

Patients and Families

The story of SARS is the stories of its victims. Only the details of these shattered lives can fully reflect the horror brought by the disease and our health system's inability to protect us.

As the SARS story recedes into history, it becomes easier to forget the nightmares this unexpected killer disease made real. It becomes more difficult to convince government to do what is needed to ensure that we are spared such horror in future. Listening to the victims' voices help us to absorb and accept the lessons of SARS, critical lessons that might spare us from similar catastrophes.

No one should ever forget the pleas of a woman who told the Commission of the almost incomprehensible anguish suffered by her family:

There are still questions that need answers. The most important one, why did we have to suffer through such political chaos just because some bureaucrats couldn't agree or get their facts straight. We are little people in the grand scheme of the SARS episode and it is the little people that suffered the most and [our voices] fell on deaf ears.

We need changes to our hospitals, we need changes to our public health care system and we need changes to all levels of government departments that deal with emergency measures. Someone has to do something before it is too late for more little people.

The victims of SARS are representative of our society. Some were ordinary working people, some were doctors and nurses, some were retired and some were immigrants trying to build new lives. Their stories can be grouped as those who died, the families of the dead, those who survived and their families, and the hidden victims who did not get SARS but saw their lives affected by it. Forty-four people died of SARS in 2003 and many thousands were affected, as victims who survived, or relatives and friends or those who had to face the isolation, discomfort, fear and stigmatization of quarantine.

Their stories say much about our health system and ourselves. Some reveal specific systemic failures, like the failure to have any consistent policy for hospital visitors during SARS. This is illustrated by the family whose father died after open-heart surgery. They were told by the hospital's cardiac coordinator that they could visit him before the surgery, but the decision was reversed by a nursing supervisor who the family felt was too arbitrary. The family did not get to see the father before he died. The problem here does not rest with any individual but with the lack of a system to assist families and visitors to navigate the visitor restrictions imposed by SARS.

Some of the worst stories come from the earliest days of the outbreak in March and April, before the system learned anything about SARS. However, many of the systemic weaknesses continued, and even in an improved system, nothing can take away the devastation caused by the deaths and the serious illness.

All the stories reflect the pain inflicted by SARS on many families. In many cases, some of the pain could have been avoided had the health system been more effective. The individual hospital could have done nothing more for the family of the mother and father with SARS who shared a hospital room. After the father died and hospital orderlies wheeled away his body, the mother remained for 20 days, visited only one hour a day by her family because SARS required visitor restrictions. The hospital did nothing wrong and can't be blamed for restrictions that left the dying woman unable to see her family the other 23 hours of the day. What was wrong was a hospital system inadequately protected against the onslaught of a deadly disease.

Some stories tell of courageous selflessness of those who became afflicted because they chose to help, such as the nurses' aide who volunteered to visit a friend's elderly mother because she was ill at home and needed nursing help when her daughter was at work. Unknown to anyone, the elderly woman's illness was SARS. She passed it to the Good Samaritan nurses' aide, who carried it to the Philippines during a vacation, where she infected her father. SARS killed both her and her father.

Or the hospital clerical worker who was asked by a nurse to help lift a patient. It wasn't her job, but she wanted to help. It was discovered later that the patient had SARS. The clerical worker infected her 62-year-old father, who died of SARS.

Many health workers became seriously ill from SARS and some died. Their stories are told later on in this section and in other parts of this report.

The stories of non-SARS patients, their families and their friends, who suffered because SARS interrupted the delivery of normal, day-to-day medical treatment for

other diseases and conditions, are told in the section called “The Wider Impact.” These are the stories of citizens who entered the health care system for a variety of reasons, caught SARS and died.

The stories of the victims, their families and their friends follow a pattern. First the confusion, fear and lack of information surrounding initial treatment. Then conflicting information about quarantine, and confusion, stress and heartbreak of hospital visitation restrictions. Then not knowing for sure what your relative died of, or hearing through the media that he or she died of SARS. And the heartbreaks of a funeral process thrown into chaos because those who needed to be there were too sick to attend, or because public health authorities imposed restrictions, or because people were just too frightened to attend.

The victims’ stories tell of individual misery but grouped together they show some common themes:

- *Poor communication with families.* Different people in authority seemed unable to provide consistent answers. People were not always told directly that their relative had SARS. They sometimes learned from the media or other sources.
- *Lack of clear and consistent visitation rules.* The inability to regularly visit their sick relatives, even to be with them and to say “I love you” before they died.
- *Inability to have a traditional funeral.* In some cases, funeral visitations were forbidden or restricted. Mourners had to stand off at a distance at one burial. For some, there was no closure.
- *Stigma of being associated with SARS.* One family that lived through hell because of SARS was told by a school that their children could not return to classes even after they successfully passed through the public health quarantine period. One daughter missed her final exams because her school refused to let her return to class.

