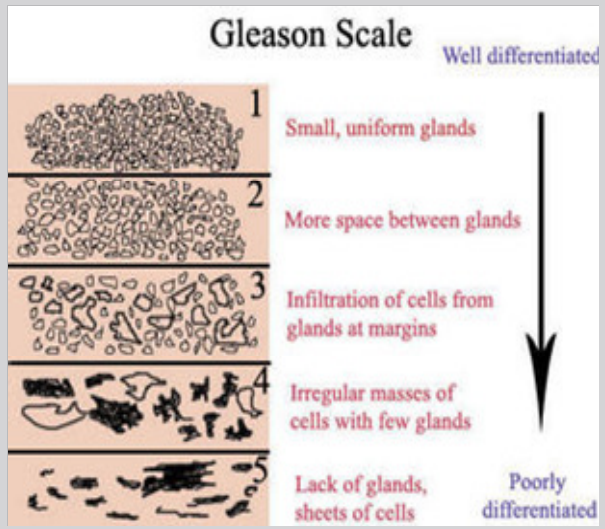


**Preliminary Considerations:
Gleason Score**

This drawing represents the 5 Gleason Scale patterns seen by the pathologist under the microscope.

The pathologist assigns a number to the most dominant pattern and then a second number to the second most dominant pattern. The two numbers are added to give the final Gleason Score or Sum e.g. 7 (4+3)

Even a small *additional* area of Gleason Scale 5 cancer can indicate higher risk for an otherwise low Gleason Score.



Gleason Scale

Well differentiated

1	Small, uniform glands
2	More space between glands
3	Infiltration of cells from glands at margins
4	Irregular masses of cells with few glands
5	Lack of glands, sheets of cells

↓
Poorly differentiated



5905 Shamrock Road
Durham, NC 27713
919.321.0365
Email: info@pccnc.org
Website: www.pccnc.org

By working together the citizens of North Carolina will see a day when prostate cancer is no longer a threat to the families of our state.

Building your Team

Critical Success Factors:

- Form a multidisciplinary team to evaluate your treatment options including urologic and oncologic specialists.
- Always consider integrative therapies to improve overall outcome such as diet and lifestyle intervention.
- Watchful Waiting/ Active Surveillance is not “no treatment.”
- Leverage support groups. It is always a good idea to seek the experienced advice and consultation of someone who has done what you are new to.
- Involving your family and friends by letting them help can give them great comfort.
- Just like most industries, there are prostate cancer specialists and subject matter experts in all treatment related professions. Seek out your local or regional subject matter expert for each area of specialty on your team.
- If you are leaning towards surgery, typically surgical outcomes (overall recovery and recovery from possible side-effects such as erectile dysfunction and incontinence) improve as the surgeon gains experience. Ask how many surgeries the urologic surgeon has preformed and what the outcomes were.

Possible Treatment Options (depending upon how aggressive your cancer is):

- Watchful Waiting/ Active Surveillance
- Surgery/ Prostatectomy
- Radiation Therapy
- Hormone Therapy
- Cryosurgery
- High Intensity Focused Ultrasound (HIFU)
- Chemotherapy
- A combination of any of the above



5905 Shamrock Road
Durham, NC 27713
919.321.0365
Email: info@pccnc.org
Website: www.pccnc.org

By working together the citizens of North Carolina will see a day when prostate cancer is no longer a threat to the families of our state.

Contacts for Support Network:

Experienced Survivors

- Acquaintances that have or had prostate cancer

- Patient support groups (meets)

Day of the week: Time: Location:

Facilitator contact:

Family & Friends

- Your spouse or partner: _____

- Friends who have experience with prostate cancer

- Your children, siblings, and other close family members



5905 Shamrock Road
Durham, NC 27713
919.321.0365
Email: info@pccnc.org
Website: www.pccnc.org

By working together the citizens of North Carolina will see a day when prostate cancer is no longer a threat to the families of our state.

Contacts for My Treatment Team:

- Pathologist: studies tissue and cells to define disease

- Urologist: specializes in the treatment of urinary and reproductive system

- Radiation Oncologist: treats cancer with radiation

- Medical Oncologist: treats cancer with hormone or chemotherapy

- Nurses and PAs: provides you with detailed care and information

- Social Workers & Therapists: helps the patient and family with adjustment

- Nutritionist: works with you to implement integrative strategies to improve odds of recovery

- Anesthesiologist: manages pain



5905 Shamrock Road
 Durham, NC 27713
 919.321.0365
 Email: info@pccnc.org
 Website: www.pccnc.org

By working together the citizens of North Carolina will see a day when prostate cancer is no longer a threat to the families of our state.

Goals and Objectives (number 1 for most important and 5 for least important):

- ___ Prolong life
- ___ Long-term general health and well-being
- ___ Maintaining sexual function and urinary continence for as long as possible
- ___ Being there for my family
- ___ Optimal quality of life

Summary of Prognostic Information

Date of diagnosis: _____ Age at diagnosis: _____

Current age: _____

Other health conditions: _____

PSA at time of diagnosis: _____

Last 5 PSA results:

Date	Value


Clinical stage: _____

Gleason Score - Total: _____ = (Primary: _____ + Secondary: _____) Highest found: _____



5905 Shamrock Road
Durham, NC 27713
919.321.0365
Email: info@pccnc.org
Website: www.pccnc.org

By working together the citizens of North Carolina will see a day when prostate cancer is no longer a threat to the families of our state.



