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Providing Care for Prostate Patients

Developed by the Sutter Health Cancer Service Line: Prostate Committee

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The Sutter Health Prostate Cancer Committee

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Introduction

With contributions from Nancy L. Brown, Ph.D., Palo Alto Medical Foundation Research Institute; and D. Jeffrey Demanes, M.D., California Endocurietherapy Cancer Center

Having just been diagnosed with prostate cancer, it is perfectly normal that you may feel scared, fragile, vulnerable, overwhelmed and unsure where to start gathering information. Given that this may well be one of the hardest times in your life, this notebook was developed to guarantee that you get the information and support you need, make the process easier for you and your family, provide you with resources to help you make the required decisions, and provide a way for you to centralize your medical information and have it available when and where you and your health care providers need it. In addition, this notebook is designed to work hand-in-hand with the nurse navigator who will help you as you go through the decision and treatment process.

When a group of concerned medical professionals volunteered to help Sutter Health develop this program, we began by acknowledging that, for many men, this may be the first time they have been asked to make a significant medical decision. Since there is no one right answer for all men, it can be a frustrating experience.

We interviewed men in Northern California who had been diagnosed with prostate cancer, most of whom had been treated, but some of whom had decided to "wait and watch." We listened to what they and their partners told us had helped them most during their decision-making process and what they didn't get that would have helped them.

Our goal is to help you make the best decision about how to treat your prostate cancer, given the context of your life, your priorities, the treatment recommendations you have or will get from physicians, how much emotional support you need, and your long-term quality of life concerns.

There are differences in how people organize and process information, how much information and control they need, and how comfortable they are negotiating the medical system. Not everyone needs exactly the same support, information or follow-up. Our goal is to give you the basic elements so that you can select and use the resources you need.

We want you to receive the best, state-of-the-art, comprehensive and integrated care available. To make sure you get that care, we have developed this resource book to help you at each stage including 1) diagnosis, 2) decision-making, 3) treatment, and 4) recovery, both immediately following treatment and over the long term.

Describe the Role of the Nurse Navigator

After being diagnosed with prostate cancer, men and their families get a lot of medical information and typically need some way to keep everything organized, understand exactly what is involved with various treatment decisions (including costs), and develop a good understanding of what to expect at each step. The information can be a bit overwhelming, and since they have not had the experience before, many men can benefit from someone who is available to help if they forget something or just didn't hear it the first time when they were trying to deal with the shock of this unwelcome diagnosis.

The nurse navigator will promptly answer your questions and is here to help you coordinate your appointments, tests, treatment, communication between doctors and follow-up care.

- Treatment goals
- Treatment process

The **second contact** will be a brief session about your treatment decision process. This may take place in-person or by phone, and will review:

- The outcome of your most recent urology consult;
- A possible upcoming joint conference (Marin only);
- Review and prioritization of treatment goals in relation to your treatment priorities;
- Coordination of appointments for any recommended additional diagnostic tests or consultations;
- Coordination of any second opinions; and
- Scheduling any treatment decided upon at that point.

The **third contact** (if needed) will be a brief discussion about your treatment decision. This may be in-person or by phone, and will review:

- Scheduling of any treatment that has been decided upon; and
- Education about what to expect during and following treatment.

Finally, there will be a small number of brief **follow-up contacts** (most likely via e-mail or phone) about your recovery and follow-up monitoring (e.g., reminders about scheduled hormone treatment if applicable or PSA tests).