In all of this we must remember that everyone who fought SARS, from hospitals to public health workers to high officials in government, were also victims in one sense because they had the misfortune to work in a system profoundly unprepared and starved by successive governments of the right resources to meet a crisis that no one expected and for which no one had planned. These administrators and front-line

workers had to cope with what they had. They cannot be blamed personally for the confusion and frustration and problems suffered by the victims of SARS. Instead of assigning blame, we must build systems and safety cultures that prevent what happened during SARS.

The Commission tried to contact all the families directly affected by SARS in Ontario. It was not successful in reaching them all. People moved, or in some cases the families contacted said they did not want to talk to the Commission or anyone about SARS.

The victims' stories that follow are as told to the Commission by the victims, their families and their friends. They suffered awfully from SARS and might recall events differently from someone seeing the outbreak from a different perspective. The Commission has not tried to corroborate details of the victims' stories. The purpose of telling the stories is to try to reflect the overall horror that smothered these peoples' normal lives during SARS, and not to confirm every detail.

A Descent into Horror

They were a family of four generations, well educated, intelligent and close to each other, until SARS arrived and placed them on a descent into madness. Only two generations emerged from the madness, shell-shocked survivors of a horror none of them could have imagined.

Like some other SARS stories, theirs began with seeking medical attention for a non-contagious medical complaint, in this case a broken hip. The elderly matriarch of the family fell and was taken to hospital for surgery. This was the second week of May, several days after the World Health Organization had lifted the SARS travel advisory for Toronto.

The surgery went well and the matriarch was well cared for by her daughter and son, both in their 60s. She also had the support of others, including a grandson we'll call Mr. U, in his 40s, his wife, Mrs. U, and their children. However, later during the week of surgery, the matriarch fell into a coma and died.

A small funeral was held but that night both the matriarch's son and daughter became ill with flu symptoms. Grandson U also reported feeling ill. All three had spent time with the grandmother during her hospital stay.

Mr. U's wife (Mrs. U) decided that all three needed to be checked, so she took them to hospital. There they were told they were probably SARS patients and they needed to go to the hospital handling SARS.

Mr. U recalled that a doctor told them there were only two beds left in the SARS ward. One of the sick people would have to go home. Mr. U decided that his mother and uncle were in worse shape than he and that they should get the beds. He had a high temperature but was sent home in a taxi, an unmasked threat to the taxi driver.

Public Health already had quarantined his wife and five children at home, but he worried about being too close to the children. So he moved to his mother-in-law's place because she was out of the country for two weeks. He and his family kept in contact by telephone as his condition deteriorated. The wife and children did not develop any symptoms.

Mr. U became so sick that he called an ambulance to take him to hospital.

In the midst of this, his wife received a telephone call from the funeral home that had handled the matriarch. The person on the line demanded to know why Mrs. U had not revealed to them that the matriarch had died of SARS. Mrs. U said no one had ever mentioned that the matriarch had SARS and that everyone assumed the three other family members simply got it from the hospital. She then called the hospital to ask if it was true. She said:

And that's how we were notified that [Mr. U's grandmother] died of SARS.

The nightmare worsened. Mr. U's mother died at North York General. Mr. U had arrived there by ambulance and the hospital administration insisted that he be told of his mother's death. Mrs. U said it would kill him but the hospital insisted and she had a doctor stand in the doorway while she delivered the news. Mr. U was so sick at the time he was given only a 20 per cent chance of living.

While trying to cope with all of this, Mrs. U received a call from Public Health, who wanted a list of everyone at the matriarch's funeral. She said the names would be in a memorial book at the matriarch's apartment but no one could go to get it because they were either in hospital or in quarantine. Public Health told Mrs. U to drive to the apartment and get the book, but to wear a mask.

Mrs. U drove to the matriarch's apartment building but the people she encountered were hostile and she left without going into the apartment:

If not for the fact that they were afraid to come near me, I honestly, I'm convinced that they would have mobbed me. The maintenance people, the people around the elevator. This was not pleasant. So I went back. I was shaking, Public Health called: "Did you get the list?" I told them no. I told them get it yourselves, and take some cops.

Another funeral was held, this one for Mr. U's mother. It was small because Mr. U, his uncle and his uncle's wife all were battling SARS in hospital. Then the uncle died. Only five people attended his funeral because he was a known SARS death.

Mr. U eventually pulled through, but his life and the lives of others in his family are changed forever. Five of them got SARS, three died and those left behind carry indelible scars.

The children will remember being confined to home and their mother asking friends to send their children to stand on the lawn outside the window and perform skits, wave signs and sing songs to cheer them up.

