

Making The System Work For You



Principles of Empowerment In Advanced & Hormone Refractory Prostate Cancer

As a prostate cancer patient becomes hormone refractory, (or androgen independent, or castrate resistant), the cancer journey becomes more involved. It requires more time devoted to treatment choices, treatment monitoring, and treatment side effects. Each of these areas can feel empowering or disarming at different times. After 10 years of advocating for my husband's metastatic prostate cancer, and over 8 years of working the PCRI Helpline, I'd like to share several lessons which have been empowering for me.

The empowerment principles in this article can be applied to almost any medical situation, and I have learned to apply them for myself and my family. Also, I am using the term "hormone refractory" in a simple context of how it is perceived by most patients and clinicians. I am referring to men who have suppressed testosterone (most likely from hormone therapy), with progressive disease, and in the process of choosing additional treatments.

As the patient, this is an important time to advocate for yourself, or accept the help from someone else who is offering. PCRI's goal is always to help empower you on this journey – the patient, the wife, the daughter, brother, or friend who is advocating.

I'd also like to encourage you that this is a journey, not an end. It is a road, not a stopping point. You are on a path that will have twists and turns, and stops along the way, followed by another journey. Keep looking forward.



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1. Medical Records

One way to keep looking forward is to have treatment choices in mind; to have an idea or two already researched. However, before you go forward (to make an HRPC treatment decision), sometimes you have to go backward. Every now and then, go back to your medical records. Even if you think you know your biology, it is meaningful, even critical to return to those written records occasionally, to re-examine them and look for new clues. In addition to the science and statistics we find in published studies, there is important scientific evidence within your own biology – in your own printed medical

records. Every man’s prostate cancer is somewhat different. No two are exactly the same.

Here is a partial checklist of medical records in case you don’t have them yet.

- ✓ **Pathology reports** from all biopsies and/or surgeries
- ✓ **Ultrasound report** from initial prostate biopsy
- ✓ **Surgeon’s notes** from prostatectomy
- ✓ **Radiation summary** from radiation treatment
- ✓ Dictated **written reports from any imaging** (CT, MRI, bone scan, etc.)
- ✓ Lab reports from **blood tests**

You do not have to have all the medical records to start learning and understanding your biology.

This is a process, so start where you can, and add to your understanding as you go. This may take some time, but only at first. If you invest the time initially, and create a way to document medical information from new records, this will become easy and very empowering. If you are not a great record keeper, perhaps someone else in your family is. Let them help.

Getting copies of medical records can sometimes be a hassle. I have found that the easiest and quickest way to get copies is to simply **ask the physician during your office visit**. Make it one of the questions on your list. Since the doctor is the only one who has the authority to give medical records, and the patient is the only one who has the authority to request them, make this happen when the 2 of you are together. This trumps trying to call the office and go through the receptionist – every time.

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Once you have your medical records, know that everyone has a different way of keeping track of information. Feel free to do it however it works for you. Here is my way:

1. Get a yellow highlighter, or an inkpen. **Highlight or circle these 3 things -**
 - * **date of record**
 - ***type of record** (bone scan, PSA, etc)
 - ***significant findings.**
2. Put the papers **in order of DATE**. Do not put all the PSA’s together, and all the bone scans together, etc. You need to be able to see things chronologically so you can

CORRELATE the PSA with the bone scan, with the treatment, etc. It may even help you to write the corresponding PSA on the bone scan or CT closest to the date of that PSA. Now you are beginning to correlate evidence in a way that is visible.

3. **Log the information that you highlighted into one document** that you can change and edit as often as you want. Log the information in order of date, not the type of medical record. I use a table in a Word document, which would look something like this: (See Figure 1)

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Figure 1. Hypothetical Patient Record – John Doe Smith		
Date	Event	Details
1/3/2005	PSA 5.05	Lupron (7.5 mg) given today
1/4/05	New treatment “xyz”	Started today at ___mg, 3 x day.
1/15/05	Side effects	Complaints of nausea. Start ___ as needed for nausea.
1/31/05	PSA 2.34	Lupron (7.5 mg) given. PSA response to new treatment. Nausea improved.
2/21/05	PSA 1.35	Lupron (7.5 mg) given
3/21/05	PSA 0.80	Lupron (7.5 mg) given. Continued PSA response.
4/18/05	PSA 0.70	Other blood tests today – vit D 35L, PAP 0.1, CTC 2
4/20/05	Bone scan #3	Slight improvement over previous

As you can see, this **allows you to correlate** treatment with response, and with side effects, etc. This is empowering for making continued treatment decisions, which is common in hormone refractory prostate cancer.

