

# MEDICAL INFORMATION MANAGEMENT FOR COVID 19 OR OTHER MEDICAL EMERGENCY/PROCEDURES

Alexandra (Sandie) Bradley, CRM, FAI

# **ABSTRACT**

This paper will examine why one's personal medical information is a critical record, why record keeping techniques are necessary to access and preserve this information, and how this information assists with successful medical treatment. Observations are based on the author's personal journey through the Canadian health care environment. Beyond treatment, a person should also consider what information to have immediately available in case of a sudden emergency. These records should be maintained for immediate access in case a person is stricken or must evacuate their home quickly.

# INTRODUCTION

A sudden emergency, an accident, or the diagnosis and care for a critical medical issue such as COVID-19 or other significant illness will catapult an individual into the medical environment of testing, diagnosis, treatment and continuing care. Each procedure will involve records creation and maintenance by the care providers, in a variety of organizations. Records managers, as professionals assume responsibility for the records of organizations. However, where our individual health is concerned, we are the subject of the various records that will accumulate about our issue. For our use and protection, we are faced with collecting and maintaining personal health information as individuals, no matter where else this information may reside. This paper will examine why this information is one's most critical record, why such personal record keeping is necessary and how our

information assists with successful treatment. Observations are based on a personal journey through the Canadian health care environment. Finally, in light of current emergencies like hurricanes and wildfires, it is essential to maintain key health records in case we are stricken or have to leave our homes quickly.

## WELCOME TO CANADIAN MEDICINE

Most people enjoy living a healthy and predictable life. However, there may come a time when, through an accident or diagnosis of illness, the healthy person suddenly becomes the "patient", and embarks on a pathway to healing, one that may involve a wide number of treatment providers and agencies. Thankfully, our universal health care system in Canada means that individuals are not deprived of access for treatment. However, across the country, various provincial jurisdictions govern the provision of health services, and within each province, diverse professional service providers may have a role to play. The information that is documented and maintained is subject to each jurisdictions' rules and responsibilities, varying from practice standards of professional groups to laws governing access and privacy. Despite progress to unify these diverse systems, health information may still be fragmented and not always universally accessible to the health care providers.

#### PERSONAL HEALTH INFORMATION

The terminology identifying medical records has evolved to the collective term "personal health information". The retention and management of this information is governed by diverse organizational requirements, and generally is maintained for the use of the creator, not the subject of the information."

As this paper will demonstrate, one patient will likely be seen by several doctors, may have many tests, and while the results may be collected or aggregated by the agencies administering the treatments, there is still no single source of truth or one "master" medical file on the patient. The cumulative personal health information collected by the patient at each step becomes their key to understanding their diagnosis and treatment, and enables accurate communication between the patient and the various medical staff involved. Furthermore, in an emergency, the patient's' ability to provide immediate and accurate medical history will speed up the provision of the necessary care.

<sup>i</sup> British Columbia. <u>E-Health (Personal Health Information Access and Protection of Privacy) Act.</u> SBC 2008, Ch. 38, Part 1 Definitions and Interpretation. "Personal health information means recorded information about an identifiable individual that is related to the individual's health or the provision of health services."

ii College of Physicians and Surgeons of British Columbia Practice Standard Medical Records, Data Stewardship and Confidentiality of Personal Health Information. Section 3-6 (2) "Records are required to be maintained for a minimum period of 16 years from either the date of last entry or from the age of majority, whichever is later, except as otherwise required by law." www.cpsbc.ca/files/pdf/PSG-medical records.

This conclusion is based on my personal experience with a serious illness. The paper discusses the management of personal health information from both the person experience as well as from a records manager's perspective in collecting, organization and managing information.

## MY CASE STUDY

#### RECORDS COLLECTION

Whether a person identifies symptoms or is suddenly stricken, whether the entrée to treatment is through a physician's office, or through an emergency facility, the treatment process generally starts with a series of tests for diagnosis. A friend warned me that an immediate reaction to medical news is shock, and that having a second person present helps with hearing and noting the information provided about treatment. (She called the shock "medicine brain", and based on my experience, she was correct. A second person heard the information I missed.)

