Mother Copes with Frustration

PROFILE:

Melissa Santini
FLORIDA

~ Mother with Chronically Ill Child Desperate for Electronic Health Records

There are a lot of things that are difficult to understand about her son's health. Why his doctors can't see a simple list of his medications and test results should not be one of them.

Melissa Santini's two-year-old son, Rocco, has six doctors and counting—not to mention other healthcare providers. When he was just 10 months old, Rocco developed severe digestive problems. Since that time, he's been referred to several specialists. After exhaustive and repeated testing, doctors have ruled out certain diseases—but no one has been able to diagnose his condition, which continues unabated. He has also struggled with asthma since he was only a few months old.

Melissa is at the breaking point. She carries around an expandable file full of Rocco's records, x-rays, and test results. Every time Rocco goes to a new doctor or new medical facility she has to repeat the litany of his medical care and fill out the same forms numerous times while trying to hang onto two-year-old Rocco and her healthy and energetic four-year-old son. With the incredible volume of information she has been forced to memorize, she can barely remember what happened with Rocco just last week, let alone recount the chronology of his entire medical history.

She cannot understand why all his information is not available on one digital record, or why she has to fill out the same paper forms every time she takes Rocco in for an appointment. She is incensed that in today's world, a nurse writes Rocco's weight down on a yellow sticky note and loses it before it gets entered in his paper chart. She wants to be able to access her son's medical test results on-line, rather than wait for days for a doctor to call her back.

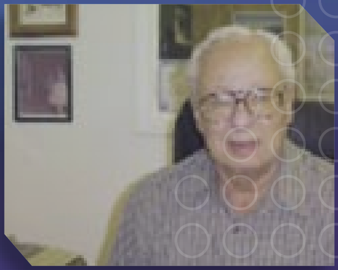
She is also concerned that her son has to repeat invasive tests. "They referred us to a pediatric GI doctor, and he basically did all of the same tests that the other doctor just did. I had to wait another two or three weeks for him to retest all of the things that had just been tested, even though I had copies of them that I had to pay for from my pediatrician's office. That just made me furious." She is concerned that there's no way for all the doctors to get together to review all the medical records. She is livid...and her son is not getting any better.

> *"I constantly have to lug records around with me. Nobody is interacting. I'm so overwhelmed by all the information, paperwork, blood tests, hospital visits...and I still don't have an answer. I am beyond frustrated."*
>
> – Melissa Santini

A Life Threatening Close Call

"Having the information about my medical records on the computer might have saved my life."

– Richard Peck



P R O F I L E :

Richard Peck

ILLINOIS

~ 80-Year-Old Man Says Electronic Health Information Proved Useful in an Emergency

Richard Peck loves to enjoy life. That is why he was surprised when his health suddenly took a turn for the worse while he was changing doctors. Fortunately for him, his new doctor was able to transfer all his information from the previous doctor and created an electronic medical record for Richard.

Richard fell ill while visiting Florida in April 2005, following a major surgery in January. He started feeling unwell while still in Florida but decided to wait until he got back home to visit his doctor. By that time, he was quite ill with a fever and irregular heartbeat. "I was just in terrible shape, and my doctor called an ambulance service, printed out everything about my medical records, which he gave to the ambulance service. By the time I got to the emergency room they had already contacted the urologist who had done the surgery on me. The doctors had a course of action planned out. They did everything right."

Richard was later told that if he had delayed going to the doctor, he would have died within 24 hours. The fact that his entire medical history was available to the hospital and printed out for the ambulance crew allowed the emergency room to have the course of treatment available when he arrived, saving precious time. For him, it meant more than the convenience of having to repeat his medical history. Access to electronic information meant the difference between life and death for Richard.

> *"I was told I ask too many questions about Tommy's health…but what the doctor says is not always clear to the patient. It is my right to know."*
>
> – Gay Quick

PROFILE:

Gayetta and Tommy Quick

MISSOURI

~ Dedicated Wife Acted as a Walking Medical Record for her Husband Dying of Cancer

The Waiting Game

Beginning in April of 1985, Tommy Quick's family was introduced to "the waiting game." He was diagnosed with a brain tumor and had his first brain surgery in Minnesota in 1986. This was to be the first of Tommy's 19-year battle against cancer. Next came a string of over 100 magnetic resonance images (MRIs), multiple rounds of chemotherapy and radiation, and more than three brain surgeries in four hospitals nationwide. During this time, Tommy would not have been able to accurately recite his medical history without the help of his wife, Gayetta (Gay).

Managing Tommy's medical record became Gay's full-time job. His life depended on real-time information in order to receive quick and accurate treatment. In 1985, his doctors in Missouri and Minnesota told Tommy he had only two to three years to live. The Quicks lived on a farm 100 miles away from his nearest doctor, and his battle against cancer took place between Kansas City, Minneapolis, and San Francisco.

Gay understood the importance of accurate and quick medical information. By setting aside a few days to schedule his medical needs, Gay learned to schedule Tommy's blood work, MRI, and doctor appointments on the same day. To speed up his appointments, Gay says, "I finally wrote down everything, so when he went to the doctor, I would take my satchel…Tommy's life was in my satchel." This included a list of significant dates, descriptions of seizures, doctor visit details, medications, insurance information, and even a collaboration of all of Tommy's MRIs that doctors would not otherwise have.

