

## CHAPTER FIVE: The Victims of SARS

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### Death on the Front Lines

Three medical workers on the front lines died during the SARS outbreak. One was a family doctor and the other two were nurses.<sup>793</sup> The deaths shook the health care community, spawning calls for a better information flow to family doctors and better protection in the workplace for all who work in hospitals.<sup>794</sup>

### Nelia Laroza

Nelia Laroza was the first of two nurses to die during the SARS outbreak. She worked at North York General Hospital and succumbed when SARS reappeared after authorities thought they had beaten the outbreak. She was 52 years old and died on June 29, 2003.

Her death sent shockwaves through the nursing and medical communities. Her funeral was attended by union leaders and politicians, including Ernie Eves, Ontario's Premier at the time. An honour guard of nurses, wearing black armbands, paid tribute to her at her funeral.

Nelia Laroza was known for her skills and was well respected by doctors and colleagues. She was an unlikely candidate to be struck by SARS because she was meticulous about precautions against infection.

A nurse who worked with her for a decade told the Commission:

... a great loss. And she was so paranoid about SARS that when they first came forward and told us, she always dressed in a gown. We were

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793. A fourth medical worker, Adela Catalon, a nursing aide at a Toronto retirement home, also died of SARS, in the Philippines. Her story is told in the chapter "The Lapsley Family Doctors' Clinic."

794. Because the names of these three health workers and the particulars of their illnesses are already in the public domain, they are disclosed openly in this report.

100 percent dressed in gowns, she was 120 per cent dressed in gown. She was so paranoid about SARS.

And we just couldn't understand why she died.

Nelia Laroza feared SARS from its first outbreak at Scarborough Grace Hospital. She did not work there, but it was not far from her family home. Members of her family told the Commission that she bought masks and family members carried anti-bacterial hand wash at all times.

Whenever her daughter picked her up from work, she had to wait in the parking lot and call her mother on a cellphone. Nelia did not want her daughter to wait inside the hospital, fearing that the air was contaminated.

When she came home, she headed for the shower and changed her clothes before hugging any members of her family.

A doctor who worked with her had nothing but praise for Nelia:

She was a good nurse, very casual, without any sort of announcement, was very professional, good with her patients, and had the ability to pick up on if something was changing in them. She would identify it; she'd let you know.

Nelia was someone who, if she called you, and said "I'm worried about so-and-so," it would be because they've done this and this. Other people might not be as clinically observant or have the ability to communicate it ... Nelia was just very good that way. She was as good as it gets for anyone, she was just your good, basic, decent person.

Nelia followed the strict protection regimen even after the authorities declared that SARS was contained.

She worked on the orthopedic ward of North York General, where the second outbreak started and many of her colleagues became ill.

Toronto Public Health records show that she became ill with fever and muscle aches on May 16. She went to hospital on May 21, but was sent home with a diagnosis of "viral illness."<sup>795</sup> She returned to the hospital on May 23 as a patient and was admit-

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795. Toronto Public Health Case Review.

ted with a diagnosis of possible SARS. She died on June 29.

Nelia Laroza was born in the Philippines on October 10, 1951. She worked as a nurse for more than 20 years, 13 of them at North York General. She lived with her husband, Emiliano, daughter, Grace, and son, Kenneth. At the time, her children were 23 and 16 years old.

All were quarantined but only her son was infected. He recovered. More than 1,500 members of his school were also quarantined.

The doctor who worked with her told the Commission:

... she took great pride in her work and her kids, and ... Nelia [and I], we both followed protocol. But Nelia was seeing those patients, a larger number of patients more frequently. And I've often said, the reason that she contracted SARS is because she was a good nurse, in the sense that she was a bedside nurse, made good notes, looked after her patients.