A notebook was also recommended, to keep track of conversations, notations about medications provided, and reminders for activities, follow up meetings, etc. (Notetaking on my smart phone was not convenient, often not permitted because of proximity to medical equipment or difficult without access to WIFI.) My husband was able to attend all meetings, and his observations assisted with my notetaking.

Record collecting began after the first meeting with the family doctor, when we both recalled what the doctor said and noted the discussion. The notebook became "the Blue Book" which evolved past note-taking to include handouts and other materials. When the collection of information grew beyond five pages of documents, the Blue Book was added to the Blue Briefcase, to hold the accumulated material which had evolved into a personal case record and diary of all that happened in the journey. This information was retained in chronological order, and corresponded to the dated notes in the Blue Book. At each stage of my treatment, the notes provided me with quick recall and summation of treatment to discuss with the attending health staff.

My diagnosis arose from a sister's medical event. At a regular check-up, I made a casual comment in the family physician's office. On the basis of my sister's issues, the family doctor ordered a series of routine tests. One of them, a blood test, detected anomalies, and the doctor ordered more testing.

As discussed above, notes of the conversation with the family physician were made in the Blue Book. Doctor's patient notes and medical laboratory records were created. While doctors' records are still not universally available in our province, a patient can sign up for access to the laboratory records and create copies of their laboratory results. These copies are vital for future discussions (such as when complications arise).

A referral from the family physician to an internist was also given, and at his office, medical history (from the Blue Book) was provided. There were several sets of tests ordered. The dates and results of these tests were recorded in the Blue Book as they were completed, and were also shared by the internist's office to the family doctor, who discussed them with me.

Another referral from the family physician was made to a gastroenterologist, for a colonoscopy, properly called a "CT Scan of Abdomen and Pelvis with Contrast", which took place in the local hospital. Preparation for the test including detailed instructions and medication. On arrival for the test, a nurse provided a form requesting personal and family medical history, use of medications, allergies, and previous medical tests taken.

Now, in addition to this third physician's records, there were pharmacy (prescription) records, test procedures, the hospital test record, and discharge instructions<sup>™</sup> following the test. The discharge instructions provided a brief description of the test results, which were soon followed by another record, the laboratory results of the colonoscopy. These results were forwarded automatically to the family physician, and a copy was provided to me. All documents were collected into the Blue Book. Note: My husband was also present after the colonoscopy and heard the instructions from the gastroenterologist to the surgeon. (Sedated, I heard nothing.) The next day, the family physician provided confirmation of the diagnosis and the prompt need for surgery. As part of the discussion, the family physician provided a printed copy of the analysis of the colonoscopy, which was noted in the Blue Book collection, and added to the Blue Briefcase collection of documents, now including three sets of physicians' tests and notes. I am uncertain if the provision of copies to patients

<sup>iv</sup> Vancouver Coastal Health, Providence Health Care. <u>Discharge Instructions Following Colonoscopy/Sigmoidoscopy/Polypectomy/Gastroscopy/Endoscopic Ultrasound.</u> Vancouver Coastal Health, March 2017.

iii In British Columbia, this service is called "my ehealth". www.myehealth.ca

is a standard procedure or just the practice of our family physician. If such documents are not provided, I recommend asking for copies to be provided.

#### TREATMENT

The next step in the process was surgery.

At his office, the surgeon (Physician#4) confirmed a date for the procedure. Again, there was a review of medical history, from the well-thumbed Blue Book. His staff provided more information about the surgical process, including more handouts for the Blue Briefcase including "Dialogue for Patient Fasting Guidelines", "Bowel Preparation Instructions – Surgery" and a checklist of the various departments of the hospital to be cleared before surgery.