1. Starting A New Treatment

Finding A Treatment

Sometimes you, as the patient, need to find the right questions to get the right answers. This may mean that you are the one who discovers the idea for the next treatment option. Part of the reason for this, is that there is a shortage of “proof”, or Level One evidence for developing a uniform treatment protocol in advanced prostate cancer (see PCRI Insights Aug 2009, *Levels of Evidence*). This is not your doctor’s fault. If you ask, you will probably find that he/she is just as frustrated by this lack of uniform protocol as you are. But finding a medical oncologist who will discuss this openly with you, and work with you on evaluating treatment options can be very empowering.

In the absence of level one evidence, there are still many smaller studies which present options that are worth considering and discussing with your medical oncologist. One of the best resources I have found for this is the website, www.HRPCA.org. This site is driven by patient reviews of medical literature, and includes a **free online discussion list** that can connect you with other patients who are trying to deal with hormone refractory prostate cancer issues. The late Harry Pinchot, PCRI’s Program Director for many years, was a member of this group for much of his own HRPC battle, and a long-time contributor.

When you research a treatment, remember that **every drug has two names**. If you reach back far enough

into the earlier studies of a drug, you will find it had a 3rd name, which is usually an acronym of letters and numbers. For example, the generic name for Provenge® is sipuleucel-T, but in beginning trials it was called APC8015. The other name for Taxotere® is docetaxel, Casodex® is also bicalutamide, and Nizoral® is the other name for ketoconazole.

Double Benefit?

Learn to watch for HRPC therapies that might have more than one benefit. Some drugs that have action against prostate cancer, also have action against something else. For example – **ketoconazole** has action against prostate cancer, and ac-



tion against fungal infections, such as thrush or yeast infections. In fact, that is how the drug is “labeled” by the FDA – for fungal infections. Using ketoconazole for prostate cancer is called “off label” because its action against prostate cancer was found years after it was FDA approved for fungal infections. (See May 2007 PCRI Insights, *High Dose Ketoconazole Plus Hydrocortisone (HDK+ HC)*) So, a patient who needs extensive antibiotic treatment and may be at risk for developing thrush or some other type of yeast infection, might benefit from taking a low dose of ketoconazole to help prevent or treat the yeast (fungal) infection. This yeast infection would be a “side effect” of the

antibiotic treatment, not a symptom of the cancer (see below). Although we may not have level one evidence on this idea, it is still a good question to research, and bring up with your physician(s).

Another HRPC treatment example might be **estrogen**, either in skin (transdermal) patches, or in oral (pill) form. Estrogen (estradiol) skin patches might include Vivelle® dot or generic transdermal estradiol. Oral estrogen is most commonly oral DES + Coumadin®. Estrogens can help build bone, or prevent bone loss, even in a man. 1,2 So, for a man who cannot tolerate a bisphosphonate like Zometa®, his bones may benefit from an estrogenic drug that was chosen to fight his HRPC.

A third example might be **Leukine®** (GM-CSF). Leukine is a treatment for low white blood cells, or low ANC, which can be a side effect with some chemotherapies. But some studies show that Leukine also has action against prostate cancer. 3,4 So, if WBC is low, Leukine as the drug of choice may possess additional benefit for the patient.

Again, these statements are not based on proof, but based on very good evidence. This is not medical advice, but information to help create better discussions and treatment decisions.

Researching Side Effects

I am convinced that I have seen many cancer patients stop important therapies because of treatment side effects - not because their cancer was no longer responding. Since **many side effects can be prevented, or treated early**, this becomes a great place to advocate for yourself. You can empower yourself to continue a certain treatment because you asked about, prevented, or got early

treatment for a significant side effect. PCRI.org has an entire webpage called Treatment Side Effects, devoted to dealing with this issue.

