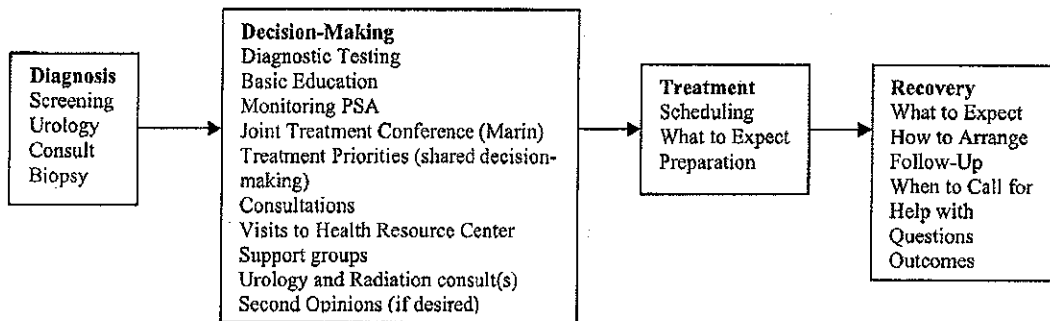


## Chapter 1. Organizing My Care

*With contributions from Angeles (Les) Price R.N., M.S., CNS, AOCN, Oncology Clinical Resource Nurse Coordinator and Clinical Nurse Specialist, Sutter Solano Medical Center; and Nancy L. Brown, Ph.D., Palo Alto Medical Foundation Research Institute*

The figure below describes the prostate cancer care pathway. It is meant to reflect how your care will be organized.

Figure 1. Prostate cancer decision-making and care



In general, your care will start with your **diagnosis**, which will include your prostate specific antigen (PSA) blood test, a consult with an urologist and a biopsy (procedure to take tissue samples from your prostate). The next step will be other tests to help with **decision-making**, some basic education about prostate cancer and its treatment, and deciding what treatment is best for you. Once that decision is made, your **treatment** (if any) will be scheduled, and there will be some more education about how to prepare and what to expect after the treatment (both immediately after treatment and long-term). Finally, during your **recovery** from the procedure(s), there will be some follow-up to monitor the success of the treatment, and provide any support you need.

In the following sections, you should record the information that is requested to keep track of what you are told about your condition in various meetings and about the people who will be involved in your care. It is easy for notes and pieces of paper to get misplaced, and you may forget important things you are told. You will not complete all of the sections at once; you will complete them as you move through diagnosis, decision-making, treatment and recovery.

### Background

- Date of diagnosis: \_\_\_\_\_
- PSA at time of diagnosis: \_\_\_\_\_
- Other illnesses (co-morbid conditions): \_\_\_\_\_
- Current medications being taken: \_\_\_\_\_





- **Questions** that come up between appointments to ask at the next appointment or on a call with the nurse navigator or doctor.

Remember to ask:

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- **Services available** (pocket will follow)  
Please place relevant local information (e.g., business cards, flyers, brochures) for future reference in the holder that follows this page.
- **Second opinions** (pocket or sleeve will follow)  
Please record second opinion visits and notes below for future reference, and place a copy of any letters or findings in the holder that follows this page.

If a copy was not sent to your primary care physician (PCP) or urologist (and you want him or her to know), please send a copy ASAP.

Second Opinion 1:

- Name: \_\_\_\_\_
- Specialty: \_\_\_\_\_
- Phone numbers: \_\_\_\_\_
- Address: \_\_\_\_\_
- Date of visit: \_\_\_\_\_
- Notes: \_\_\_\_\_

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Second Opinion 2:

- Name: \_\_\_\_\_
- Specialty: \_\_\_\_\_
- Phone numbers: \_\_\_\_\_
- Address: \_\_\_\_\_
- Date of visit: \_\_\_\_\_
- Notes: \_\_\_\_\_

