What is informed consent and what does it mean?

In cases where there are larger possible risks, you may be asked to agree in writing to the doctor's plan for your care. This is part of informed consent. It recognizes your need to know about a procedure, surgery, or treatment, before you decide whether to have it.

It's common to go through the informed consent process before starting cancer treatment. If you're getting more than one type of treatment, you will likely need separate informed consents, for instance, one each for surgery, chemotherapy, and/or radiation.

After your first talk with your doctor, you may have only a general idea of the treatment plan. You'll likely want to know more so you can think about the ways this plan might affect your health and your life. You must understand the risks and drawbacks of the plan to decide if the benefits you expect are worth it. Most people find that they need to get some questions answered before they can decide on a treatment plan that carries some risk for them.

Informed consent is a process that includes all of these steps:

- You are told (or get information in some way) about the possible risks and benefits of the treatment.
- You are told about the risks and benefits of other options, including not getting treatment.
- You have the chance to ask questions and get them answered to your satisfaction.
- You have had time (if needed) to discuss the plan with family or advisors.
- You are able to use the information to make a decision that you think is in your own best interest.
- You share your decision with your doctor or treatment team.

If you have gone through these steps and decide to get the treatment or procedure, you are usually asked to sign a paper called a *consent form*. The completed and signed consent form is a legal document that lets your doctor go ahead with the treatment plan. The consent form names the procedure or treatment to be done. The rest of the form may be very general, stating only that you have been told about the risks of the treatment and other available options. Or it may be very detailed, outlining what the risks and other options are. Depending on how it's presented, you may sign for one certain procedure or treatment, or you may give approval for any treatments and procedures that the health provider decides are needed.

From the doctor's viewpoint, informed consent means that:

- A doctor or nurse must make every effort to be sure the patient understands the purpose, benefits, risks, and other options of the test or treatment. Then the doctor or nurse must get the patient's consent before starting. In some cases, even a simple blood test or an injection ("shot") requires written consent from the patient.
- As long as adult patients are mentally able to make their own decisions, medical care cannot begin unless they give informed consent.
- If the patient is a minor (under age), has a serious mental disability, or cannot give consent, then the parent, legal guardian, or a person authorized by the court must give consent before treatment can start. This is usually a close family member who has reason to know what the patient would want. (See "Who besides the patient can give consent?" in the section "What are the legal requirements of informed consent?") As some very public court cases have shown, an elaborate legal system is in place to guide cases in which the patient is mentally or physically unable to give informed consent for treatment. These cases tend to come up when the patient is in a coma (unconscious) or on life support.

Sometimes health care workers refer to the consent form itself as an "informed consent." This is not quite accurate. Informed consent is the process and actions that take place as you learn about and think about a treatment before you agree to it. Your signature on the form is taken to be evidence that this took place. If you decide that you don't want the procedure or treatment, you should not sign the consent form. In this case, you may be asked to sign an *informed refusal* form or a form that states you are choosing not to follow medical advice. Your signature on this form implies that you know the risks of refusing, so be sure that you understand these risks and know your other options before you sign. (See the section called "What if I don't want the treatment being offered?")

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Written by

The American Cancer Society medical and editorial content team

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