Tony Clement, Minister of Health for Ontario at the time, had this comment on Nelia's death:

Anyone who works day in, day out to protect the rest of us from any manner of disease, when you lose one who is acting heroically, it's a loss for everyone.<sup>796</sup>

## Tecla Lin

Tecla Lin was one of the first health workers to volunteer to take care of SARS patients, and the second nurse to succumb to SARS. She worked at the West Park Healthcare Centre, where ill staff from Scarborough Grace Hospital were brought into a SARS unit established especially to cope with the outbreak.<sup>797</sup>

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796. CTV News report, July 4, 2003.

797. West Park Healthcare Centre, media release, July 21, 2003.

Ms. Lin's first shift was on March 24, 2003, and her last on April 2, 2003. The following day she had fever, muscle pain and a cough and on April 4 was admitted to Sunnybrook Hospital and later transferred to William Osler Health Centre. She died on July 19 from complications of SARS. Tecla Lin was 58 years old.<sup>798</sup>

Her husband, Chi Sui Lin, also developed a fever and after a brief quarantine period because of his wife's exposure to SARS was admitted to Toronto East General Hospital, where he died on April 26. Mr. Lin was 77 years old and had previous health problems.<sup>799</sup>

Ms. Lin was a popular and respected nurse who had a special empathy with patients. Her death devastated those who worked with her.

A doctor at West Park told the Commission:

When Tecla Lin died it was the worst. I did not think I was very well for a while. I did not want to go anywhere, I just wanted to be home. I was tired ... it was like [I] had been through an earthquake.

Tecla Lin was born in Hong Kong on December 18, 1944. She had more than 35 years' experience as a registered nurse in Hong Kong and Canada. She began her nursing career in 1968 in Kowloon, after graduating from the Government School of Nursing. For the next five years, she worked as an operating room nurse.

In 1973, she moved to Canada with her husband and two sons. From 1977 to 1998, she worked at the Doctor's Hospital in Toronto, where she developed specialized skills in monitoring intensive and critical care unit patients. During that time she earned a Bachelor of Applied Arts in Nursing and a Certificate in Critical Care Nursing from Ryerson University.

She worked at West Park part-time and also had another part-time job, at the Toronto Rehabilitation Institute.<sup>800</sup>

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798. Toronto Public Health Case Review.

799. Toronto Public Health Case Review.

800. West Park Healthcare Centre, media release, July 21, 2003.

Survivors include her sons, Wilson and Michael Tang, who were toddlers when the family moved to Canada.

Michael Tang told the *Toronto Star*:

My mother died on the battlefield of SARS. She was ready and willing to take on risks and dangers. She died with a lot of honour and dignity.<sup>801</sup>

Tecla Lin never told her children that she was caring for SARS patients. Michael Tang told the *Toronto Star*:

I don't believe she considered it a lethal career decision.<sup>802</sup>

Politicians and medical dignitaries attended her funeral at Elgin Mills Cemetery. Tecla Lin was a Buddhist and believed in reincarnation. Her sons placed items she would need in her next life with her body: her glasses, purse, makeup, photos of her deceased husband and a calculator.

Her son told the *Star*:

She always had tons of calculators.

## **Dr. Nestor Yanga**

Dr. Nestor Yanga, a family physician working at a small family doctors' clinic in Toronto, was the only North American physician to die of SARS. Dr. Yanga, 55, was one of four doctors at the Lapsley Clinic in northeast Toronto. Two other doctors at the clinic also contracted SARS but survived. The story of the Lapsley Clinic is told elsewhere in this report.

Many of Dr. Yanga's patients were members of Toronto's Filipino community of about 200,000 people. When SARS struck, some its members who had attended a religious retreat started showing symptoms and came to the clinic to be checked.

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801. *Toronto Star*, "Tecla and Chi Sui Lin," September 27, 2003.

802. *Toronto Star*, "Tecla and Chi Sui Lin," September 27, 2003.