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• **Referrals**

- Further tests
  - **Bone scan** (not always necessary)
    - **What is it?** The bone scan uses a relatively harmless radioactive fluid to help the doctor determine if the prostate cancer has spread into the bones.
    - Phone to schedule: \_\_\_\_\_
    - Location: \_\_\_\_\_
    - Appointment date and time: \_\_\_\_\_
    - Preparation: \_\_\_\_\_
  - **CT scan** (not always necessary)
    - **What is it?** A computerized tomography (CT) test helps stage the cancer. It is painless and non-invasive, although you may be asked to drink a lot of water before the test, and a dye may be used to identify any abnormalities that may be tumors.
    - Phone to schedule: \_\_\_\_\_
    - Location: \_\_\_\_\_
    - Appointment date and time: \_\_\_\_\_
    - Preparation: \_\_\_\_\_
    - Notes about CTs:
      - Tell the doctor if you are allergic to iodine or shellfish, have any kidney problems, or asthma, or if you are allergic to the dye used in the procedure.
  - **MRI** (not always necessary)
    - **What is it?** Magnetic resonance imaging (MRI) is another test that helps stage prostate cancer. It is a non-invasive imaging test that uses magnetic waves to provide a picture of the internal organs. The test can also help detect tumors (localized or spreading).
    - Phone to schedule: \_\_\_\_\_

- Location: \_\_\_\_\_
- Appointment date and time: \_\_\_\_\_
- Preparation: \_\_\_\_\_
- Notes about MRIs:
  - A closed MRI is a small chamber and can make you a little claustrophobic if you do not like **small, enclosed spaces**. Discuss this with your doctor.
  - MRI machines are also very **noisy**, even with the earplugs you will be provided.
  - Some doctors will use an **endorectal coil** that may be inserted into your rectum during the MRI to collect additional information about the extent of the prostate cancer.
- **Consults.** Many urologists will suggest that you speak with a radiation oncologist, and some may suggest you see a nutritionist or other clinician. Here is a place for you to keep track of those consults.

**Radiation Oncologist**

- Name: \_\_\_\_\_
- Specialty: \_\_\_\_\_
- Phone numbers: \_\_\_\_\_
- Address: \_\_\_\_\_
- Date of visit: \_\_\_\_\_
- Notes: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Consult 2**

- Name: \_\_\_\_\_
- Specialty: \_\_\_\_\_
- Phone numbers: \_\_\_\_\_
- Address: \_\_\_\_\_
- Date of visit: \_\_\_\_\_
- Notes: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Consult 3**

- Name: \_\_\_\_\_
- Specialty: \_\_\_\_\_

- Phone numbers: \_\_\_\_\_
- Address: \_\_\_\_\_
- Date of visit: \_\_\_\_\_
- Notes: \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

After much discussion and contemplation, you will have made your decision. Please record them below, or place the papers given to you in the pocket that follows.

• **Treatment plan**

- Surgery
  - Date: \_\_\_\_\_
  - Hospital: \_\_\_\_\_
  - Surgeon: \_\_\_\_\_
  - Type of surgery: \_\_\_\_\_
  - Appointment time: \_\_\_\_\_
  - Phone: \_\_\_\_\_
  - Preparation: \_\_\_\_\_
  - Don't forget: \_\_\_\_\_
- External Beam Radiation
  - Appointment for placement of gold fiducial seeds: \_\_\_\_\_
  - Date beginning: \_\_\_\_\_
  - Number of treatments: \_\_\_\_\_
  - Location: \_\_\_\_\_
  - Radiation oncologist: \_\_\_\_\_
  - First appointment time: \_\_\_\_\_
  - Phone: \_\_\_\_\_
  - Preparation: \_\_\_\_\_
- Brachytherapy (Seeds)
  - Date of first treatment: \_\_\_\_\_
  - Number of treatments: \_\_\_\_\_
  - Location: \_\_\_\_\_
  - Radiation oncologist: \_\_\_\_\_
  - First appointment time: \_\_\_\_\_
  - Phone: \_\_\_\_\_
  - Preparation: \_\_\_\_\_
- Hormone therapy
  - Drug/dosage: \_\_\_\_\_
  - Date started: \_\_\_\_\_

- Date completed: \_\_\_\_\_
- Drug/dosage: \_\_\_\_\_
- Date started: \_\_\_\_\_
- Date completed: \_\_\_\_\_
  
- Drug/dosage: \_\_\_\_\_
- Date started: \_\_\_\_\_
- Date completed: \_\_\_\_\_
- Chemotherapy
  - Date started: \_\_\_\_\_
  - Number of cycles: \_\_\_\_\_
  - Drug: \_\_\_\_\_
  - Other medications given: \_\_\_\_\_
  
- Other (clinical trials, etc.)
  - First appointment time: \_\_\_\_\_
  - Phone: \_\_\_\_\_
  - Preparation: \_\_\_\_\_