In 1996, when his tumor began to grow more rapidly, communication between San Francisco and Kansas City became vital. MRIs traced the tumor growth and because San Francisco made many treatment decisions, including two major brain surgeries, MRIs needed to be sent from Kansas City to San Francisco quickly. Gay took the responsibility when the hospital informed her that it could take up to a few weeks to mail the MRIs. Gay called every day to ensure that Tommy's doctors in San Francisco received the MRIs that were overnight mailed at about $20.00 each. Tommy's condition called for routine blood work and a MRI every six months beginning in 1996. Following each test or appointment, the Quick family began a new round of the waiting game—waiting for an update on Tommy's battle against cancer—afraid to leave home and miss a call from San Francisco or Kansas City.

Continued

Gay's efforts to manage Tommy's medical records were especially vital when he lost the ability to speak and to use much of the right side of his body. Gay went above and beyond to maximize Tommy's quality of care. Tommy passed away in September 2004 following his long fight against cancer.

> *"The waiting game was the hardest game to learn to play."*
>
> – Gay Quick

Did You Know?

~ The National Cancer Institute estimates that approximately 8.9 million Americans with a history of cancer were alive in 1997.

Source: American Cancer Society. Cancer Facts and Figures, 2002.

Lack of Access to Health Information Kills

PROFILE:

Dave and Jeanne Canfield

SOUTH CAROLINA

~ Active Elderly Couple Managing Multiple Health Conditions

Eighty-four-year-old Dave Canfield is on dialysis and has two knee replacements, two stents, and a pacemaker that his life depends on. Dave's wife, Jeanne Canfield, is thorough and proactive when it comes to his medical care. She carries a briefcase detailing all procedures and medications that apply to Dave's health to each and every medical appointment. But, unfortunately Dave is a patient who has witnessed multiple medical oversights due to a lack of electronic health information.

In April 2005, Dave had a magnetic resonance image (MRI) appointment at a local hospital. Dave and Jeanne filled out the two pieces of paper that they were handed and marked "yes" notifying the physicians of his knee replacements, stents, and pacemaker. The completed questionnaire failed to catch the attention of the hospital staff. The Canfields were escorted to a private waiting area where Jeanne vocally mentioned Dave's stent and pacemaker information to the staff members. It was at that moment that Dave and Jeanne were informed that an MRI would cause his pacemaker to stop completely, killing Dave. Had Dave's nephrologist, who manages up to 250 patients, had access to Dave's medical records from all of his specialists, this potentially fatal mistake could have been avoided.

Sadly, in May 2005, Dave experienced a similar situation regarding preparation for an operation. Jeanne was unable to read the handwriting of Dave's doctor instructing him to stop taking Plavic, a prescribed blood thinner. Plavic is dangerous to take if you are going into an operation. Dave was still taking Plavic up until the day of his operation due to Jeanne's inability to read the doctor's handwriting. The hospital staff caught this oversight and postponed the operation until Dave stopped taking the medication.

These two examples of potentially serious medical oversights could have been prevented with the use of interoperable electronic medical information. Jeanne does her best to follow Dave's care and inform medical professionals about his existing conditions and medications. However, it is not always possible for her to be in the right place at the right time, especially lacking the necessary professional medical knowledge.

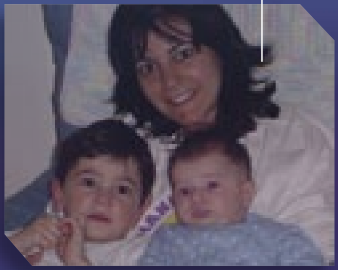
> *"We got in the car and my husband looked at me and said, 'I could have been dead.'"*
>
> – Jeanne Canfield

FACT

~ Inadequate availability of patient information, such as the results of laboratory tests, was directly associated with 18 percent of adverse drug events.

Source: Connecting for Health...A Public Private Collaborative. "Facts and Stats." Connecting Healthcare in the Information Age, 2003.

Electronic Access Equals Peace of Mind



PROFILE:

Lisa Tumpowsky
ILLINOIS

~ Busy Working Mother of Two Young Boys Wishes Her Sons Could Have Access to Electronic Records

> *"You don't always remember, 'What was the name of that drug I was allergic to?' 'When was the last tetanus shot I had?' It just simplies life a lot."*
>
> – Lisa Tumpowsky

Lisa Tumpowsky was diagnosed with a thyroid condition called Graves' Disease in April of 2004. At almost the same time, her doctor started using a system of electronic health records—a change that revolutionized the way Lisa thought about her health and her children's health.

This electronic system helped her when she changed to a new endocrinologist. Lisa had discovered she was allergic to a particular thyroid drug, but when she went to the new doctor, she couldn't remember the medicine's name. The new doctor simply went to her computer, looked up the information, and prescribed a different medicine. Lisa's pharmacy is also connected to all her doctors, who are able to send prescriptions directly to her local pharmacy, saving her the hassle of carrying around the paper with the prescription scribbled on it.

Lisa's dealings with her doctor were not always this efficient. Until last year, she was—like so many others—at the mercy of her doctor's office staff to get her health information. She is still at their mercy when it comes to her children's health. "I still have issues with my children's doctors, who are not on any sort of system whatsoever."

But the lack of access for Lisa's children's doctors is more than just inconvenient. It is dangerous. Lisa never knows which doctor of the four in the practice she will see, or whether they have all of her sons information available to them. Not long ago, her one-year-old son was given a chickenpox vaccine, and a short time later he came down with a virus. The doctor she saw at the time was unaware of the recent vaccine and prescribed a steroid treatment that would have reacted with the vaccine. Lisa caught this as she was reading the label on the prescription bottle, which said: "Do not administer if the child has been exposed to the chickenpox vaccine." In today's world of technological marvels and instant access, this is more than ridiculous, it is an outrage.