Appointments were made for these pre-surgical consultations at the hospital, first with the anaesthesiologist who reviewed my hospital testing record, and confirmed physical information, and a surgical nurse to brief me on the pre- and post- surgery requirements. Again, I was required to provide my medical history (accumulating in the Blue Book), family medical history, medication use and allergies. The anaesthesiologist indicated that the surgery would be 1.5 hours in duration, and that, prior to the surgery, no medications or supplements are permitted. The surgical nurse provided two booklets: instructions of the surgery preparation: showering, hair washing, no use of deodorant or makeup prior to arrival at the hospital on the day of surgery. She also confirmed the requirements of the post-surgical recovery outlined in the second booklet:vii deep breathing, use of sugarless gum, coughing and stretching to ensure no complications from the surgical procedure. She instructed me to bring the second Enhanced Recovery after Surgery (ERAS) booklet to the hospital when I came in for surgery. I answered questions about a representation agreement and final preparations if a full code was called. Again, all was noted in the Blue Book and the surgical instructions filed into the Blue Briefcase. The last stop was at the hospital laboratory where blood work was done with results forwarded to the surgeon prior to the operating date.

Surgery took place two weeks later. Tissue samples were sent for biopsy, with the results forwarded to my family physician and the surgeon.

<sup>&</sup>lt;sup>v</sup> Office of Dr. Eiman Zargaran, North Vancouver, BC., August, 2019.

vi Vancouver Coastal Health. <u>Preparing for your Surgery: Information for Patients having an Operation.</u> Vancouver Coastal Health, February 2016

vii Vancouver Coastal Health. <u>Enhanced Recovery after Surgery (ERAS) Colon Surgery.</u> Vancouver Coastal Health, January 2018.

During the hospital stay, physicians, nurses and physiotherapists checked my progress, charting information into an integrated electronic record keeping system. All interactions with me were noted into the system, either by the nurses on a mobile computer that was brought to the bedside, or in the various locations of the hospital, including the laboratory, pharmacy or imaging department. It look no notes during this time.

Five days later, I was discharged. More information was provided by hospital staff, beyond the ERAS booklet, to cover diet. A daily injection of medication was prescribed, to ensure no blood clotting after surgery. All conversations were noted in the Blue Book.

#### **EMERGENCY FOLLOW UP**

Ten days later I was back at the Emergency Department with sharp pains and difficulty breathing. Blue Book notes provided my recent medical history to the attending doctor. After initial examinations by the emergency staff, including referral to my recent surgical history in the hospital's electronic system, Physician #5 sent me for scans to determine the cause of my pain. The scans revealed an infection as well as thrombosis in my lungs. I was readmitted to the hospital. The infection site was drained and I was isolated for three days, until further tests revealed that the infection was not contagious. All of this treatment was noted into the hospital electronic system, and forwarded to both my family physician and surgeon. Two days later, I was discharged again, with medication to treat the infection as well as the thrombosis (a three month treatment of drugs). Once again, I updated notes in the Blue Book to cover new medications and treatments.

A visit to my family physician was necessary, to prescribe the complete course of medications for the two conditions. She also provided me a copy of the report by the BC Cancer Agency, which indicated that the surgery had successfully contained the tumour. This report was added to the Blue Briefcase. She also referred me to a haematologist, (Physician #6) to confirm what further treatment might be required from the thrombosis.

Ten days later, I visited the surgeon for the surgical follow up. Despite the complications described here, he pronounced the surgery a success, and indicated that he would see me in a year for further examination. He also referred me to an oncologist (Physician#7) for review of the tumour and any further treatment. Ten days later, in our meeting, the

viii Clinical + Systems Transformation. On April 28, 2018, Lions Gate Hospital and Squamish General Hospital were the first of approximately 40 acute care sites across the Vancouver Coastal, Provincial Health Services Authority and Providence Health Care, to implement a multi-year project including a new shared computer system to replace aging systems. https://cstproject.ca.

lbid. "What's changing for clinical care: Mark's Patient Journey" illustrates the various components of the electronic health system as a patient arrives at a hospital for care. The video matches my experience in the hospital setting.

x "Your first 6-8 weeks after surgery", Lions Gate Hospital, n.d..

oncologist stated that there was no need for further treatment. This was duly noted in the Blue Book.

