Gathering Information for a Cancer-Focused Family History

Your doctor or genetic counselor may want to have detailed information about your family history of cancer. This can sometimes feel overwhelming 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 looked at by a health professional, typically, a genetic counselor. They will determine the chance that you could have a type of cancer that runs in families. The information helps determine who in your family is a good candidate for genetic testing, who may be at a higher risk for cancer, and if your family should consider more aggressive cancer prevention and screening options.

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 (your cousins and sometimes great aunts/uncles)
- Both living and deceased people on both sides of the family.
- Both relatives who had cancer and those that have **not** had cancer.
- The current age of each relative or the age at which they passed away.
- Any cancer diagnoses and the age of diagnosis. It's important to know what organ the cancer started in, and whether the relative may have had more than one cancer.
- Your ancestry (the country or countries that your ancestors came from originally, i.e. Germany, England, Mexico etc.)

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

- If you have a family history of breast and/or ovarian cancer, you may also want to ask:
  - 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?
  - Have any women had hysterectomies and if so, were their ovaries removed? What age was it done?

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- If a family member had “female” cancer, was it cervical, ovarian, or uterine cancer?
- If you have a family history of colon and/or uterine cancer, you may also want to ask:
  - Which family members have had colonoscopies?
  - Have any family members had polyps and if so, how many polyps total? Were they pre-cancerous polyps?
  - 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? What age was it done?

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.
  - Pathology reports are the medical records that tell what type of cancer someone had
  - Hospitals can release records directly to the patient. 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.
- 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.
- It is easy to confuse the difference between having more than one unrelated cancer and having a cancer that has spread (metastasized). For example, if a person had breast cancer that spread to her lungs, this person just has one type of cancer (breast cancer). This is different from a person who had breast cancer and had a lung cancer that was unrelated to the breast cancer.

Even if you cannot get all the details asked by your doctor or genetic counselor, they will still be able to give you an estimate of the chance for a genetic form of cancer. However, the more accurate the family history, the more accurate the assessment will be.

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