

## **PATIENT EMPOWERMENT**

Charles (Chuck) Maack – Prostate Cancer Advocate/Mentor

"Patient Empowerment" is particularly important and requires involving one's self in research and study. To that end you should obtain and maintain your own record of all lab reports, pathology reports, and medications prescribed you, as well as come to understand what those medical reports reveal and what the medications are intended to do for (to?) you. Pathology information is of particular importance. When it reports biopsy results it should identify number of tissue samples extracted, the location from which extracted, of that number how many evidenced the presence of prostate cancer, of those identified with prostate cancer the percentage of cancer present and Gleason Score assigned each individual sample, whether there was any presence of perineural invasion (PNI) or prostatic intraepithelial neoplasia (PIN), and an overall total Gleason Score. Pathology information from a surgically removed prostate gland would confirm or add to that determined from biopsy whether the cancer may have migrated to and beyond margins, to seminal vesicles, and/or to adjacent lymph nodes. Check around to determine if there is a prostate cancer support group in your area. Go on the internet and type in "Prostate Cancer Support Organizations" to determine websites, support lists, and contact information to help address and understand your prostate cancer concerns. Before each appointment to your physician, write down any concerns you expect your physician to explain - make a copy for the physician to read and another for yourself - then take notes as your concerns are addressed. It is important that you insist that your physician not only listen to your concerns, but provide you reasonable time to address and discuss/answer those concerns. By doing your homework, your physician will recognize that you know more about your situation than may have been expected. If your physician is not willing to work WITH you, then you really need to consider seeking another. You need to recognize that the physician is being "employed" by you to address and treat your ailments. It is naive to permit yourself to be treated in any manner "the doctor ordered" without you personally understanding the reasoning for everything being prescribed in that treatment. This is based on the recognition that "what the doctor ordered" has, too often, not been in our best interest. Physicians are not infallible. The majority are in their profession because they have a calling to help others and care; while others have become complacent in patient attention and permit themselves to be rushed and harried by their patient load.

On the one hand I recognize that physicians are likely so busy "reacting" to ailments and attempting to treat many different ailments that they cannot (or do not) find the time to keep up on improved treatment options. Yet, on the other

hand, it should be for this very reason that the physician should listen to we empowered patients who have been researching and studying our disease and have become aware of up-to-date improvements in treating our ailment. In my opinion, this is only possible if we have become empowered sufficiently to be able to elucidate what we have learned in a manner that the physician cannot help but be aware that he is dealing with a knowledgeable patient and it may be in that physician's best interest to pay attention and look into what we are explaining. Will it work with all physicians? Unlikely. But if we get through to any number, that is an improvement. And if it is not working with your physician, as I noted earlier, it is time to visit others until you determine one who is willing to listen. Support groups are good places to learn of those physicians who are more understanding to the concerns of their patients as well as practicing up-to-date procedures.

Of further interest in this regard:

<http://tinyurl.com/kkmvly>

<http://tinyurl.com/dhclvq>

Disclaimer: Please recognize that I am not a Medical Doctor. I have been an avid student researching and studying prostate cancer as a survivor and continuing patient since 1992. The comments or recommendations I make are not intended to be the procedure for you to now follow; rather, they are to be reviewed along with the comments or recommendations of others for your own further research, study, and discussion with the physician providing your prostate cancer care to come to your own, personal conclusion.