The last medical visit was the haematologist, who reviewed my medical history from my Blue Book notes and the electronic hospital records. He indicated that after the three month period of medication was completed, I was cured, and should expect no further complications, unless a similar set of circumstances arose in future. There were final notes (I thought) in the Blue Book, and much dancing and celebrating by me.

## RECOVERY

Once hospitalization was finished, I started on the path to "back to normal" health. The two challenges post-surgery were to regain strength and resume physical activity. Clearly, improved muscle tone and increased energy levels were needed after the two month interval of surgery and recovery. Normally I would swim or walk or play golf. At our local recreation centre's medical physiotherapy unit, I obtained an appointment with a specialist in post-surgical recovery. She assessed my condition, reviewing my Blue Book notes and the documents associated with the surgery and post complications. Through the next three months, she led me through a series of strengthening and balancing exercises, providing me with an illustrated set of instructions. These were well-thumbed, copied and added to the Blue Briefcase. I had graduated to the Weight Room for independent exercise, just as the facility closed because of the COVID 19 pandemic. However, a regime of walking and now golf have replaced the inside activities.

Finally, the last and continuing post-surgical issue is diet. In the booklet provided upon discharge, the instructions were to follow a moderate diet for 6 to 8 weeks and then resume "normal" eating. However, the notes from the Blue Book indicate that the physicians can assume, but don't guarantee, when "normal" returns. Six months post-surgery and after trial and error with different types of foods, digestion was definitely not back to normal. Through a friend, I heard about Inspire Health,\* a cancer support agency approved by the BC Ministry of Health. I registered with them, providing permission for them to access and review my hospital, laboratory and Cancer Agency medical history. Inspire Health provides referrals to individual specialists, and I obtained the services of a dietitian. Resulting from the closures caused by COVID, Inspire Health adopted a model of remote learning. The dietitian booked a Zoom conference and my health history and subsequent diet issues were discussed. The Blue Book notes were essential to provide context to the issues. After the

 $<sup>^{\</sup>mathrm{xi}}$  InspireHealth Supportive Cancer Care. https://www.inspirehealth.ca

first meeting online, we booked a series of Zoom calls. I was asked to maintain a food diary, and to submit it two days prior to each Zoom call.

She immediately placed me back on the restricted diet provided when I was discharged from hospital. In addition, she identified food allergies and reactions to specific food types, which I was instructed to remove from my diet, as well as supplements and electrolytes to add to my diet. Each Zoom call resulted in six to eight pages of notes in the Blue Book, as well as copies of handouts about aspects of diet that related to my particular circumstances.xii She requested further blood tests be undertaken, so I contacted my family physician, providing her with all of the information I had been given via my Blue Book notes, and she ordered the tests. Results indicated that I needed more iron and vitamins, which the physician ordered. These were noted in the Blue Book.

In all, there were four consultations with the dietitian, each resulting in recommendations for diet and supplements. I shared the results of her recommendations with my family physician, who is now monitoring my results for iron deficiency.

A follow up visit to the internist who had been part of my diagnosis was the last step in the immediate care. He concurred with the recommendations about diet supplements, and requested another follow up in six months to ensure progress.

#### CONTINUING CARE

This case will not be completed for at least five years, when the surgeon will pronounce that my treatment is completed. At year one past surgery, a scan and colonoscopy are required, to ensure no return of cancer cells. If none are found, the tests will drop to three years post-surgery, and then five years. Each of the tests and scans will generate a set of additional records and notes, which are filed in chronological order within the Blue Briefcase and Book.