Putting your Plan into Action

- Preparing for side-effects
 - Talk to experienced patients and survivors. Support groups can help you prepare both mentally and physically.
- Redevelopment plan
 - Think about lifestyle modifications that may help prevent recurrence.
- The need for ongoing surveillance
 - As many as 1/3 of successfully treated patients recur within 25 years of primary treatment.
 - How often you need follow up may vary, but should be more often during the first few years after your primary treatment.

"You cannot sit back and do nothing because you'll never have perfect intelligence on the enemy...Get on with it."

-General Norman Schwarzkopf

"Do your homework, seek advice, get that second opinion, then make your decision and don't look back."

-John H. Lynch, M.D.

"Life is all about stalling the disease and living and having a good time."

-Israel Barken, M.D.

"At some point in a person's life one will learn to enjoy and treasure each day. The younger we are when we reach that point the more we will enjoy our lives."

-Bob Anderson, Founder of the PCCNC



5905 Shamrock Road
Durham, NC 27713
919.321.0365
Email: info@pccnc.org
Website: www.pccnc.org

By working together the citizens of North Carolina will see a day when prostate cancer is no longer a threat to the families of our state.

So you've been diagnosed with prostate cancer, DOs and DON'Ts

Excerpted from The Human Side of Cancer by Jimmie C. Holland, M.D., of Memorial Sloan-Kettering Cancer Center,

1. DON'T believe the old adage that "cancer equals death." There are eight million survivors of cancer in the United States today.
2. DON'T blame yourself for causing your cancer. There is no scientific proof linking specific personalities, emotional states or painful life events to the development of cancer. Even if you may have raised your cancer risk through smoking or some other habit, there is no benefit from blaming yourself or beating yourself up.
3. DO rely on ways of coping that helped you solve problems and handle crises in the past.
4. If you've been a talker, find someone with whom you feel comfortable talking about your illness. If you're an inveterate non-talker, you may find relaxation, meditation or similar approaches helpful. The secret, however, is: use whatever has worked for you before, but if what you're doing isn't working, seek out some help to find another way to cope.
5. DO cope with cancer "one day at a time." The task of dealing with cancer seems less overwhelming when you break it up this way, and it also allows you to focus better on getting the most out of each day, despite illness.
6. DON'T feel guilty if you cannot keep a positive attitude all the time, especially when you don't feel good. Low periods will occur, no matter how good you are at coping. There is no evidence that those periods have a negative effect on your health or tumor growth. If they become frequent or severe, though, seek help.
7. DON'T suffer in silence. Do use support and self-help groups if they make you feel better. Leave a group that make you feel worse, but don't try to go it all alone. Get support from your best resources -- your family, friends, doctor, clergy, or those you meet in support groups who understand what you are going through.
8. DON'T be embarrassed to seek counseling with a mental health professional for anxiety or depression that interfere with your sleep, eating, ability to concentrate, or ability to function normally if you feel your distress is getting out of hand.
9. DO use any methods that aid you in getting control over your fear or upset feelings, such as relaxation, meditation, as well as spiritual approaches.
10. DO find a doctor who lets you ask all your questions and for whom you feel mutual respect and trust. Insist on being a partner with him or her in your treatment. Ask what



5905 Shamrock Road
Durham, NC 27713
919.321.0365
Email: info@pccnc.org
Website: www.pccnc.org

By working together the citizens of North Carolina will see a day when prostate cancer is no longer a threat to the families of our state.

side effects you may expect and be prepared for them. Anticipating problems often makes it easier to handle them if they occur.

11. DON'T keep your worries or symptoms (physical or psychological) secret from the person closest to you. Ask this person to accompany you to visits to the doctor when treatments are to be discussed. Research shows that you often don't hear or absorb information when you are very anxious. A second person will help you interpret what was said.
12. DO re-explore spiritual and religious beliefs and practices such as prayer that may have helped you in the past. (If you don't consider yourself a religious or spiritual person, garner support from any belief system or philosophy that you value, such as humanism.) These beliefs may comfort you and may even help you find meaning in the experience of your illness.
13. DON'T abandon your regular treatment in favor of an "alternative" treatment. Work with your physician(s) to use complimentary and integrative treatments that do no harm and that can safely be used along with your regular treatment. Be sure to tell your doctor which complementary therapies you are using or want to use, since some should not be used during chemotherapy or radiation treatments. Discuss the benefits and risks of any complementary treatments with someone you trust who can assess them more objectively than you when you are under stress. Psychological, social and spiritual approaches are helpful and safe, and doctors encourage their use today.
14. DO keep a personal notebook with all your dates for treatments, laboratory values, x-ray reports, symptoms and general status. Information is critical in cancer treatment, and no one can keep it better than you.