Keeping a Personal Medical Record [1]

This section has been reviewed and approved by the Cancer.Net Editorial Board [2], 06/2014

Listen to theCancer.Net Podcast: Keeping a Personal Medical Record[3], adapted from this content.

Key Messages:

- A personal medical record combines all of the medical information collected by each facility or doctor involved in your care into a single file that is easily accessible.
- A personal record should include test results, treatment reports, and notes from each hospital, clinic, or health care provider you have visited.
- Federal law requires doctors and medical facilities to allow patients to access to their medical records.
- Hardcopy files of medical information should be kept in a safe deposit box or fireproof home safe, while online files should be password protected and backed up onto a CD, flash drive, or cloud.

Keeping track of your personal medical information is an important step in managing your care. This includes all of the test results, treatment reports, and notes written by your doctor from each office, hospital, or clinic you have visited. Although each facility keeps its own record of your medical care, it is a good idea to maintain an up-to-date personal copy as well.

Reasons to keep a personal medical record

There are several reasons to keep a personal medical record.

- Each facility or doctor involved in your care has a separate medical record for you. A personal medical record combines these separate files into a single, more complete medical record.
- A personal medical record is always available when you need it. This is especially important if you go to a new doctor or facility or if a record is lost or destroyed.
- A complete and accurate medical record gives new doctors the information they need to provide you with the best possible care, including follow-up care and management of any side effects.
- An accurate personal medical record is especially important for survivors of childhood cancer.

It provides important treatment details that children may not remember later in their lives.
- Having your medical records at home gives you private time to read and understand them, which may help you feel more in control of your health care.
- A personal medical record can help you better manage health insurance claims, taxes, and other legal matters, such as disability insurance and life insurance claims. Learn more about managing the cost of cancer care [4].
- If your cancer comes back, details about your original diagnosis and treatment can help your doctor design a treatment plan.
- Because some types of cancer have a genetic component, which means an increased risk can be passed from parents to children, a personal record of your diagnosis and treatment may be important for relatives, such as siblings and children. Learn more about keeping track of your family cancer history [5].

What to include in your personal medical record

A complete personal medical record should include the following information:

- Your diagnosis, including the specific cancer type and stage. The stage describes where the cancer is located, if it has spread, and whether it is affecting other parts of the body.
- Date you were diagnosed
- Copies of diagnostic test results and pathology reports [6]
- Complete treatment information, such as chemotherapy drug names and doses or the sites and doses of radiation therapy
- Start and end dates for all treatments
- Treatment results, including any complications or side effects
- Information about palliative care [7], including medications or procedures used to treat pain, nausea, or other side effects, as well as other types of care, such as occupational therapy or nutritional support
- A schedule for follow-up care
- Complete contact information for doctors and treatment centers involved in your diagnosis and treatment

The record should also contain information about other aspects of your health, such as:

- Contact information for other doctors, such as your family doctors (past and current)
- Dates and details of other major illnesses, chronic health conditions like diabetes or heart disease, and hospitalizations
- Your family medical history
- Details of past physical examinations, including cancer screening tests and immunizations

The American Society of Clinical Oncology (ASCO) offers cancer treatment plans and summaries [8] to help keep track of information about your cancer, cancer treatment, and follow-up care. Use these treatment plans to begin discussing your care with your doctor.

How to compile your personal medical record

If you have recently been diagnosed with cancer or are currently in treatment, the best way to compile your personal medical record is to collect information on an ongoing basis.

- When you have a diagnostic test or procedure, ask for a copy of the test results or procedure report.
- At each appointment, ask your doctor or nurse for a copy of any new information that has been added to your file or electronic medical record [9]. You may also want to write your own notes to keep track of what happened at the appointment.
- If you spend time in a hospital, ask to take a copy of your medical record with you when you leave. Since April 2003, the federal Health Insurance Portability and Accountability Act (HIPAA) has required doctors and medical facilities to give patients access to their medical records.
- Consider keeping a health diary or using the Cancer.Net mobile app [10] to keep track of your symptoms and any side effects you may experience.
- Keep copies of medical bills and insurance claims.

If you have completed treatment, it is not too late to create a personal medical record.

- Contact your oncologist and ask for a written summary of your diagnosis and treatment.
- Contact your doctor's office and the medical records department of health facilities where you were treated to ask about how to get a copy of your medical records. You may need to request a copy in writing or complete an Authorization to Release Medical Information form. It may take up to six months to receive a copy of your medical records. In addition, you may be charged for the copying of medical records, but the fee is regulated by state laws.
- If you need help figuring out which records you need, ask your doctor, nurse, oncology social worker, or someone from the medical records department at your treatment facility.
- If creating a personal medical record seems like an overwhelming task, ask for help from relatives or friends. You have to sign any requests for personal medical information, but others can make phone calls and fill out forms for you. Ask other cancer survivors for advice.

Organizing and storing your personal medical record

There are different ways to organize the medical information you collect. A filing cabinet, three-ring binder, or simple desktop divider with individual folders can help you keep important information all in one place. Many people organize this information by date, but you can also divide your record into categories, such as tests, treatments, and doctor appointments. Ask other cancer survivors what worked for them, or visit an office supply store to see what types of organizers are available.

If you prefer to use a computer to keep track of your medical information, you can type up notes from your appointments or scan papers into a computer file. You may also store your personal medical record on the Internet through a number of companies that offer eHealth tools either for free or a fee. With your permission, records stored online can be accessed by family members and doctors. If you decide to digitally organize your medical information, you should print a copy of your files to take with you to doctor appointments and regularly back up your record onto a CD, removable flash drive, or cloud storage account.

However you choose to organize your personal medical record, make sure it is secure, either in a safe location, such as a safe deposit box or fireproof home safe, or by using password-protected files. If you decide to use an online service, carefully check the security and confidentiality measures the company uses to protect your medical information. You may also want to give a copy of important information to a relative or friend in case of an emergency. Get more tips for organizing medical information [11].

More Information

Managing Your Care [12]

Organizing Your Cancer Care [13]

Medical Forms [14]

ASCO Answers: Cancer Survivorship [15]

Additional Resources

LIVE**STRONG**: Organizing and Keeping Important Records [16]

MedlinePlus: Personal Health Records [17]

American Health Information Management Association: myPHR [18]

HealthIT.gov: Maintain Your Medical Record [19]

Links:
[1] http://www.cancer.net/navigating-cancer-care/managing-your-care/keeping-personal-medical-record
[2] http://www.cancer.net/about-us
[3] http://www.cancer.net/sites/cancer.net/files/Keeping_a_Personal_Medical_Record.mp3
[4] http://www.cancer.net/navigating-cancer-care/financial-considerations
[5] http://www.cancer.net/navigating-cancer-care/cancer-basics/genetics/collecting-your-family-cancer-history
[6] http://www.cancer.net/node/24715
[7] http://www.cancer.net/node/25282
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[10] http://www.cancer.net/node/29951
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[12] http://www.cancer.net/node/25015
[13] http://www.cancer.net/node/25065
[14] http://www.cancer.net/node/25064
[15] http://www.cancer.net/sites/cancer.net/files/cancer_survivorship.pdf
[16] http://www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Practical-Effects-of-Cancer/Important-Records-Survivors-Should-Keep
[17] http://www.nlm.nih.gov/medlineplus/personalmedicalrecords.html
[18] http://www.myphr.com/
[19] http://www.healthit.gov/patients-families/maintain-your-medical-record