WHAT COMBINATION OF FACTORS PREDICT MY OUTCOME?

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S A PERSON DIAGNOSED WITH PROSTATE CANCER, you'll need to make decisions about your disease that will affect your life in many ways. To make these decisions, you need to know what to expect in terms of his disease and its treatment so that you can discuss your options with your doctor and loved ones.

In the last 10 years a great deal of research has gone into predicting outcomes and providing men with prostate cancer with the kind of information they need to make informed decisions. In order for men to use these predictions wisely, they need to understand what is behind the predictions they are receiving.

What Is a Prognosis?

Doctors cannot foretell a person's future health with perfect accuracy, so they provide a man with prostate cancer with a prognosis, a prediction of the probable course of his disease and an indication of the likelihood of recovery from that disease. A favorable prognosis means the cancer is likely to respond well to treatment. An unfavorable prognosis indicates that the cancer is expected to be difficult to treat and control.

A prognosis is not absolute. Cancers don't always grow or respond to treatment as expected. A person's situation may also change (for example, if treatment is effective or a person's cancer progresses) and ongoing cancer research may provide new developments in cancer treatment and result in an improved prognosis.

Requesting prognostic information is a personal decision. Consider how you will cope with the information you may be given. It is up to you to decide how much information you want and what decision you will make next. You may want to discuss this issue with your doctor. Remember that all prognoses are only predictions. You are not a number, your situation is complex, and no one can be sure what your outcome will be.

FACTORS THAT HELP DETERMINE EXPECTED OUTCOMES

A variety of factors affect a man with prostate cancer's likely outcome, such as his age and general health. However, doctors rely heavily on certain infor-

> mation about the cancer to determine the likely progression of the disease and the best treatment for it. The key factors considered at diagnosis include:

- tumor volume (how large the tumor is at diagnosis)
- the location and extent of the primary tumor (TNM stage)
- pre-treatment PSA
- the Gleason score (how aggressive the cancer would likely be if it were allowed to progress without treatment)

HOW PROGNOSES ARE DETERMINED

To determine a patient's prognosis, doctors consider everything that could affect that person's disease and outcomes (these are called prognostic factors). Then they consult published studies and clinical trials to learn more about the past outcomes of other men with prostate cancer in similar situations and try to predict what might happen in an individual's case.

However, no study exactly reflects an individual's situation, and even if the group's prognostic factors are similar to an individual's, multiple studies of similar factors may provide different results (and therefore different outcome estimates for

Alternatively, doctors may rely on data from individual patients to create individualized predictions. We'll explore both of these approaches here.

Keep in mind that simplified methods of gauging the likelihood of certain outcomes may not be useful in determining your course of treatment and how it could affect your prognosis.

Facing a Prognosis

When I was diagnosed, my Gleason was 7 plus. I started out from the standpoint of, you know, "You're really in bad shape. Where are we going from here?"

- John D.

My cancer was detected early. When the doctor told me, "If you choose not to do anything about your prostate cancer, you may live 10 or 15 years without any threat or danger to your life," I felt quite positive.

- Tieh Huei

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INDEXES AND NOMOGRAMS

Indexes and nomograms are tables and charts that help translate information into prognoses. They translate what may be a complicated set of data into a simplified prognosis, but because they are only able to reflect a small number of prognostic factors, they may produce a potentially inaccurate prognosis. Nomograms are frequently used for men with prostate cancer. Indexes and nomograms do not focus on survival, and they cannot advise doctors or patients on how to alter or improve outcome.

Indexes. An index is a system of developing probabilities of outcomes that provides a weight for each prognostic factor. The weight indicates how important that factor is in determining the outcome. Then the weights of each factor are added for a total score, which appears in a table. An individual's outcome is the one in the table associated with his total score. Using indexes provides only limited information. For example, indexes don't take into account the effects of factors on each other.

Nomograms. A nomogram is a chart representing the relationship between one or more prognostic factors and an outcome. This chart shows a numbered scale for prognostic factors and outcomes. A doctor draws a line at a number corresponding to each of a patient's prognostic factors, such as PSA or Gleason score. The point where this new line intersects the outcome line represents the patient's outcome. It is difficult to represent complex prognostic factors in a nomogram.

STATISTICAL MODELS

Another, more precise approach is to use a computer program based on a statistical model to determine prognosis. Inputting the patient's exact prognostic factors allows the program to calculate that individual's probability of having a particular outcome. This is more accurate than other approaches because it indicates an *individual*'s probability rather than the *average* probability of a group of people with similar prognostic factors.

Statistical models are generally limited to physicians' use. In the future, these programs will likely become more widely available to patients through the Internet. (Some elementary versions are already available online.) Patients will be able to enter their information and receive their outcome predictions, for example, entering prognostic factors and receiving a probability of recurrence and survival over the next 15 years.

Keep in mind the several limitations of statistical models. Statistical models are built around past results. Therefore, men's outcomes from 10 or 15 years ago—when biopsy rates were unavailable, radiation doses were different, and hormonal therapy was not as widely used—may not accurately reflect the future of men

today. Most numbers used in statistical models are from major academic centers; it cannot be assumed that results at other treatment centers will be the same. It is also important to keep in mind that the future of an individual with prostate cancer is not dictated by numbers; many complex factors determine prognoses and a man's prognosis may change over time as his prognostic factors change.

HOW PROGNOSES ARE EXPRESSED

Doctors use statistics to help predict prognoses, and numbers to express those results. These numbers are usually expressed as a probability over time—for example, that a patient has a 90 percent chance of surviving 10 years.

Survival statistics indicate how many people with a certain type and stage of cancer survive the disease. The most common measure used is the 5-year relative survival rate.

SURVIVAL RATES

Five-year and 10-year survival rates refer to the percentage of men who live at least 5 or 10 years after their prostate cancer is first diagnosed. Relative (also known as disease-specific) survival rates exclude patients dying of other diseases. This means that anyone who died of another cause, such as heart disease or a car accident, is not counted. Because prostate cancer usually occurs in older men who often have other health problems, relative survival rates are generally used to produce a standard way of discussing prognosis.

Unfortunately, it is impossible to have completely up-to-date survival figures. To measure 10-year survival rates, records must be available for patients diagnosed at least 13 years ago (10 years of follow up plus the time it takes to assemble the data). The death rate (also called the mortality rate) from prostate cancer has been decreasing, in large part because more men are being diagnosed at earlier stages, where they have a broader range of treatment options available to them. This means that men diagnosed recently probably have more positive prognoses than what is reflected by the numbers available now.

It is easier for some people to cope if they know the survival rates for their cancer type, stage, and grade; others become confused and afraid when informed of statistics for their cancer. If you would like such information, your doctor is familiar with your individual situation and is most capable of explaining information about your likely outcomes.

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TREATMENT OUTCOME PREDICTIONS

Before choosing a course of action, you probably want to know which treatment will offer you the lowest chance of recurrence and spread, and the highest chance of survival. Doctors know a great deal about the long-term success and side effects of treatments like prostatectomy and external beam radiation, but they know less about the long-term success and side effects of newer treatments. If results are only available for 5 or 10 years following a particular therapy, doctors are not able to accurately predict beyond that 5-year or 10-year period.

The expected outcomes for prostate cancer treatment options are found in the treatment chapters of this book.