

WEB EXCLUSIVES

Creating a Caregiver Notebook

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Take it from a chronically disorganized caregiver: You want your cancer information organized and accessible. And you want to start that way because the amount of paper generated by a cancer diagnosis can quickly get overwhelming. Rifling through a stack of insurance detritus looking for a lost pathology report is the kind of stress you don't need.

Helping put together the notebook is also the perfect caregiver's task. You'll have to tailor any system to the needs and wants of the patient, but important components to include are listed below.

- > Front-page summary, with official treatment regimen and any other regularly needed information, important phone numbers, and relevant health information such as the nutritional supplements the patient takes or other existing conditions.
- > A calendar to keep track of appointments.
- > A detailed account of the patient's treatment plan.
- > List of questions. It's very easy in the course of an appointment for the patient to forget what was on his or her mind all the previous week. Help them develop a quick and easy system for jotting down questions as they come up. Keep extra paper here for note-taking.
- > Sections for each doctor, as well as for pathology, radiology, and lab reports. It's best to ask for reports and records as they are taken, and it is easier to review records when the most recent reports are in the front.
- > A business card holder might be helpful to store all the contact information from each person in your medical and support team.
- > Getting stranded in the waiting room is inevitable. Bring entertainment, like Sudoku or crossword puzzles, inspirational stories, or pictures of loved ones.
- > If the research goes deep there will soon be more paper than you can carry around. Use different binders, or a filing cabinet, to keep them under control.

Even if you don't get too specialized, just classifying things into simple categories like background, treatment options, side effects, and clinical trials will pay dividends down the line.

> File all explanation of benefits, bills, and other correspondence with the insurance company in one section. Be sure to take notes, including names and dates of any conversations you have with insurance companies.

> A lot of research will be conducted via the computer, and you should consider mirroring whatever structure you use for organizing your paper in the file structure of your computer. Web-based resources change all the time, so if you find something you like you should either print it or save it. Storage space is cheap; finding that elusive article again can take forever. In addition to organizing these files as you go, a tool like Google Desktop or Mac's Spotlight can help you find things quickly. Back it all up to a flash drive that you keep with your notebook.

For more information on compiling a cancer notebook, see *CURE's* Fall 2002 issue. You can also order cancer notebooks from the [Lance Armstrong Foundation](#), [Cancer101](#), or ask if your hospital or cancer center has one.