



Practice Tips

Keep a purple book

Record every detail of an elderly person's care

Margaret L. Morrison, PhD

My family is among those facing health care crises with aging parents. Three weeks after the sudden death of her 14-year old grandson, our mother was taken by ambulance to the medical centre and diagnosed with congestive heart failure. We soon realized that she was entering a new phase in her life, as her health had been compromised by the tragedy of Gordon's death. Much has been written about electronic health records for patients and the importance of having instant access to health care information. Systems for managing personal patient information are steadily improving, but it will take several more years for families to trust that all data being entered are current and accurate.

The purpose of this article is to pass on some practical advice to other families just entering the marathon of dealing with the medical community. My best advice is that, at the first sign of serious illness, you buy a purple book and write down everything you hear.

Our purple book

Our purple book is a drugstore-variety, cheap, spiral notebook that chronicles every appointment, every laboratory test, and every doctor's and nurse's comment since April 12, 1999. Each page has a date and the name of the medical professional visited. We designated one section for charting our mother's medications and any changes in dosage made by her doctor. There is also space in the book for our mother to record her personal thoughts and comments as her illness progresses. She likes to jot down her feelings, as it gives her a sense of control over her disease.

With 5 siblings in our family, everyone has, and is entitled to, an opinion. Our role as a family has been to maintain a chronicle of this medical journey in order to safeguard our mother's health. A crucial triangle surrounds each patient: patient advocates,

the family doctor, and a range of specialists, including geriatricians and cardiologists. We have found that information was often entangled in the bureaucracies of this triangle and that we needed better access to data missing from our mother's medical records at important points in her treatment. Our purple book became a journal outlining what the experts told us about her health and served as an accurate reminder of what had been diagnosed over the years. By recording every word said at each appointment, we have been able to check and double-check information explained to us by myriad health professionals.

Our mother has met with a geriatrician and a cardiologist since 1999. Each of them is a brilliant doctor in his own field, but I do think that our book is the *glue* that binds our mother's treatment program together. One of the things I learned very quickly is that senior citizens are reluctant to answer direct questions. It is important that someone be there to advocate for them, as I have found that women like my mother simply shut down and become passive. The purple book is needed as an aid to communication.

Source of important information

Our mother's general practitioner is a wonderful man and very proactive in her care. She has monthly appointments, and one of our family members attends with her in order to hear what is recommended. Over the years, her GP has come to count on our purple book for providing him with current information gleaned from various specialists and hospital staff. Our purple book contained the information he needed to make recommendations for further care because reports from the hospital and specialists took a long time to circulate. As a family, we were able to relay what had transpired in the hospital and bring him up to date with what

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had been recommended. Obviously he would wait to hear the official news from his colleagues, but I do know that our purple book provided him with anecdotal information that was useful in making changes to our mother's medication and treatment plan.

It became important to record thoughts and impressions in the purple book as a reminder of what we were feeling as we interacted with health care professionals and navigated the labyrinth of the medical community. Many of us have written statements in the margins outlining the frustration we felt when one hand of the medical system did not know what the other hand was doing. Fortunately for our mother, we are a united front and are relentless in pursuing the best medical care for her.

Over the years, we have received calls that our mother was being taken immediately to an emergency department. One of the first things we grab to take with us is our purple book, as patients arrive at hospital emergency departments with minimal information available to the receiving medical staff. With our book, we are able to review what our mother's medical history has been so far, which specialists are involved in her care, and what medications she is currently taking. The book also indicates when she was last seen at the medical centre and by what team of professionals, along with their prognoses.

Write everything down

Our mother is alive at 89 and still battling vascular dementia. There are times when we have found her reading the purple book and becoming quite upset as she finds it filled with negative information concerning her declining health. This is part of her condition and another phase with which our family must cope. For now, our purple book is a case history of her long medical journey and has allowed her children to know that we have been true partners in finding the best care possible for our mother. Our wish is that your family can learn from our experiences and be better prepared for what might lie ahead as you face the illness of someone you love. In times of health crises, write everything down! 

Editor's note

Mrs Irene D. Morrison died on March 13, 2006.

Acknowledgment

This article is dedicated to my brothers and sisters—Jim, Kathy, Bob, and Susan—as we have traveled a very long and arduous path together. I am glad I had your company along the way.

We encourage readers to share some of their practice experience: the neat little tricks that solve difficult clinical situations. Tips can be sent by mail to the **Scientific Editor, Canadian Family Physician**, 2630 Skymark Ave, Mississauga, ON L4W 5A4; by fax 905 629-0893; or by e-mail mabbott@cfpc.ca.