For Lisa, convenience—as well as safety—is the key. "If my children's doctors were on a system like this, every single time I sign my son up for school or for summer camp, I wouldn't have to fill out a manual form, go to the doctor, wait in line, wait for the receptionist to fill in the information, you know, allow human error to intervene. I would just be able to push a button and send my child's health records, or proof of immunizations, directly to the school."

Lost in the Mail

Mary has suffered from scleroderma—a potentially life-threatening condition—for nearly nine years. When she was first diagnosed, the doctors in her hometown of Springfield felt that she would be better served by going to a clinic.

So Mary packed her bags—and copied her medical records to hand-carry the numerous papers and files to her new doctor. "I had gone to my doctors that I'd been to and got copies of all their information that they had on me. And for some reason, I made copies before I mailed them, which turned out to be a very good thing, because when I mailed them...we don't know whether the mail lost my records, or whether they got lost at the clinic. We just don't know."

Now, copies of Mary's health information have been "misplaced," leaving her with concerns about her privacy and the security of the records her doctors are keeping about her condition.

> *"We don't know whether the mail lost my records or whether they got lost at the clinic. We just don't know."*
>
> – Mary Blades

PROFILE:

Mary Blades

MISSOURI

~ 63-Year-Old Woman Longs for Efficient, Secure Communication with Doctors

Realizing the Importance of Accurate Records

"As we get older, issues come up and you need to know what your medical history is, and even your family medical history."

– Sandy Silins

» PROFILE:

Sandy Silins

ILLINOIS

~ Retired School Teacher and Grandmother Knows the Value of Accurate Medical Records to Her Family's Health

Sandy Silins is on the cutting edge of technology. She is also a wife, mother, grandmother, and retired school teacher. Sandy loves being kept "in the loop" when it comes to her health and her family's health, and was thrilled when her doctor introduced her to their new system of electronic health records (EHRs).

"I am on the computer a lot, so for me it was a very seamless switch to being involved with my doctor. I use it to keep in touch with my doctor, track all my health records, make appointments, get test results, refill medications; all without having to be involved in telephone calls with office staff and so forth. I find it to be tremendously efficient, time-saving, and accurate."

Sandy was the first in her family to start using the EHR, and within just a few months she had the rest of her family—including her daughter, Lisa Tumpowsky—sold on the system. Having access to her health information brings her peace of mind and reassurance and makes switching doctors easy. When her mother-in-law moved to Illinois from Florida, Sandy made sure that the doctor she chose had an EHR so that she could be involved in health decisions. Sandy is also comforted that she can reach her mother-in-law's doctor anytime she has a question.

Sandy first became interested in electronic health records after she lost her own mother a number of years ago. "I spent enormous amounts of time in the hospital with her, talking to doctors. If I had this it would have made my life so much easier."

"When my mother-in-law became chronically ill, I spent half my life trying to reach doctors and get answers. The other issue was accuracy. She was in the hospital a lot, and every time we went into the hospital, there was the whole issue of having to have her whole history repeated again, and there were mistakes made because they didn't have accurate records. I used to carry a book with me with all of her information because it was so long. I became very concerned about medical records after that."

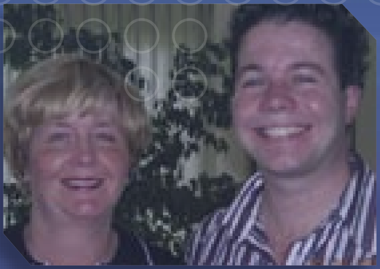
Now, Sandy has the peace of mind that she is in control of her health and her family's health. Going to the doctor is no longer guesswork.

Did You Know?

~ Caregivers of people over the age of 50 spend an average of 17.9 hours per week providing care. Twenty percent (4.5 million out of 22.4 million) of those caring for family or friends aged 50 and older spend over 40 hours per week providing care, with some providing constant care.

Source: Family Caregiver Alliance. "Selected Caregiver Statistics." August 5, 2005. http://www.caregiver.org

Concerned Mother Takes Control



PROFILE:

Cynthia and Alex Solomon

CALIFORNIA

~ Mother Creates a Personal Health Record Following Son's Medical Emergency

Cynthia Solomon awoke startled at 2 a.m. by a panicked phone call from a Nevada emergency room. Her son, Alex—who has a condition leading to excess fluid in his brain and was allergic to most antibiotics—had an accident and was in a rural hospital far from home. The emergency room did not have any idea about Alex's condition, or that if they were to lay him flat he could die, or that he was allergic to any medications. They were totally in the dark, and Cynthia had a horrible time even getting through to the neurosurgeon, much less relaying all this vital information.

At that time, all of Alex's medical information—scans, test results, history, surgeries—were stored in numerous boxes and binders at his mother's house in California. Alex came through the ordeal alright, but Cynthia and her son were left shaken.

Cynthia, with the help of some college-age computer whizzes, went on to develop a personal health record (PHR) where she was able to store all of her family's medical information and access it over the Internet—and allow her doctors to do the same. The reasons for creating and using such a record are common sense, she says. "Because doctors and clinics close, and hospitals consolidate, the information that we used to count on being with the local doctor for 20 years of our life is no longer the case."