Their mother, Mrs. U, remembers the panic and the confusion:

That's what bothers me, is they allowed fear and panic to take over, and fear and panic is indicative of a lack of knowledge, not about the disease itself, but about procedure. And then right into the community, that people don't understand that a quarantined home is not a house of plague, there is a difference ... lack of information results in extreme responses that only makes the situation worse for everyone involved, and that's when you watch everything break down. The school systems break down in terms of response, public health breaks down in terms of what it can handle.

Mr. U will remember the fear:

I tell you, the fear, the gripping fear, that's what I will remember about SARS. Not so much that I was afraid. Sure I was afraid. It was the fear on the part of others, particularly the medical personnel. They were scared out of their minds. And as much as I can appreciate them being

scared, what I cannot appreciate is that they still had to do the job, although they were scared. Some could, some could not.

He sums up the SARS tragedy in four words:

It's a horror story.

Not Being Able to Say Goodbye

Mrs. J⁸⁰⁸ suffered the torture of not being able to be with her husband when he died in hospital of SARS. As if that was not enough, she was unable to locate his body for 10 days and had no say in determining his final rites.

Her husband was 68 when he suffered a stroke in late February 2003. He was treated in hospital, then sent March 20 to a rehabilitation hospital where he later developed respiratory problems and a fever. He was transferred to hospital on May 13.

Mrs. J visited him daily until the third week in May, when the hospital was closed because of SARS. She never saw him again because he died of SARS on June 16. Her husband's body was taken away for autopsy, but no one told her:

He died the 16th and I did not know what had happened with him to the 26th. Because they told me that he died and he is going to be cremated and I made arrangements with the funeral home and I told them, you know that you have to find out where is my husband's body.

She couldn't find out what happened to the body so she called a funeral home, where the operators made some calls and located her husband's remains. She said:

It was terrible. I called everywhere I can call and they did not tell me anything. That is the truth. They did not tell me that he died of SARS, they did not tell me where he was taken, they did not tell me that they were going to send him to the crematorium or whatever, they did not tell me nothing. I just found out from the funeral home that he was at the crematorium on the 26th.

808. As noted earlier, the initials of SARS victims have been changed. In this case, the initial J does not correspond to the victim's name and is not related to the J family whose story is told in the Scarborough Grace chapter.

After telling the Commission her story, she broke into tears:

I was a piece of glass; they looked through me.

Who Will Look After the Children?

The strained health system, stretched medical staff and a general lack of preparedness created special hardships for families with young children where one or more family members became ill.

One such family, the Ps, gave a detailed account of their ordeal to the Commission. It took four trips to emergency before Mr. P was diagnosed with SARS. The family are members of the Bukas Loob Sa Diyos (BLD) religious community, whose members came in contact with SARS. The BLD story is told elsewhere in this report.

Mr. and Mrs. P had two children, five and 11 years of age at the time. There were no provisions for the children in place when quarantine was ordered and when both parents contracted SARS and required lengthy hospital stays. The children were symptomatic but did not get SARS. Both parents did and survived. The children spent the critical period of their parents' illness in hospital. The parents had to deal with heart-wrenching anxieties, including the possibility of having to turn the children over to Children's Aid.

The Commission drew attention to this problem in its second interim report:

Whatever legal authority there is for quarantine, it will only work if emergency response plans provide the resources and machinery to help those who must go into quarantine ... For those individuals with children at home, the hardship and stress of quarantine proved to be even more overwhelming.⁸⁰⁹

Mr. P became ill on April 1, 2003. He was not feeling well at work and came home with a high temperature. After a couple of days, he phoned his family doctor, who asked him whether he got his flu shot. Mr. P hadn't, and the doctor prescribed anti-flu medication over the phone and advised Mr. P to drink lots of fluids. Mr. P did not

809. SARS Commission, second interim report, pp. 259-60.

get any better and his wife called an ambulance to take him to hospital. He was diagnosed with pneumonia. He made two more trips by ambulance to the emergency room. Each time he was put in isolation, x-rayed, diagnosed with pneumonia and sent home.

Mrs. P sensed that something was drastically wrong and on the third trip tried to get the doctors to admit him:

For the third time he ended up in the hospital after I called the paramedics ... he was examined, put in the isolation, just following the usual routine, being placed in the isolation room and being examined again. And this his third time visit the emergency ...

When the doctor came to examine him, he was told that he's experiencing pneumonia and he was prescribed sleeping pills. He was given a sleeping pill ... I was concerned when he called me and I decided that I wanted to speak with that physician who examined him at the emergency.