#### BENEFITS OF THE PERSONAL RECORDKEEPING

The case study illustrates the varied sources and diverse types of records that will accumulate as a patient is diagnosed and treated for a medical condition. Despite the evolving state of centralized electronic record keeping in the medical environment, the uncoordinated systems are still not linked, particularly the physicians' records and those of outside service providers like the physiotherapist and dietitian, where the records are

xii "Health Eating for your Condition". "HealthLink BC is a government-funded telehealth service launched in 2001, which provides non-emergency health information to the residents of British Columbia, Canada through combined telephone, internet, mobile app, and print resources." www: British Columbia HealthLink BC

created within their office environments. (Depending on the doctor's relationship with the hospital, there may be access from the doctor's office to the hospital information, but this access will not be universal.) Consequently, when required to describe their medical condition and history, a patient must have a comprehensive and reliable information source at their fingertips. In my case, the Blue Book and Briefcase started as reminders for me, and evolved into the story of my health, which I was required to recite with each specialist consultation.

The need for this personal record keeping may be short-term, for the duration of the immediate treatment, or long-term, depending on the medical condition. In my circumstances, because I will be treated for my condition for five years, this set of records will become a vital and ongoing active record until such time as I am declared "cured". Subsequently, this record keeping will become an historic record of my treatment, with a summary available at my fingertips should I require medical treatment for any reason in the future. As previously noted, the physicians' records may be retained for 16 years past my last contact or treatment, but for me, these become a permanently valuable set, and will be retained for my lifetime.

### IN CASE OF EMERGENCY - MAKE YOUR OWN INFORMATION AVAILABLE

An emergency situation requires a different, less detailed, but equally important set of personal medical information. If a patient is suddenly stricken and must be carried into emergency treatment, a succinct summary of medical information will be essential for the immediate treatment and assistance to the first responders. Such information should be readily available to an emergency medical technician, ambulance attendant or other individual who is responding to the sudden event, accident, collapse, or other immediate event.xiii Sometimes called the "ICE" file, this vital record should include the information that a paramedic or first responder will require to treat the patient, and also provide to the emergency staff at the hospital.

The original idea for the ICE file was based on an observation by a paramedic in the United Kingdom that most people have their smartphone with them at all times, so it was logical to encourage people to carry their essential information on their smartphone and in an unlocked file for ready access. Various types of phones have software and procedures

xiii Rod Brouhart. "Where to Keep Medical Information for Emergencies." Emergency response organizations have varying recommendations, ranging from a bracelet or device on a person's body to various locations in the home, in a wallet or purse or on a cell phone. <a href="https://www.verywellhealth.com/where-should-l-leave-medical-information-1298503?print">https://www.verywellhealth.com/where-should-l-leave-medical-information-1298503?print 10/1/2020</a>

available so the phone will remain secure, yet the first responders will be able to access the information they need.xiv

Across Canada, various agencies have identified and provide template forms for the individual to complete and have available should emergencies arise, when the individual may not be in a position to provide the information. As an example, the West Toronto Support Services organization\*\* provides a two page form which includes a section for relevant medical history, medications, medical allergies, and special considerations, such as dialysis or extensive medical history. This form is brief enough that it can folded and carried in a wallet or purse. A second, more detailed form is provided from Patient Pathways\*\*i which is described as "one of the most thorough available and takes into consideration any Advanced Care Planning documents that outline your preferences for future healthcare." This eight-page document covers full identification as well as important circumstances (e.g. deafness), life-threatening allergies, mobility and sensory issues, medical conditions and recent surgeries, prescription medication record, non-prescription medications, medical emergency contacts, current physicians, and personal and household contacts. Both agencies recommend that the completed forms, one for each family member, are stored in a clear plastic bag and attached to the front or inside of your refrigerator, where paramedics are trained to look. It is also recommended that these forms are updated annually, or when medical circumstances change.