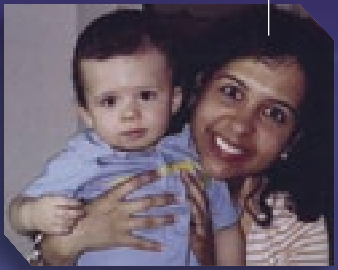
Today, Cynthia's PHR has expanded into a dynamic business, and she has been able to help hundreds of people from all backgrounds and financial positions become more in control of their health. The most widespread success the system has seen is within the migrant farm worker communities of California. With a modest grant from The California Endowment to local nonprofits, Cynthia's company has been able to connect numerous families to their health information, creating a personalized account complete with e-mail and printable medical history and emergency card.

The biggest challenge Cynthia sees to being able to truly help people become connected to their health is the systems themselves. Once the standards are in place, she says, these systems will no longer be reserved for large hospitals and established doctors, and everyone will be able to communicate freely, which will ultimately save thousands of dollars and lives.

Allowing patients to be in control of their own information will be empowering, and families will be better off.

> *"Medical errors aren't just the fault of doctors or hospitals; it's really the issue of not having the right information at the right time."*
>
> – Cynthia Solomon

Electronic Access is a Birthright



PROFILE:

Jennifer and Jack Edwards

FLORIDA

~ Mother Wants Electronic Access to Her Son's Medical Record

Jennifer Edwards is the mother of Jack, a healthy 18-month-old baby boy. Fortunately, she has not had to deal with multiple doctors and a sick child, but she is aware of the way technology would help her family's health.

When Jennifer's son was born she had many questions. She was a first-time mother and needed answers quickly to basic questions about Jack's health. These questions led to multiple phone calls and a game of phone tag with Jack's pediatrician's office. Jennifer simply needed to ask the things that a new mother would not know the answers to, such as the results of her son's anemia screening as an infant. Jennifer states, "It would have been helpful to be able to e-mail Jack's doctor questions and receive an answer quickly, and to see basic test results on-line."

Earlier this year, Jack cut his foot on a rusty carpet tack, requiring an after-hours call to the doctor to find out if Jack needed a tetanus shot. This incident, while minor, could have been simplified by an electronic record showing Jennifer the status of Jack's immunizations. Jennifer knows just how valuable having a complete history of Jack's doctor visits, medications, and immunizations would be in providing the best healthcare for her son at her convenience.

Last winter, Jack had several ear infections and was on a variety of antibiotics. Some worked for him, some didn't, and others had side effects. If Jack needs antibiotics again in the future, Jennifer will have to rely on her memory or the pediatrician's notes to know which ones to use. With an electronic record, Jennifer and any healthcare provider Jack visits could easily access an accurate medication history whenever it is needed.

Even providing daycare for her son requires a copy of his up-to-date immunizations, and a lack of this simple piece of information can keep Jack out of daycare. According to Jennifer, "If you've got the [immunization record] on-line, you can always go at your convenience and check it or print it out."

> *"I believe having access to Jack's health information is a basic right I should have."*
>
> – Jennifer Edwards

A High-Stakes Puzzle

PROFILE:

Anne Henegar
GEORGIA

~ Woman Struggles with a Chronic Disease, Multiple Doctors Across the Country...and a Life of Uncertainty

For Anne Henegar, uncertainty has become a way of life. For 10 years she has struggled with a disease without a name, and all the confusion and frustration that has gone along with it. Her husband is a minister, so she has lived in four different cities since she first became sick and has seen numerous doctors and specialists along the way. With each new doctor and city, Anne has accumulated piles of paper: test results, x-rays, and forms. She has been forced to carry her extensive medical records to each new physician, always fearful she is missing a critical piece of information.

Anne is most concerned that a missing piece of paper could hold the key to unlock her mystery condition. "For me, my condition is very systemic. I have to have somebody that's constantly thinking of me as a whole, because one thing affects the other. Each part of the puzzle is very important, and I'm the one having to remember that." But even more than that, Anne wants to be more in control of her health, to be able to work with her doctors and look for patterns in her condition that could allow her more days of feeling good.

"Being able to access my records is important because it's my life and my health. I mean, it's who I am. All these details and the time and money that I've put into having these tests and going to see doctors, I need to have access to my records because I want to be able to analyze them and interpret them myself. I'm as much a major contributor to this investigation and discovery as they are, but I'm not privy to that information. I'm the one that lives with this body 24/7, and I think I'm one of the most important people to have the information. I feel like there's got to be some kind of pattern I've gone through with this illness, but I'm the only person who could probably see that, because no doctor has my vantage point."

The scattered information means more than just inconvenience for Anne and her family. It also means countless dollars lost due to duplicated tests and repeated procedures. "A lot of repeat tests have been done. Every time new doctors see me, they want to run their own tests. I feel like the conductor of a really bad orchestra; like I'm trying to make sense of all these incongruent parts."

More than anything, Anne wishes that her many doctors could have the same information available to them at the same time. She knows that someday, having all the facts could mean more than a convenient trip to the doctor—it could mean finally having the answers she has searched for and the peace of mind she craves.

> *"Each part of the puzzle is crucial, and I'm the one having to remember each piece."*
>
> – Anne Henegar

> *"The time spent responding to all the paperwork collectively took more time than it took the surgeon to remove my tumor!"*
>
> – Tracey Ryan

PROFILE:

Tracey Ryan
CONNECTICUT

~ A Psychologist and Cancer Survivor Says the Stress of Endless Paperwork was Worse Than the Cancer Itself

Surviving a Mountain of Medical Forms

Tracey Ryan went through a terrible ordeal at the end of 2004. Within just a few months, she discovered she had brain cancer, saw up to 12 different doctors, underwent surgery to remove the tumor, and became cancer free. While the experience of having cancer by itself is more than most people think they can handle, for Tracey, the stress of playing the document game between all her different doctors was much more trying.