I got a hold of the attending physician ... I pleaded with him that this was his third time at the hospital and being told that he only got pneumonia ... I told the doctor that I'm only a housewife and I don't know what to do with him anymore, and I'm very, very much concerned about his condition, having the high fever and all the flu-like or pneumonia-type symptoms. And I pleaded with the doctor that they have to keep him for further tests or whatsoever for further examination.

But then I was told that I should come down and pick up my husband so that they could attend to other patients at the hospital. My plea to that doctor was ignored. I could not do anything but go to pick him up ... we just went straight home. We just prayed to God that being told three times by different doctors that it was pneumonia, we'll just take it from there.

Mrs. P became exhausted taking care of her husband at home. She booked off work and kept her kids home from school. She became more desperate until a nurse friend suggested taking Mr. P back to the hospital. She called the paramedics again and took him to hospital:

I was saying to the nurse that that's his fourth time in the emergency and – and he already finished his antibiotic by that time and his condition

was really, really worse ... About three or four hours later I was told that they're keeping him in for further tests. I should go home.

The next day Mrs. P was advised by the doctor in the infectious disease department:

that I should quarantine myself and the children and it's already been confirmed by them, after doing numerous tests, that he is a probable SARS patient ... and I was advised to stay in the house and that we're all being quarantined and that I would be hearing from public health to advise me what to in that situation.

Mrs. P developed a high fever and her daughter, too, was showing symptoms:

But then my daughter woke up maybe around 1:00 or 1:30 and crying about the pain on her ankle area. I was aware that one of the symptoms is feeling the fatigue and having joint or muscle pain, being associated with a high fever. I was very concerned about that and she's flushed with rosy cheeks and the high fever ... I decided that we have to call in for paramedics.

When the paramedics arrived, Mrs. P told them that the instructions from public health were to take them to the hospital where her husband had been admitted. But the rules called for the ambulance crew to take them to the nearest hospital, which they did.

Mrs. P and the children were kept in an isolation room well into the next day. She kept asking that her husband's hospital be contacted. She managed to reach her husband on a cellphone. He said the hospital had been looking for her and the children. A bulletin about the BLD congregation and its contact with SARS had now gone out to hospitals. Arrangements were made to admit her and the children to hospital:

They were taken in a separate ambulance directly to [hospital], accompanied by a nurse ... a female nurse. She was very, very good with my daughter, carrying my daughter. And of course we all cried.

Mrs. P, who was now admitted to hospital, started telephoning to get information on the kids:

I got a hold of the emergency department to inquire about my children. And I was only told that they're okay and someone will get a hold of me later that evening.

The parents were able to speak to the children by telephone. Friends and relatives visited the children, who were in separate but adjoining rooms.

Mrs. P took a turn for the worse. She was transferred to the intensive care unit, intubated and treated for two weeks until she recovered. The doctors wanted to intubate Mr. P as well, but he pleaded with them to hold off so he could continue talking to the children on the telephone. Mr. P said:

I pleaded with the doctor, I said, give me a couple of more days. If I don't improve, okay, go ahead but right now I have to talk to my kids and my wife and make sure that they're okay. I was already having problems breathing, just a few steps walking around a few steps, I would grab something. I was already huffing and puffing and was getting dizzy already. And then my wife got worse. She was taken to ICU before me. She was intubated and, I mean, the, she was already intubated, she was taken for ICU intubation and that made me even worse now because now my wife that, won't be able to contact my kids.

I told my kids that they are taking my wife to another room with no telephone but she's okay and that the doctors just decided to separate us now rather than put us in the same room. So I lied to them just to prevent them from worrying. I called them every time and every time it's very hard, emotionally because they're pretty young kids and I was already thinking about what would happen if something happens to my wife and then something happens to me. Where are they going to go?

The children spent a month in hospital. So did the parents. All recovered.

The Pain of Visitor Restrictions

Two other families who lost relatives to SARS told of how hospital visiting restrictions made dealing with the deaths so much more difficult.

One family had organized hospital visitation shifts to be with their father who was dying of cancer. SARS then forced hospitals to impose restrictions. A doctor wrote a

letter that the family was to show to hospital security staff. The letter noted that because the father was dying, one family member at a time could be at his bedside. When the man's son arrived to take his shift, a security guard took the doctor's letter and threw it in the trashcan.

A daughter-in-law told the Commission about what happened next:

My husband got very upset and tried to explain that his father was upstairs dying and he had to be there. But the security officer took it upon himself to disregard the special permission letter. My husband had a verbal argument with the security officer and they were about to phone the police and have him arrested for causing a disturbance until I happened to intervene and calm everyone down. With our insistence the security officer called upstairs to the nursing station to find out if indeed we were allowed in and sure enough we were.

You can imagine what my husband went through knowing that he may not be able to be with his father in the last moments. All because of what we judged was a security officer who thought his shoulders were a little too big and let a bit of power go to his head. Unfortunately, though, he had no compassion or common sense.