**Side effects (SE's),
are also called:**

- ✓ *adverse events (AE's),*
- ✓ *safety issues,*
- ✓ *toxicities, or*
- ✓ *risks, as part of a
"risk-benefit" profile.*

So, what is the difference between a symptom and a side effect? A symptom points to disease (in this case prostate cancer), and a side effect points to the treatment you're taking for that disease. It can be confusing for cancer patients when they are feeling poorly to understand exactly why. Men often experience this when they first begin hormone therapy. Initially they may have very few cancer symptoms, but the cancer is in need of treatment based on PSA, imaging, and other staging information. So, when hormone therapy is started, they soon may feel fatigue, and initially a few new aches and pains. This can be confusing because the first thought may be "my cancer is getting worse, because I feel worse". But the reality is that "feeling worse" is a treatment side effect, not a cancer symptom. So, the good news may be that the treatment is working, and the cancer is being suppressed, even though you feel a little worse. Again, this can be confusing, but understanding why you're feeling poorly is important – is it a cancer symptom? or is it a treatment side effect?

When considering a new treatment, spend considerable time asking about, and researching for the treatment's side effects. This can be a great conversation with a nurse, as

the nurses of your oncology site often have a more sensitive understanding of which side effects are common and significant, and how to prevent or treat them. The nurses are the ones who engage in conversation with patients in the treatment room, and usually the ones who return follow-up phone calls to patients at home.

When researching side effects (SE's), know that they are also called adverse events (AE's), safety issues, or toxicities. They may also be called "risks", and be part of a "risk-benefit" profile. This can be researched online, but make sure you seek information about what % of men had a particular side effect, and how serious it was (the grade). For example, a serious side effect may be mentioned, which can be frightening, but the fact may be that less than 5% of men encountered that side effect. If it is a rare side effect, it is likely that the small group who endured the SE had risk factors for it. Inquire and research.

It also may make sense to **start some treatments at a lower dose**, to make sure side effects are not overwhelming, or to give the body a chance to adjust to the new medication. Discuss this with both your prescribing physician, and your pharmacist.

How Long?

Make sure you also ask your prescribing physician, **"How long should it take before a response is seen to this treatment?"** Since

"I have seen many cancer patients stop important treatments because of side effects"

different treatments have different lengths of time before they are effective, this is information you need to understand up front. Otherwise you will not be reasonably equipped to make the next decision, which is "Is this treatment working?" For example, if it takes 4 to 6 weeks to show a response, evaluating at 2 or 3 weeks is probably too soon, and may lead to an uninformed decision. Also, some treatments may cause a slight increase in PSA before the PSA drops. Taxotere has been shown to cause this temporary increase in some patients, which has been called "Taxotere flare" in some studies. 5,6

Taking Pills

Drug Interactions

Whenever starting a new treatment, make sure it does not interact with other drugs being taken. One of the best resources I have found to check interactions is www.DRUGDIGEST.org. It has most drugs, including some chemotherapies, and it also cross checks with some food and supplements. Also, **discuss this in depth with your pharmacist**, who is often the most knowledgeable medical professional on the subject. Keep in mind that even if 2 drugs do interact, you may be able to take them a few hours apart to avoid the interaction. It may not necessarily mean you have to discontinue one or the other. Again, ask your pharmacist, and your prescribing physician.

Your Stomach

As you get older, you may find yourself taking more pills in general. As you change prostate cancer treatments, you will often find yourself adding and changing pills. Keep in mind that simple stomach upset can become a problem. Stomach upset can come in many forms, *(Continued on page 28)*

and is a side effect, as mentioned above. I have seen men stop important medications because of this side effect, instead of researching and asking how to take those pills differently, to prevent the stomach problems.

Here is a personal example that may help someone else.

My husband was responding well to ketoconazole + hydrocortisone. But the nausea and stomach burning (side effects) were about to cause him to stop this medication that his cancer was responding to. This made no sense to me, and I took some time to focus on preventing or treating this side effect. Speaking one day with Dr Snuffy Myers, and asking for new ideas for dealing with stomach issues, he recalled a drug he used for his wife when she was taking multiple medications. The drug was Cytotec® (misoprostol). It was designed to help prevent ulcers in patients taking NSAID's, and does so by simply protecting the stomach lining. Since ketoconazole requires stomach acid to work, there was some question as to whether or not the Cytotec would interfere with the ketoconazole's effectiveness. But after discussing this with my husband's oncologist, the decision was made to simply try it and see what happened. We watched PSA response, and asked my husband about his nausea and stomach burning. Although this idea might not work for someone else, it worked for my husband. Although this might not be the answer for everyone, it will generate a great question for someone. One of the simple lessons is to keep finding the right questions. You will eventually find a meaningful answer.