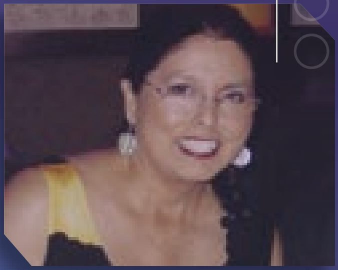
"Each specialist, each physician that I saw, each institution that I dealt with had their own set of forms, waivers, and requirements. There was no communication between them except if you requested verbal communication. But even when the doctors talked to each other verbally, you still needed to go back and fill out all the forms again. I spent hours filling out forms."

As a professor of psychology, Tracey is keenly aware of the effects of stress—she had plenty of it due to her doctors' inefficient record keeping. She was able to cope with the stress of having cancer because she knew her options—she knew what she was dealing with. With her medical records, it was another story. She never knew what the doctor knew or didn't know, and she eventually delegated the task of filling out piles of paperwork to her willing husband. "It was the minor hassles that really got to me more than the major ultimate health problem that I had to deal with, which I could deal with because I had the information about it."

"It wasn't a problem going to the doctors. The most stressful aspect was really filling out these forms—the really minor hassles associated with the bigger problem. It was kind of a running joke...another form, another paper." The scariest part was that even with the information on the forms, many doctors acted surprised when, for example, Tracey told them about a medication she was on, even though she had indicated it on numerous forms.

Tracey found it hard to believe that, with all the other amazing advances in healthcare—such as those that saved her life—doctors were so far behind the times in the way they handled her medical records, most often faxing or mailing them from one place to another and having her repeatedly give the same information that they had on file. "The time spent responding to all the paperwork collectively took more time than it took the surgeon to remove my tumor!"

Navigating the Paper Maze



PROFILE:

Juanita Pahdopony-Mithlo

OKLAHOMA

~ A College Professor and Chronic Disease Patient Struggles to Connect the Details of Her Health History for Electronic Health Records

Juanita Pahdopony-Mithlo began having health problems in 1987, but she was not diagnosed with scleroderma until 2000. Both before and after her diagnosis, Juanita has been the victim of a technologically challenged healthcare system. The inefficiency has only added to her discomfort and prolonged the pain of her condition.

Because her disease is systemic, Juanita has seen multiple doctors and had countless tests performed. She has traveled from doctor to doctor, making her care even more complicated. Juanita has been forced to become a walking file cabinet in order to maintain her volatile health. "I have a big file on myself, and I have to haul medical records from place to place. My doctor from the Indian Hospital has sent me to the rheumatologist. I normally don't see the same rheumatologist from year to year. They've asked me to bring my last few months' charts and copies of my medical records, so I hand-carry them to the rheumatologist." To each new doctor, she brings copies of her extensive medical records, test results, and medication lists, and must retell her entire 20-year ordeal. Most times, a new doctor has no idea what her background is before she walks in the door and plops down her stack of papers and files.

She tells a horror story about seeing a new gastroenterologist for reflux problems associated with her disease. "They did a test on me over and over and over again. And they said, 'We can't understand what's going on....' I overheard them talking, and I thought they knew what I was there for. They couldn't understand why it wasn't working. I didn't have very much movement in my lower esophagus when I swallowed. Finally, I said, 'I have scleroderma,' and they said, 'Oh! That explains it! Of course.' I thought they should have known why I was there, but apparently they did not have that piece of the puzzle. I had to do that particular test pushing that tube down my throat and into my stomach, at least three times before they figured it out."

Juanita lives in constant fear that the one doctor who knows all about her condition and helps her to coordinate her care will move away. "Since I have my doctor, I feel a lot better knowing that at least one person is somewhat following my case. It scares me to think about what I would do if he left."

> *"I have a big file on myself, and I have to haul medical records from place to place."*
>
> – Juanita Pahdopony-Mithlo

Did You Know?

~ A study by The Commonwealth Fund shows that 63 percent of adults 19 and older do not have a regular doctor for more than five years at a time.

Source: 2004 Commonwealth Fund International Health Policy Survey of Adults' Experiences with Primary Care; www.cmwf.org/surveys/surveys_show.htm?doc_id=245240

Better Health…Anytime, Anywhere

"I really feel kind of comforted that I can get access almost immediately to my doctor, my records, and everything else just by stopping at an Internet café anywhere along the line."

– Keith Belcher

PROFILE:

Keith and Margy Belcher

OREGON

~ On-the-Go Couple Managing Chronic Diseases While Traveling

Seventy-year-old Keith Belcher and his wife, Margy, feel right at home almost anywhere. They've spent the last several years of their retirement traveling the western United States in their RV—despite the fact that both Keith and Margy have chronic health conditions that require regular contact with their many doctors. They have been able to live their dream of traveling because of their doctors' commitments to making their patients' health information electronically available to them—and to their other doctors—anytime, anywhere.

Keith and Margy decided to move from northern California to Sweet Home, Oregon, in 2002. Originally, they had planned to find a new primary care doctor after the move, but they found it difficult to find someone who was taking new patients in the small rural town. They eventually decided to keep their doctor in Palo Alto, partly because they planned to go back to visit family at least three times a year. It would be easy for them to come in for annual checkups, but mostly because they could stay in regular contact with her via a Web portal and e-mail.