Dr. Yanga examined a BLD (Bukas Loob Sa Diyos) member as well as other members of the S family, whose story is told earlier. Details about SARS had not yet reached all the family doctors, and he wore no protective equipment when he examined the patients. Late on April 4, Dr. Yanga developed fever, muscle pain and fatigue. The next day he began to cough and went to a SARS assessment clinic in nearby Markham. He was sent home and told to quarantine himself. When his condition became worse, he was admitted to Sunnybrook Hospital on April 8. He died on August 14, 2003, from complications of SARS.<sup>803</sup>

More than 2,000 people attended his funeral at St. Michael's Cathedral in downtown Toronto. The mourners included Tony Clement, then Ontario's Minister of Health, and Dr. Larry Erlick, then President of the Ontario Medical Association.

In a statement, Dr. Erlick said:

Dr. Yanga's caring and devotion to his patients serve as an outstanding example of the commitment and professionalism that define what it means to be a physician.

Doctors put their lives on the line every day that they go to work. Dr. Yanga demonstrated determination and dedication to the profession and to his patients – he is an example for us all.<sup>804</sup>

As the *Toronto Star* reported, many at the funeral wept as Dr. Yanga's younger son, Ronald, 16, said he was planning to buy a "Welcome home, Dad" banner when he got the news that his father had died:

I always thought he would be there forever and I wouldn't have even to think of him being gone ... It's hard to know that he's not going to be home anymore.<sup>805</sup>

Dr. Bina Comendador, a friend of Dr. Yanga, told *The Globe and Mail* newspaper:

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803. Toronto Public Health Case Review.

804. Ontario Medical Association media release, August 14, 2003.

805. "Poignant tribute to MDs' rare spirit," *Toronto Star*, August 20, 2003.

He was the kind of person you could respect and really care about, and I think his patients felt that too. He would make you feel that you were special and that you were the most important patient.<sup>806</sup>

Dr. Yanga was a former president of the Canadian Filipino Medical Association and a dedicated general practitioner and church volunteer. According to friends, he was passionate about everything he did. He loved dancing, gardening and spending time with his two sons, Nelson and Ronald. At the time of his death they were 20 and 16.

Dr. Yanga was born on October 8, 1948, in Malabon, the Philippines. He studied medicine at the University of Santo Tomas in Manila. He specialized in surgery and graduated in 1975. He immigrated to Canada in 1981. In the same year, he married Remy, whom he had met during a visit two years earlier. He took his medical exams in Canada and interned at a hospital in Newfoundland and then at two hospitals in Toronto.

He studied at McMaster University and the University of Toronto, intending to become a psychiatrist, but he changed his mind in his third year and chose family medicine instead.

While at the Lapsley Clinic, Dr. Yanga assisted with surgeries at Scarborough Centenary Hospital and worked as a volunteer at the sexual assault centre at Scarborough Grace Hospital. He and his wife were dedicated members of the charismatic Catholic group Bukas Loob Sa Diyos (BLD).

Dr. Yanga had a lifelong passion for ballroom dancing, which he enjoyed with his wife. He was a consummate family man who reserved time for his wife and two sons.<sup>807</sup>

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806. "A life cut short by Severe Acute Respiratory Syndrome," *The Globe and Mail*, September 5, 2003.

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## Patients and Families

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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. J<sup>808</sup> 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 16<sup>th</sup> and I did not know what had happened with him to the 26<sup>th</sup>. 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 26<sup>th</sup>.

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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.<sup>809</sup>

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

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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.<sup>810</sup>

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

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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,<sup>811</sup> 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

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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?"<sup>812</sup>

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.

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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.

## Health Workers

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Nearly one-half of Ontario's SARS victims in Ontario were health workers, doctors, nurses, lab technicians, cleaners, ambulance drivers and others who daily walked into the face of SARS. Unlike the rest of us, they had little choice. SARS was where they worked and they couldn't run away from it, even if they wished.

The experiences of the health workers who became ill with SARS are especially chilling because they are so unexpected. We don't expect our doctors and nurses and other health staff to get ill, even though this is an unreasonable expectation. We particularly don't expect them to get ill because of their work. We like to see them only as the knowledgeable professionals who try to keep us safe from disease and who look after us when it does strike us. When they begin dropping ill, we realize we are in a health crisis in which we are all at risk.