Perhaps in the future the security personnel who are hired should be a little more experienced in dealing with the public rather than just night patrolmen who really can't handle such extreme circumstances.

The Commission notes again that these stories are told entirely from the victims' perspective. This story and others, however, confirm the need to establish workable systems that in future outbreaks will help hospital staff do their jobs while assisting visitors to connect with those who are ill.

One Daughter's Loss

Mr. I was a 62-year-old family patriarch who succumbed to SARS. The outbreak turned the life of his family upside down and left many of its members traumatized. How it happened and the events leading up to his death contain elements of nearly everything that went wrong during the outbreak in Toronto.

There was a wrong diagnosis, bad communication, misleading or inadequate information, fear and stigma.

The story begins not with Mr. I, but with his adult daughter. She was a part-time clerical worker in a hospital, and was asked on a Saturday in March 2003 to help a nurse lift a patient out of his bed. It was not her job, but as a part-timer who wanted to keep her job, she was accommodating. Unknown to anyone, the patient had been in contact with SARS in the hospital's emergency room.

Several days later, she developed a fever but didn't think too much of it and so went to work. When she returned home she told her family that she still was not feeling well and that she still had a temperature. Her family and her parents shared a home. She called the hospital's health and safety department several times and left messages, but never received a response.

A couple days after that, she went to see a general practitioner who told her she had sinusitis and prescribed an antibiotic. Her condition worsened and by early Sunday morning, around 4 a.m., she went to another hospital, where she was x-rayed and again told that she had sinusitis.

Not feeling better by Monday, she telephoned public health. After a brief conversation, the public health worker asked to speak to her mother and said: "I think your daughter is having symptoms of SARS."

The health worker arranged for the woman to be admitted to the hospital where she worked part-time, but she was transferred to another hospital. The husband delivered her to hospital and when he returned home two or three hours later learned that the whole household would have to be quarantined and that they would have to clean her room and wash anything she may have touched.

Toronto Public Health sent them N95 respirators to wear and they settled into a routine of using one set of dishes and cutlery per person, washing everything with bleach for 20 minutes. The family had no dishwasher.

After five days, the family patriarch showed no symptoms and returned to work. The family said he thought he had finished his quarantine. His wife, who was keeping track of everyone's temperature, checked his, and it was 36.3°C, within the normal range. Mr. I worked a 12-hour shift and when he got back home, his temperature began to climb. It rose to 38 and an hour later was 38.2. He had no other symptoms and said he was feeling fine.

His condition worsened during the weekend and into the following week. He lost his appetite and was experiencing shortness of breath and coughing. His son-in-law was showing symptoms too. The two drove to a newly opened SARS clinic. The clinic admitted Mr. I. The son-in-law returned home. To the family's surprise, he rang the doorbell rather than using his key. He said:

They told me to be in strict isolation.

His mother-in-law cleared out a room for him. As she shut the door after him, she wondered why they sent him back home.

Mr. I's return to work after five days of quarantine turned out to be a big mistake. He had infected a co-worker and his place of employment had to quarantine everyone and shut down. The infected co-worker recovered.

The co-worker's illness and the economic impact on the enterprise weighs heavily on the surviving family. The media reported that Mr. I had broken his quarantine. However, the family maintains that they misunderstood how long the quarantine should last. The family told the Commission that on the day Mr. I went to work, he had a normal temperature and showed no symptoms.

Following Mr. I's trip to work, Public Health kept close check on the family's quarantine. They sent inspectors to the door and telephoned frequently.

It took a long time to get word to the family about Mr. I's condition after he was admitted. Hours into the night after the son-in-law's return, there was no word to Mr. I's wife about what was happening. There was no further word from the hospital into the next day. Mr. I's wife slept with her phone by her bedside, waiting for word, but the hospital never called. Her niece called the hospital, pretending to be Mr. I's daughter. She was told that he was in the intensive care unit and that he had a chest tube to drain fluids from the lungs.

It was more than two weeks before Mrs. I was allowed to see her husband. He was getting worse. She had to ask permission from the hospital and Public Health. The rules were that a person had to face imminent death before relatives were admitted. In fact, he lived several weeks longer. He was admitted on April 3 and died on May 25.

His wife went to see him every day. But his children were less frequent visitors. They had gone back to work and visits to the hospital did not go over well with their bosses and co-workers. One was even afraid of being fired after her quarantine ended.

SARS or its symptoms played havoc with various members of the family: Mr. I's wife, his two daughters, his son-in-law and one of the daughter's two children. Their temperatures were continuously checked during the quarantine period and when the six-year-old's went up suddenly and he lost his appetite, the family took him to a SARS clinic for a checkup.

