Patient Handout: The Power & Limits of Your Prognosis



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Dear Patient,

One tool in cancer care is the prognosis (plural = prognoses). This handout discusses how to use your prognosis to help you make wise decisions and look forward with hope.

What does your prognosis tell you?

Your prognosis is an estimate of the likely outcome. You can have a prognosis for…

- Life expectancy
- Side effects of treatment
- Course of illness (e.g., remission; cure; chronic cancer; remitting-relapsing disease)
- Late effects (problems that develop months or years after treatment)

How is a prognosis different from a prediction?

A prognosis is not a prediction. A prediction declares that a specific future outcome will happen. In the world of medicine, no tests or experts can foretell how an individual patient will do (unless the patient is literally taking the final breaths).

Nobody can predict—i.e., know ahead of time—how your cancer will respond or how long you will live. Many patients live longer and better than expected. There are long-term survivors of every type of cancer, including patients cured of cancers usually associated with a poor prognosis. Sadly, patients with a good prognosis can end up doing poorly. In all those cases, their prognosis was not wrong. Rather, those patients had an outcome in keeping with the many possible outcomes. Whatever your prognosis, we are moving forward with hope that you do as well as possible.

Why can't a prognosis predict what will happen to you?

A prognosis is a statistical estimate based on patients like you—not on clones of you. Those patients don't have the exact combination of factors that make you "you": age, height, weight, genetic makeup, past illnesses, non-cancer medical conditions, medications, diet, exercise routine, environmental exposures, social situation, and unmeasurable factors such as "will to live."

Also, a prognosis is based on past patients. That means those patients may not have had access to the newest treatments. They certainly didn't benefit from treatments currently in research trials that may become available to you in the future—treatments that may improve your prognosis.

Still another reason the future outcome will always be uncertain is that it may be impacted—for better or worse—by new diagnostic tests, changes in health care delivery, unexpected events such as a pandemic, or unimaginable discoveries and life events.

Given that a prognosis does not predict the future, what good does it do?

A prognosis is a key piece of information that helps you…

- Compare treatment options.
- Understand the seriousness of your condition.
- Make wise decisions about work and home.
- Take any needed steps to prepare for a likely outcome.

How does a prognosis help in decision-making about cancer treatments?

When choosing a treatment path, a key factor to consider is the prognosis—the likely outcome—for each option. What are the average life expectancies for patients who decline all further treatment, pursue Option "A," pursue Option "B," and so on? What are the likely side effects and aftereffects with each option? Those prognoses help you construct a list of pros and cons for each option.

How might a prognosis hamper wise decision-making?

If the prognosis is not favorable, any combination of shock, fear, sadness, anger, and confusion may hamper your ability to think rationally or to feel hope. Even for patients with a 90% chance of cure, facing their mortality highlights the uncertainty of life, which may stir emotions that interfere with the clear thinking needed to choose the best treatment path.

Please take care to avoid the trap of equating "prognosis" with "prediction." Whatever the prognosis, heed the wise words of the ancient philosopher, Cicero: "While there's life, there's hope."

Beyond the treatment decision, how might a prognosis help you?

Whatever the prognosis, try to use it to motivate you in positive ways. There's wisdom in preparing for the worst and hoping for the best. That's because preparing for the worst does not make it happen—and preparing may help you find hope. Many patients report relief after taking care of all the "what ifs." With their affairs in order and delicate conversations behind them, they feel greater energy to direct toward measures that may help recovery (such as eating well) and finding ways to enjoy today.

In addition, you can use your prognosis to help you make informed decisions about home, school, and work. Whatever you decide and whatever happens, from now on you may find peace in knowing you made the best decisions for you.

During and after treatment, how might a poor prognosis be used positively?

Some patients focus on the uncertainty: "Someone is part of the 10% long-term survivors, and it might as well be me!" Others use a poor prognosis to energize a fighting spirit: "I'll show them!"

What if during and after cancer treatment, thinking about the prognosis only causes anxiety or hopelessness?

If, like many patients, the prognosis only increases your anxiety, it's time to forget it and move on. Forgetting the prognosis may seem impossible. It's not. You can know something frightening without thinking about it all the time. Consider that you don't think about the risk of car accidents every time you ride in a car. If the prognosis comes to mind, remind yourself that there are no statistics about "you." Highlight things that distinguish you: "I'm special because ….my tumor showed up in an unusual spot, I'm not the typical age for someone with this cancer, I'm more fit than most people, I am (*fill in the blank*)…." If receiving treatment in a clinical trial, take comfort in the fact that there are no statistics for patients like you.

Whatever your situation, the best approach may be to shift your focus to making the most of today.

Can a prognosis change over time?

Yes. For example, at the start of treatment, you are lumped together with all patients in your situation. If your cancer responds quickly and completely, then at the end of treatment your prognosis is better than that of patients whose cancers didn't respond. For patients whose cancer doesn't respond to a first course of treatment, their prognosis may then improve if their cancer responds well to a different treatment regimen.

What now?

Your prognosis is key to getting good care. It can help you make wise decisions and take proper action. Once you've decided on treatment, it's time to focus on making the most of today. OT

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