Keith has struggled with diabetes for years and more recently learned he had heart problems and underwent triple-bypass surgery. "When I was down there for an annual checkup, having absolutely no clue as to anything being wrong, I went in and had my normal checkup, and she put me on a treadmill test, which I failed. And I failed my echogram, and I failed the angiogram, and ended up about 10 days later having a three-way bypass." Although it was a scary situation for both Keith and Margy, they feel much better knowing that they are able to contact their doctor anytime with any questions or concerns.

Now Keith is managing both his heart condition and his diabetes no matter where he is. Keith's doctors order tests and treatments for him while he is in Oregon, and they check on his status and test results almost immediately, even though they are hundreds of miles away. "Because all the treatment I get here, whether it be therapy or anything else, all of that is initiated through the prescriptions from my doctor in Palo Alto." Margy also manages her arthritis on the road, and she is able to e-mail her doctor about any changes in her treatment or unusual symptoms or side effects. Her doctor orders tests for her that she can have done near home as well.

Continued

For the Belchers, their newfound freedom means more than just convenience. They can rest with the knowledge that wherever they are, their health information is accessible. "When we're in eastern Oregon, or we're thinking about possibly going to Lake Powell, I really feel kind of comforted in that I can get access almost immediately to my doctor, and my records, and everything else just by stopping at an Internet café anywhere along the line. If I were ever on the road and I needed to go to another hospital, I could just log on and wherever I was my medical professionals could be on the same page."

FACT

~ One in five Americans live in rural areas and only one in 10 physicians practice in rural areas.

Source: Rural Emergency Response - the Safety and Health Safety Net;
www.cdc.gov/nasd/docs/d001701-d001800/d001781/d001781.pdf

Deadly Disconnect

The Name of This Person Has Been Changed to Preserve Anonymity

PROFILE:

Tameka Blackwell
MINNESOTA

~ A Minnesota Woman Struggles to Come to Grips with the Lack of Information That May Have Cost Her Father His Life

Tameka Blackwell knows firsthand that being able to access important health information can mean life or death for a patient. Three years ago, Tameka's father was a relatively healthy 70-year-old. He was a smoker and had mild emphysema, but he was not taking any medicines and led a fairly active life. Everything changed when he developed a common cold. At first, he refused to go to a doctor, but when he started having trouble breathing, Tameka took him to an urgent care facility. They did a chest x-ray and told him to go home and take an over-the-counter cold medicine. His condition continued to deteriorate, and three days later Tameka's mother called to say that her father was sitting in his chair unable to breathe and shaking.

When they arrived at the hospital, her father and her mother were both diagnosed with pneumonia, but her father's condition was much worse, and he was immediately admitted and began undergoing tests.

Once Tameka confronted a nurse hanging up a bag of medicine to be given to her father through his IV and asked her what it was. The nurse explained that it was a heart medication. When Tameka asked why her father was taking such a drug when he had absolutely no history of heart problems, the nurse replied by saying that she could not discuss the medications, but to ask a doctor. "Find me a doctor," Tameka quickly responded. She tracked down a resident, who asked her what medication her father was taking for his heart before he came to the hospital. Tameka was flabbergasted. "My father was on no medications when he stepped into this hospital, not even aspirin. I mean, if you look at your records you would know that," she said. A week later, a surgeon explained to Tameka that they did not know who initially prescribed the heart medicine, but that "everything seems to be working so let's just leave it alone."

Multiple surgeries and several months in intensive care later, Tameka's father eventually passed away. But not from cancer or pneumonia. Tameka's father died of sepsis, an infection that developed after one of his last surgeries. "The only thing that I would like is to have information accessible to all the parties who are taking care of a patient. With my father, it seemed at many times they did not have it readily available, or it was too difficult for them to go back and look at. He had many different teams of people taking care of him at separate times, and it seemed like the right hand never knew what the left hand had done. If the lack of information didn't lead to my dad's death, it definitely led to a lot of misery on his part."

> *"If the lack of information didn't lead to my dad's death, it definitely led to a lot of misery on his part."*
>
> – Tameka Blackwell

Did You Know?

~ More than one in five Americans report that they or a family member had experienced a medical or prescription drug error.”

Source: The Commonwealth Fund website; www.cmwf.org/publications/publications_show.htm?doc_id=221270

Living with a Chronic Condition

> *"I have to travel to make a living, and everytime I get on a plane, I put myself at extreme health risk. I've got to make sure I'm awake long enough to give whatever medical professional who is going to be treating me the appropriate information so that they don't kill me!"*
>
> – Amye Leong

PROFILE:

Amye Leong
PENNSYLVANIA

~ A California Native Copes with the Complications of Constant Travel with a Chronic Disease

Traveling today is dangerous enough, but traveling with a chronic disease can be life-threatening. Amye Leong tells her story of one particular incident where the lack of medical information could have abruptly ended her life. "I've had rheumatoid arthritis (RA) for 26 years, since I was 18 years old. I've had to focus more energy on it than anything else I can remember."

"Two years ago I was based in Paris but happened to be in Washington, D.C., for a conference. I awoke one morning at the hotel vomiting and in such physical pain. I know arthritis pain but this was very different. I called the hotel concierge and the conference organizers, who all suggested that I get to an emergency room right away. I was scheduled to take my flight back to Paris but I was going into shock and was beginning to feel like I was going to pass out. Unfamiliar with the medial terrain of D.C., I had the conference organizer call a friend a National Institutes of Health. If they got me to a certain hospital, a physician friend would be waiting for me.

"I got into a cab at my hotel with another person from the conference. I was doubled over in extreme pain, throwing up and having a hard time focusing. We told the cab driver which hospital to take me to. He did not take us there, but of course, I didn't know that. I didn't know one hospital from another I was so out of it. I didn't even have my eyes open. He took us to the closest hospital because he thought I was going to die in the cab."