The clinic decided to send him to hospital. They would not allow the mother to ride with him in the ambulance. She was near the end of her 10-day quarantine, still wearing a mask. The hospital would not let her in. Another relative had to bring some clothes for the child. The boy spent seven days in the hospital by himself. He had no visitors but he was in almost constant telephone contact with his mother. He even went to bed with the phone. Fortunately, he did not have SARS.

The family members are upset about the lack of information that was given them during the crisis. They have gotten on with their lives. But the widow still takes her own temperature every day and writes it down. "It's for my own peace of mind," she is reported to have said.

The point of this tragic story is not whether the father knowingly broke quarantine, and nothing would be gained at this time by an investigation into the issue. The story shows how the quarantine system depends on voluntary cooperation and systemic supports that encourage voluntary compliance.

The One Left Behind

He's not 50 yet, but Mr. K already is talking about having a shorter than usual life expectancy. But he considers himself lucky because he has a life after surviving a SARS cluster within his family. He survived, but his mother and younger brother didn't.

It began in early May 2003, when his mother, in her early 80s, broke her hip at home and was admitted to hospital. She was there for two or three weeks, and Mr. K and his younger brother took turns visiting her. She developed a fever and so did the two brothers.

The younger brother died of SARS June 19, followed by the mother two days later. Mr. K could not attend the funerals because he was in hospital fighting for his life.

Their deaths were part of the second SARS outbreak and it is Mr. K's personal belief that hospital precautions were relaxed too soon.

When his mother was first admitted to hospital, Mr. K said security and precautions were tight and visitors had to wash their hands and wear masks. Later security began to loosen:

I firmly believe that the loosening up has something to do with Toronto trying to say SARS is behind us and so on. I think the hospital was under pressure to loosen up so that it won't be seen as "we still have the virus around." I think if the hospital did not relax precautions my brother might not get sick and I might not get sick.⁸¹⁰

Mr. K had pretty much recovered from the effects of SARS. He is thankful that when he returned to work he had the full support of his employer and colleagues:

When I walked into the office no one avoided me, which is important. Being accepted back into society is important. I'm not sure everyone was that lucky.

The scars of SARS remain on his family, however. He has lost close contact with his brother's widow:

My sister-in-law definitely does not want to talk about that and doesn't want any people to know about it. I think she went through a prolonged period of denial. Even now she doesn't want to talk to me or my family.

Missing Mementos

Sometimes things that might appear less significant in the broader picture are the memories most remembered by the victims. Little things can provide some comfort in times of grief. Or like a drop of water in a dam that is on the verge of overflowing, little things can tilt the balance.

A 77-year-old woman went to hospital suffering from diverticulitis. While in hospital, she contracted SARS and later was transferred to another hospital, where she later died. On arrival, paramedics placed her personal effects, stored in a plastic bag, under

810. This perception, not uncommon, is discussed elsewhere in this report in the context of the relaxation of precautions through the Ontario system.

the bed. The bag contained her wedding rings, glasses, credit cards and false teeth. Somehow, it went missing and was never found.

Her daughter told the Commission:

So we ended up burying her without her teeth, without her wedding rings, without her glasses. She was buried with my sister's glasses and stuff like that. It was very difficult.

Added another daughter:

That was the final indignity. I keep hoping that I will wake up soon.

Secrecy, Insensitivity and Stigma

Victims often perceived the lack of information about SARS to be secrecy imposed by the medical establishment. They could not get clear answers they felt they needed to help them deal with radical changes in their lives. For instance, a man was in hospital dying of cancer and became exposed to SARS. His wife developed a slight fever and was admitted so she could be monitored and be with her dying husband. The husband died and the family wanted to plan his funeral but could not get an answer on when their mother would be released. She had been in hospital for more than three weeks but never displayed any signs of sickness other than fever. As one family member told the Commission:

They had already observed her for so long and she hadn't displayed any sickness of any kind except for a broken heart.

During the funeral planning, the funeral home called and said the father had died of SARS. There would have to be special handling of the body and a glass enclosure for the coffin. The family felt the father died of cancer and did not want the stigma of a SARS funeral. They were plunged into a frustrating search to get a definitive answer on the cause of death.

The coroner's office said an autopsy had not revealed SARS. A second autopsy test determined the same. However, Public Health authorities said there had to be a SARS funeral because they didn't know what they were dealing with.

The hospital discharged the mother, but she still could not attend the funeral because

she was quarantined. As the family told the Commission, the loss of their father was compounded by what followed his death:

What should have been a huge Italian funeral with several hundred people turned out to be a funeral with little more than 50 people in attendance. Nobody wanted to come to a SARS funeral and those that did kept their distance.

Nobody would answer any questions that we had. Nobody would tell us if my father-in-law or mother-in-law had SARS or what their suspicions were.