While organizations may vary in the recommendations for the content of this information and where to keep it, generally, first responders agree that what they will need is information on whether there is a life threatening condition, whether there is a condition that could appear threatening but is not, and information (signed by your physician) that you are DNR (have indicated Do Not Resuscitate) if you have chosen this approach.xvii

# THE "GO BAG"

Another type of emergency medical information you may require is the evacuation or "go bag", information that should be prepared in advance, and ready when and if you must leave your home on short notice. With the recent wildfires, storms, floods and other disasters, emergency planning authorities are encouraging all citizens to have a carry-all or backpack,

xiv TechGuy Labs. Put Emergency Medical Information on Your Smartphone. https://techguylabs.com/blog/pt-emergency-medial-information-your-smartphone. Identifies processes for setting up through the Apple Health app on iPhones, or through free third party apps available for iPhone and Android phones.

<sup>&</sup>lt;sup>xv</sup> Toronto Paramedic Services. <u>Information Sheet,</u> West Toronto Support Services, n.d. https://wtss.org/news/incase-of-emergency-form

xvi PatientPathways. In Case of Emergency Form. Guidelines and Forms, 2019. http: PatientPathwaysca xvii Op. cit. Brouhard.

prepared in advance and filled with the essential items you need to live in an emergency shelter or other facilities.

Along with other household information, emergency planning organizations are encouraging families to collect family health information.xviii As an example, within their Home Emergency Plan kit template, Prepared BC includes a page for family health information, including names and medical card numbers, lists of medications, medical equipment and other health information and family physicians. There is also a tip about keeping extra amounts of up to date prescriptions in the emergency kit, along with extra glasses and contact lenses, a first aid kit and other basic COVID disinfecting supplies. In popular media,xix articles featuring the emergency needs of families also stress the need for the medical information and supplies of medicines needed to be top priority for the emergency bag or pack.

## **CONCLUSION**

As a healthy person, I had no significant medical history, other than giving birth to my children, and receiving immunizations and dental care, before my diagnosis. However, as I collected the information during my adventure<sup>xx</sup> of the cancer treatment, my professional training alerted me to collect, organize and retain the medical information that accumulated. My case record, at my fingertips, will have value for the duration of my treatment, and following, will contribute to my medical history. In five years, upon conclusion of my treatment, I can foresee a file closing and culling of the documents to retain the essential information: laboratory reports, doctors' notes and medications. I will include a summary in the "in case of emergency" and "to go" information that I will retain within the house. Hopefully, there will be no need for another adventure. If a hospital stay is required in future, the comprehensive medical information of the hospital treatment is in the CST system and available to the doctors and staff who will treat me. However, until the physician's office records are also online, some type of bridge record keeping will be required. Another notebook, perhaps.

Every person's medical adventure is unique, and may include fewer or more steps than the one described in this paper. However, the ability to document and track the treatment

xviii ww2.gov.bc.ca/gov/content/safety/emergency-prepared-response-recovery/preparedbc/guides&resources. This template covers the full gamut of emergency information including vital identification, property and other records

xix Shilton, A.C. "Prepare a 'Go Bag' Today. The New York Times, September 20, 2020. P. D10
xx In his seminar Re-Envisioning the Retention Schedule, ARMA Canada and RIMTech Consulting, September
17, 2020, Bruce Miller referred to case records as individual "adventures". Considering my contact with the
various medical services for my treatment, the term "adventure" I agree that the term is a perfect description for a
personal medical case file.

provides assistance to the health care professionals and enables the patient to contribute to his or her immediate care.

# **ABOUT THE AUTHOR**

Alexandra (Sandie) Bradley has been a records and information manager for over 45 years, and a member of the ARMA Vancouver Chapter for 38 years. Through her chapter, regional and International roles within ARMA, she has been a mentor and teacher, researcher, writer, and advocate for our profession. She is a librarian and Certified Records Manager and was made a Fellow of ARMA International (Number 47) in 2012. She is currently a member of the Sagesse Editorial Board and focusses on research and writing.

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Vancouver Coastal Health Authority. <a href="http://www/vch.ca/for-health-proessionals/library">http://www/vch.ca/for-health-proessionals/library</a>. Various publications provided by physicians and hospital staff.