"We got to the ER and told them our doctor was waiting for us and they said, 'What are you talking about? You have to fill out these forms.' I was passing out. They threw me into a wheelchair and said to the woman with me, 'You have to fill out these forms if she can't.' So my conference organizer, who knows nothing about my medical background, and only knew that I had RA, had to keep me awake long enough so I could give her the information to fill out the form."

"Finally, she just started screaming and said, 'Can't you see this woman's in distress? She needs help!' She started screaming so loud that the triage nurse came out to find out what was going on. And she took one look at me and said, 'Get her in here right away.' So it was a health professional that finally usurped the clerk who wanted me to fill out forms. She immediately got me into medical care. They instantly put me through tests and hospitalized me for a kidney stone that lodged itself in the worst possible spot."

Continued

"Then we found out we were in the wrong hospital all along. It was too late to be transferred, so we had to go through all kinds of, 'What's her medical history? What kinds of drugs is she taking?' I passed out cold at that time. Someone who only knew me as a speaker at a conference—did not know my medical history, did not know the drugs I was taking, only had a phone number of my mother who was not home—was responsible for telling them all this vital information. They had to wait until I was awake long enough, and they hoped by treating me they weren't going to do something to me that would be counter-indicated for the medications I was already on."

"When I woke up, I was in a hospital room with three doctors standing over me. They told me I had a kidney stone and needed surgery as soon as possible, and then I passed out cold again. The only thing I remember after that is someone saying, 'Stat, stat, get her into surgery.' When I woke up, it was a day and a half later. I had gone through surgery, which would normally have taken only an hour and a half, but because my blood levels were so low and my condition was unstable, I was in recovery for seven hours."

"When I finally got out of surgery, my friends who live in Washington were at the hospital. They are not my blood relatives so the hospital would not let them in to see me. We convinced the hospital that my friends who were there to help me were not necessarily blood family, but they were the closest thing to me at that time. My friends were the ones who knew my medical condition and treatments. I ended up spending 12 days in the hospital, most of it waiting for treatment because the doctors didn't have the information they needed."

"I can tell you the importance of having some kind of electronic record as someone with a chronic disease who faces all kinds of problems. I go through airports all the time and set off all kinds of alarms, because I've been through 16 surgeries. Twelve of those were joint replacements. I've been hospitalized for 298 days in my lifetime so far. But that has not stopped me from being a productive member of society."

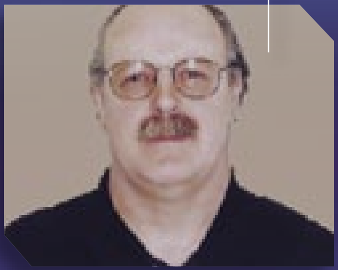
"Chronic disease, unfortunately, is more mainstream than not. We are a highly mobile society. For people with chronic diseases who are trying to lead active lives, who travel as I do, we put our lives on the line every time we leave home. What do we do when we're not at home in our neighborhood medical care system? I have to travel to make a living, and every time I get on a plane, I put myself at extreme health risk. I've got to make sure I'm awake long enough to give whatever medical professional who is going to be treating me the appropriate information so that they don't kill me!"

FACT

~ Nearly half of the U.S. population, more than 125 million Americans, suffers from some sort of chronic medical condition.

Source: www.gingrichgroup.com/Transforming_Examples/Transforming_Examples_Resource_Center/139.cfm

Improving Health Through Online Access



PROFILE:

Ron Brimmer
MARYLAND

~ 50-Year-Old Veteran and Frequent User of My HealtheVet, an Electronic, Interactive Medical Record

Ron Brimmer's health is a lot better these days because of My HealtheVet. The Department of Veterans Affairs (VA) began the interactive electronic medical records program in 2003 at VA hospitals to better connect doctors with patients and to provide both of them with critical medical information whenever they need it. Ron was one of the first veterans to test this new electronic patient records system, and he is now one of its biggest advocates.

Nearly 30 years ago, Ron injured his back, knee, and both shoulders. He is mobile only with crutches or using his electric scooter. Maintaining mobility is an ongoing process, which includes physical therapy and visits with three to five doctors on a regular basis. But My HealtheVet makes managing his care a lot easier. It enables him to access his VA medical records at home; review his prescriptions, blood test results, and notes from the doctor; and even add information or update his record.

With My HealtheVet, Ron is healthier because his visits to a VA doctor are now more focused, and his care is more personally directed. Ron is better informed about his treatment and as his health has improved, his visits to the doctor have actually decreased. When he sees a doctor outside of the VA system, he can print his VA medical records and take them along—that's a real time and trouble saver for Ron, who lives 35 miles from the hospital and would otherwise have to drive in and request his records in person. In addition, My HealtheVet allows him to e-mail his doctor at any time with questions. Electronic records at the VA have even kept Ron from taking medications that would interact with each other.

> *"Going to the doctor is no longer guesswork."*
>
> – Ron Brimmer

Did You Know?

~ Of the 25 million veterans currently alive, nearly three of every four served during a war or an official period of hostility. About a quarter of the Nation's population—approximately 70 million people—are potentially eligible for VA benefits and services because they are veterans, family members, or survivors of veterans.