You can imagine my mother-in-law, who barely speaks any English and doesn't believe that she was sick in the first place, watching her husband's funeral on television and wondering why these people made her go through this.

All she wanted was a little bit of honour for her husband as she was not only robbed of that but also robbed of the closure to his death. She lives daily with questions that have no answers and no faith whatsoever in our health care system.

My family has gone through such a traumatic and horrific ordeal. In the end there is nobody to comfort us. There is a stigma that we are only now beginning to overcome. There are lifelong scars that we will go to our graves with.

In another case, the daughter of a woman who died of SARS said she and her sisters never did get official confirmation that SARS was responsible for her death:

We would often ask if someone could confirm the SARS diagnosis; we were told that it could take a couple of weeks and someone else said that it could take a couple of months, so we really just stopped asking. We thought when we heard, or we saw in the paper that she was one of the SARS statistics, that maybe the coroner had made the determination but ... someone from professional standard, I believe with EMS, said that they had it down as confirmed SARS for the transport so I guess it was confirmed, but we were not told.

Another family told about living with the stigma of a "SARS house."

Ms. Tecla Lin,⁸¹¹ a nurse who worked at West Park Hospital and whose story is told earlier in the report, lived with her husband in their family home. When both Ms. Lin and her husband contracted SARS and passed away, Ms. Lin's son found himself trying to settle his mother's affairs, including selling her house, which was mortgaged and costing him heavy monthly expenses. However, selling it for fair market price was hampered by the stigma of being the house of SARS patients:

In order to remove the stigma of the house, I had to do many things. I had to completely remove all of the personal belongs, possessions, furnishings completely, which meant selling everything, and I did that. Now it is very difficult just because there was so much stuff. There is a lot of stuff and I had to get new furniture, full furniture, and refurnish the house. And I did that and I put it up for sale this week. And it looks great and from the inside, the stigma is completely removed and that was a lot of work and cost a fortune, a small fortune, but that is the price of selling a house with a stigma attached to it.

A Simple Procedure, Then Death

Mr. L was no stranger to hospitals. He had health problems stretching back at least a decade. He had had a liver transplant, a triple bypass and prostate surgery, and he had diabetes. He may have been sickly and not young at 74 but his family did not expect him to die. His visit to the hospital was to get his nails clipped, a medical procedure for diabetics.

The story of Mr. L and his family, as told to the Commission, reflects the confusion in the early days of the outbreak and ends with their complaints about the lack of information and stigmatization within their community.

After the procedure, Mr. L returned home and developed a high temperature. The family doctor suspected a urine infection. His family drove him to a hospital, where they noticed there were more people in emergency than usual. Mr. L was admitted and when his family visited him the next day, things were not going well. He had trouble breathing and a nurse said he had had a very bad night. His breathing got worse and around 11 a.m. the family was told he would be taken to the intensive care unit. At 4:30 p.m. they were told Mr. L must go to another hospital because there was

811 Because Ms. Lin's name is already in the public domain, her name is used in this report.

no room in intensive care. At the new hospital, he was taken directly to intensive care. A doctor there began asking the family about Mr. L's liver, and his family recalls:

He had to go back and forth to the hospital so we are used to that. We said his breathing is what we were afraid of. There is talk about SARS going around. Do you think maybe he has it? We asked the doctor. He looked at us and said: "Do you think if he had SARS we would be like this? With no masks?"⁸¹²

During the night the family got a call that Mr. L was transferred to yet another hospital. Here he ended up in a closed room and the family had to wear masks, gloves and gowns. They were told they would not be able to go back. Hospital staff said they were not exactly sure if he had SARS.

Mr. L died while both his wife and his daughter were in the same hospital under quarantine. That is where they learned of his death:

We told my mom that my dad had died. I went to the bathroom. I just could not take it anymore. I was not crying. I was numb. I said to the nurse, "Can you bring me some Gravol?" I told her that my dad just died and she said, "Oh my God." My 25-year-old son had to go and sign all the papers for my dad because he was the only one not in quarantine.

The community in which the family lives reacted by stigmatizing them. Newspaper clippings about SARS were sent to the home, and a bakery they had frequented for 30 years declined to send food for the funeral:

After I was out of quarantine, I was walking at the mall to get some shopping and people would walk away from me. We wanted an open funeral and everyone to come but we were hearing so many people saying we do not know what to do, we should not come, but I said everyone is out of quarantine ... but there was an outbreak at a funeral home ... and we finally said we will just have a private service, we will not put anyone at risk.

812. As with the stories of other victims, the family recollection is described as reported and without verification because nothing can be gained by adversarial inquiry into who said what when. The point is the degree of confusion and misunderstanding that prevailed during SARS.

