

# Gathering Information for a Cancer-Focused Family History

Based on your family history of cancer, your doctor requests that you collect information about your family members and their health. You may feel overwhelmed by this task and it may seem difficult to know where to begin. The information below may help you in gathering the important details needed to evaluate your family history.

## How will my family history information be used?

The information that you gather will be used to develop a medical family tree, also called a pedigree. A pedigree is a well-established method that is used to recognize medical conditions that may be genetic. When a condition is genetic, it can affect multiple family members.

## What kind of information is recorded on a pedigree?

- All of your first degree relatives (parents, brothers and sisters, children), second degree relatives (nieces, nephews, aunts, uncles, grandparents), and third degree relatives (cousins, possibly great aunts/uncles), both living and deceased on both sides of the family.
- The current age of each relative or the age at which they passed away.
- Any cancer diagnoses and the ages at which your relatives were diagnosed.
- Details of the cancer diagnosis, such as location where the cancer started, how the cancer was treated (i.e. surgery, chemotherapy, etc), did the person have a second, unrelated cancer diagnosis, etc.
- Family members with unusual lumps, bumps, dark or light spots, etc. on their skin.
- Family members with major birth defects or genetic disorders.
- Your ancestry (the country or countries that your ancestors came from originally, i.e. Germany, England, etc.)

## What are some helpful hints for gathering this information?

- Talk to your relatives.
  - Older relatives are usually good sources for this information.
  - Holiday gatherings can be a good time to discuss and update family history information.
- Gather hospital records or death certificates when there is some uncertainty.
  - Hospitals can release records directly to the patient or if your relative has passed away, they can release them to the next of kin (the closest relative(s) entitled to the deceased individual's property).
  - Your county clerk's office or state health department should have death certificates on file.

## What problems may I encounter?

- Some people do not know or may have lost touch with an entire side of the family.
  - This is relatively common, try not to get discouraged.
  - Even limited information is helpful – a little information is better than none.
  - If you cannot get information on one side, focus on the other side of the family.
- Relatives may be hesitant to share personal information.
  - It may help to explain the reason why you are gathering this information – perhaps offer to share the information that you discover about your family history.
  - Word your questions carefully and try to listen without judgment or comment.
  - Some relatives may choose to keep their health information confidential – if they do not want to share, respect their privacy.

## Is there any other information to collect?

Based on the type of cancer in your family, there are other pieces of information that may be useful:

- Family History of Breast and/or Ovarian Cancer
  - Did any family members have bilateral breast cancer (cancer in both breasts)?
  - Did women have breast cancer before or after menopause?
  - Which women (age 40 and over) have mammograms?
  - If a family member had “female” cancer, was it cervical, ovarian, or uterine cancer?
  - Have any women had hysterectomies and if so, were their ovaries removed?
- Family History of Colon and/or Uterine Cancer
  - Which adult family members have had colonoscopies?
  - Have any family members had polyps and if so, how many polyps total?
  - If someone has had polyps removed, are medical records available (specifically, pathology reports) that explain the type of polyp
  - If a family member had “female” cancer, was it cervical, ovarian, or uterine cancer?
  - Have any women had hysterectomies and if so, were their ovaries removed?

## Why is family history information important?

Using this information, a health professional can perform a risk assessment to determine the likelihood that there is a genetic form of cancer in your family. In addition, this information can help prevent cancer by determining who is at risk for cancer and who needs to have a more aggressive cancer prevention and screening schedule.