2. Monitoring Treatment

As you continue to monitor the cancer, understand that PSA is usually your best marker, but also



seek an understanding about how much PSA your cancer is currently making. (See November 2005 PCRI Insights, *Hormone-Refractory Prostate Cancer: A Continuum of Diseases and Options*, and January 2001 PCRI Insights, *The Gleason Score: A Significant Biologic Manifestation of Prostate Cancer Aggressiveness On Biopsy*.)

Furthermore, PSA pattern, especially PSA doubling time, is usually a better tool for evaluation, than one static PSA. In this situation, taking more PSA's (every month? every 2 weeks?) can give the kind of information you need for evaluation, as opposed to taking one PSA every 3 or 4 months. Taking more PSA's can help you evaluate a pattern, which can prevent you from reacting too strongly to just one PSA result. Research this for yourself, and discuss with your oncologist.

In addition to evaluating the PSA pattern, ask about further testing that can add to the assessment of treatment response. Extra blood tests such as CTC, or circulating tumor cells (see Nov 2008 PCRI Insights, *The 2008 Prostate Cancer Conference Summary*; Dr. Nicholas Vogelzang),

and perhaps PAP (prostatic acid phosphatase) can add more evidence. Imaging such as bone scan, CT scan, MRI, maybe ProstaScint can help you understand what the PSA response means – or doesn't mean. Research this for yourself, and discuss with your physicians.

Keep in mind that some men who are undergoing treatment are fighting treatment-induced anemia, as seen in a low HGB (hemoglobin). Be thoughtful about your choices of blood tests, and make them count. In other words, how much blood do you want to draw from a man who is constantly fighting anemia?

3. Using Treatments a Second Time

This is a very interesting topic. The truth is – this hasn't really been studied, which puts it on the list of "We don't really know". However, I personally have spoken to men who have responded to ketoconazole + hydrocortisone more than once. I know men who have responded to Taxotere more than once. And my own husband has responded to DES + Coumadin more than once. This is anecdotal evidence, as opposed to proof. However, we

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need to remember that all scientific proof starts as anecdotal evidence somewhere, at some time. In the absence of other treatment options, this is an idea worth considering and discussing. Keep in mind that each subsequent response may be shorter, or less significant. But that doesn’t make the idea worthless.

One recent study that supported this theory of using a treatment

Again, this is not actual advice, but the discussion of ideas based on experience and reasonable theory. This is intended to create new questions for you on your journey. Always research yourself, and discuss with your physician(s).

4. Facing Your Fears

Somewhere between curing cancer, and losing your life to cancer, is a middle road. This is where you probably are. Can we call it remission? Sometimes the definition doesn’t exactly fit. Can we call it cancer suppression? How about cancer control? It is a road that can turn some cancers into chronic, manageable illnesses. While you travel this road,

family member who is advocating, working through you fears can make you a better advocate.

Perfection is not the goal. The advocate is not responsible for making everything right. The advocate is entitled to make mistakes. So is the patient, and so are the medical professionals. **The goal is to simply make a difference for someone you love.** To know that you made life better, or you made life longer. If you are reading this article, you have probably already done that. If you are about to start, I hope this article helps. PCRI is always here to encourage you with empowerment.

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a second time. A research paper out of France evaluated 39 castrate resistant prostate cancer patients were reintroduced to Taxotere for a 2nd time. Approximately 2/3 of the patients showed a PSA response. It was concluded that “Re-treatment with subsequent docetaxel in patients with CRPC pretreated with first-line docetaxel is safe and demonstrates some activity.” 7

watch for new treatments to develop. We never know when that will happen, but there are certainly some drugs still in trials that hold some hope without an exorbitant amount of side effects.

Keep all this in mind, and when the time is right, take some time for yourself to face some of your tougher questions; the things you fear. Especially if you are the wife, or other