Source: www.va.gov/about_va/

Coping With Chaos

PROFILE:

Abbie Pickett

WISCONSIN

~ An Army National Guard Specialist Injured in Iraq Tells Her Own Personal Health Horror Story

Abbie Pickett's life was forever changed by her experience in Iraq. As a specialist for the Army National Guard, Abbie found herself in the middle of a mortar attack on a base recreational facility in October of 2003. While she was physically injured in the attack, Abbie found that much deeper and more painful wounds would show up later on.

Abbie's eardrum was punctured in the attack, but she heroically helped care for her fellow soldiers who were more seriously wounded during and after the attack. Abbie and two other soldiers who were involved were seen by a physician's assistant after the incident. The man filled out all the paperwork documenting the attack and their wounds and informed them that he had also put in for them to receive Purple Hearts. But that paperwork was lost. It is now almost two years after the incident and Abbie has yet to find an effective course of treatment for her Post Traumatic Stress Disorder (PTSD).

Shortly after the attack, Abbie began developing symptoms of PTSD, but because her injury could not be "verified," her diagnosis was delayed. She was bounced around from caregiver to caregiver for almost two years. Instead of being treated appropriately, Abbie has been given numerous drugs for everything from depression to insomnia, and has to recount her trauma again and again with each new provider. "Out in the field my care was shifted from person to person so that every time I went to get help or get my medications refilled, I had to start at square one."

"Because mental health has such a bad stigma in the military, they try to keep it as hush-hush as they can. They tell you that as soon as you leave their office, they'll destroy your records and they'll never exist. The problem is, when you come back, you have to prove that you've been in a traumatic event or that your depression was a result of being over there, but those records have been destroyed. There are a ton of soldiers coming home trying to get help, but the waits are so long that unfortunately, in that time, there are car accidents, suicides, and they're abusing alcohol and drugs trying to self-medicate."

> *"Out in the field, there's no reliable record keeping system to verify what happens to soldiers."*
>
> – Abbie Pickett

Continued

Abbie also had a horrible time trying to claim promised benefits because she could never "prove" that she was injured in combat. "It took me a little over a year from when I got home to get my compensation. Out in the field, there's no reliable record keeping system to verify what happens to soldiers. I'm over the bitter state. Right now, I'm just struggling to get by and deal with my symptoms." To top it all off, she will never receive a Purple Heart or a Bronze Star for the wounds she sustained or the heroism she displayed in Iraq, all because of an archaic and horribly flawed system of medical record keeping.

Did You Know?

~ There are nearly 11,600 wounded from the war in Iraq and Afghanistan.

Source: PBS OnLine News Hour, April 26, 2005.; "Coping With U.S. Combat Injuries"; http://www.pbs.org/newshour/bb/middle_east/iraq/postwar/mfacts_casualty.html

The Document Game

PROFILE:

Ashley Shaff
CALIFORNIA

~ 22 Years Old,
35 Hospitalizations,
a Terminal Diagnosis,
and a Complicated
Medical Journey...

> *"I couldn't be left alone with my thoughts and pain; no, instead I was forced to regurgitate a horrific medical journey, once again."*
>
> – Peggy Frank

Twenty-two-year-old Ashley Shaff has spent her entire life in and out of hospitals. Ashley is missing genetic information on the short arm of chromosome 20. She is the only person in the world known to have this condition. The missing genes caused a hole in Ashley's heart, a lack of growth hormone, and a narrowing of the arteries in her lungs. As a result, only about half of Ashley's lungs function and her condition is described as terminal.

Ashley's mother, Peggy Frank, is Ashley's advocate and her librarian. Peggy has managed her daughter's care from the moment she was born. She keeps track of her extensive and complex medical records stored in boxes, binders, and personal memory, dating back to eye surgery at the age of nine months.

Ashley has been the patient of at least 36 doctors and has been hospitalized over 35 times in 12 different hospitals around the nation. Her list of medical procedures includes heart surgery, two adenoid surgeries, four cardiac catheterizations, and three pulmonary angioplasties. Keeping order in this jumble of critical information is a source of frustration and desperation for Peggy—and a danger for Ashley.

As the volume of Ashley's medical records grow, it becomes more challenging for Ashley and Peggy to play the "document game." Peggy is left to keep track of every detail in order to retell her daughter's medical history during even the most stressful times. She must recite it over and over—hundreds of times—because Peggy is the only source of information that follows Ashley around.

In addition to providing an oral history, Peggy transports binders filled with laboratory reports, x-rays, medication lists, and medical reports. Despite Peggy's best efforts to accumulate all the relevant data, she is always fearful she has forgotten or is missing crucial information. Hospitals and physicians are not accustomed to providing the detailed level of information that Peggy needs.

Peggy knows that even during the most critical times, she is the lifeline—the only source of information that connects Ashley's complicated medical history with her current care.

Did You Know?

~ 1 pulp tree (loblolly pine 8" (200 mm) diameter, 50 ft. (15 m tall, 20 years old) = .1 cord of wood (.2 cu. m of wood) = 10,000 pages = 1 file cabinet = 4 boxes/ drawers = .5 GB = 1 CD-ROM

~ 10 pulp trees (loblolly pine 8" (200 mm) diameter, 50 ft. (15 m) tall, 20 years old) = 1 lumber tree (20" (500 mm) diameter, 110 ft (35 m) tall, 50 years old) = 1 cord of wood (2 cu. m of wood) = 100,000 pages = 10 file cabinets = 40 file boxes/ drawers = 5 GB = 10 CD-ROMs

Source: Intergraph Solutions Group. "Data Integration, Interoperability, and Conversion Services for US Army Corps of Engineers Automated Document Conversion Strategy Initiative." US Army. Madison, 2003.