At the time the family spoke to the Commission, they had not received official word from the hospital about Mr. L's cause of death or his medical file.

Death While Waiting

SARS ended the life of a 79-year-old woman because she stayed in a hospital while waiting for a room in a long-term care facility. She lived alone and was taken to a hospital emergency room after she fell and injured her eye. Doctors said she was in good health, except for diabetes, high blood pressure and other health issues. They decided she should not live alone and would stay at the hospital while waiting for a long-term care opening.

She arrived at the emergency room March 6, 2003, and spent three days there before being admitted. Two weeks after Mrs. V was admitted, a public appeal was issued for people who had visited the hospital's emergency room to contact Public Health. Family members who contacted Public Health recall being told since more than 10 days had passed, they were in no danger.

Family members visited Mrs. V on March 21 and 22 and wore no masks and no protective clothing, believing that SARS was contained on the 4th floor. A few days later there was a public announcement that anyone who had even "delivered a package" to the hospital must go into quarantine. They did, but they had no contact with Public Health, which they had called following their first visit. The family members showed no SARS symptoms and did not become ill.

Mrs. V died at the hospital on April 26, almost six weeks after she arrived there. Relatives were not allowed to visit but kept in daily contact by telephone. Near the end, they were told they could visit but they did not want to take a chance of getting SARS.

Said one of her daughters:

I really feel deprived of those last moments with her. It's not like she was bedridden, sick and dying. I have not had closure.

Communicating Death by Telephone

One of the many horrible aspects of SARS was how relatives were told that someone close to them had died. Some people learned about the death of their relative while sick in hospital themselves. Others received telephone calls because SARS prevented them from being at the hospital.

The case of Mr. and Mrs. B illustrates the pain and confusion suffered by so many when SARS took a life.

Mrs. B was a healthy 89-year-old who lived with her husband, 87, in their own home. In May 2003, she fell and broke a hip. Doctors operated and successfully repaired the hip. Her daughter recalled:

She came through with flying colors. They'd already had her up. They wanted to know about convalescent care.

However, one week later doctors reported Mrs. B had SARS and had her moved to intensive care. She died the next day.

The daughter and some other members of the family were vacationing in Las Vegas at the time. They had planned the trip for some time and went ahead with it when Mrs. B did so well following the hip surgery. They were told of Mrs. B's death when they stepped off the plane on return:

We were landing. We didn't know. We get off the plane and my son-in-law and my grandson were there to meet us and, of course, looking at them I knew something was wrong and that is when they said that she had passed away.

The daughter and her husband had been at the hospital before their trip to sign papers related to Mrs. B's convalescence. They were told they would have to go into quarantine and wear masks sent to the airport for their arrival.

Mr. B was on his own at home. The hospital had phoned him to tell him his wife had died. His daughter was unable to help him because she was in quarantine. She recalled for the Commission:

There he was in the house, left alone, told of her death like that and told

that he had to stay in the house. The health department said he had to take his temperature each day. Nobody would go into the house, so they dropped off the thermometer at his doorstep for him to take his temperature. He had started at the time with some early dementia and I think the confusion was even worse.

He took his temperature one day and he phoned and said it was something like over 100. He was reading something 102, 104, and I said well, it can't be. So I phoned the health department and they said just tell him to put his thermometer in the cover outside the door.

His daughter went to see him as soon as her quarantine ended. She found that he had lost a lot of weight and was very depressed.

The family's troubles did not end there. Mrs. B's grandson, the daughter's son, was also quarantined. He did not tell people in his office why he was away until his quarantine was over. She said:

They almost threw him out and said, how could you do that when there were other people at risk who had families.

The family had problems finding out exactly how Mrs. B died. The doctor involved was not available. A nurse whom the daughter reached could offer no help. The phone call informing the grandson that she had died said only that a nurse found she had died during the night:

I have a real problem with that because I have no idea how she passed away. Was she looked after properly? I got no answers. To me, that is so wrong. Nobody should die alone.

Compassion in the Midst of Horror

These stories are painful to read, let alone to experience. However, not all was gloom and hurt for those who suffered through SARS and survived. There were stories of courage, hope and kindness. Some are reported elsewhere, but the following two are noted because they relate directly to victims and their families.

One involves a widow who was quarantined in hospital after her husband died of SARS. She was alone and frightened, and hospital staff avoided her because of their fear. They entered her room only to take her temperature – except one nurse who went every day to her room for 10 to 15 minutes, and talked and comforted her.

There is also the story of another widow comforted by another nurse. During the crazy days of her husband's illness, the woman met a nurse who pressed a piece of paper into her hand. The nurse said to call if she needed help. After her husband's death the widow did call. The nurse came to her house and took her out for lunch.