Because they are so important to us, we often view them as if they are not subject to vulnerabilities. But they are humans. They are people like us who worried, became tired and watched their personal lives suffer from putting in brutally long hours in the fight against SARS. They lived in constant fear that they might infect their families. Hundreds of them were quarantined, which often meant forced separations from their families. Many faced ostracism by colleagues and neighbours and, whether quarantined or not, had severely limited contact with family and friends. At times the fear and ostracism lasted for months after SARS finally ended.

Some of the saddest stories are from those who saw their colleagues suffer, and in some cases die, from SARS. One doctor who lost a member of her team told the Commission:

When Tecla Lin died it was the worst ... I do not think I was very well for a while. I did not want to go anywhere, I just wanted to be home. I was tired ... it was like I had been through an earthquake ...

Working conditions were difficult for doctors and nurses treating SARS patients, and for their support staff. The experiences of many nurses during SARS have been



related elsewhere in this report, particularly in the Nurses' Survey section. One doctor told the Commission of one of the most difficult effects of treating SARS patients, was being shunned.

We were not allowed to go the cafeteria they were sending sandwiches to us, because we could not go to the cafeteria. If we walked in the corridor and somebody saw us, they would turn around. It was not only my experience, it was the experience of a lot of people ... It took me a while to understand the ones that had been nasty to me.

I will let it go. I have to work with them anyway. But something I feel, feel that there are two kinds of people, those who will and those who will not ... when they tell you are not welcome here in this room. You cannot be here, you are not responsible by coming in this room ... it is a stigma ... it is not nice. I mean, they are all physicians for goodness' sakes, and health care workers, and they are behaving like old maids.

The same doctor had praise for many who did pitch in:

I can tell you that the people who worked in that unit were all extremely dedicated people, that I will work with them any time, because it was a risky situation.

Being a medical worker did not seem to help those who were unfortunate enough to become infected with SARS. No one can say that they received preferential treatment. The experience of one hospital nurse illustrates that. It also shows the difficulty some doctors had in diagnosing SARS.

One nurse who worked in a hospital that had SARS patients answered a call from a patient in a special unit and became ill over the following days:

I wanted somebody to admit me at the hospital. So I went to hospital ... and then I waited there for seven hours and the doctor there sent me home. He said I only have a urinary tract infection. I asked him, should I have a chest x-ray. He said no.

During her seven-hour stay, she didn't get anything to eat. Just water. Ten days after her contact with the infected patient, she was admitted to hospital. She was sent home after four days.

No one from her own hospital called her to tell her about the SARS outbreak there. She found out from colleagues that one of her co-workers had died and seven people on her floor were sick. She recovered and tried to resume work but found she was too tired, and retired from nursing.

Hospital settings were familiar to the health workers who became ill. Sometimes that made their hospital stay more difficult since most had been in contact with death during the course of their work. One hospital lab technician had been in quarantine at home when she experienced SARS symptoms and was admitted to hospital.

She recalled that one nurse refused to make up her bed:

I know that some of them didn't really want to be in the room. So she refused to make my bed. She just threw my stuff. I said, "You don't understand, I need to clean the bed, I've been sweating a lot, I need to change the bed right down and make a clean bed." And she just refused to do it and she said I have to do it myself. And I could hardly stand up. I was really upset over that ... I had other nurses who came in the morning and changed the bed. I didn't have to ask them.

This and a handful of similar stories stand in stark contrast to the compassion demonstrated by the majority of nurses and other health workers.

As Dr. Avandano of West Park Hospital told the Commission, there were many health workers from all areas of the hospital who worked very hard to contain SARS:

I suppose we were enough, or maybe at times we were not enough, but I can tell you that the people who worked in that unit were all extremely dedicated people, that I will work with them any time, because it was a risky situation. The staff that cleaned, the housekeeping, did not want to go either. So we had a woman that was absolutely amazing, she was always there working, washing and cleaning. And at one point, [something spilled on her] and she was in a panic, and we just washed her. The pharmacist was all the time there, from eight o'clock until eight o'clock at night. The infection control nurse ... was all day there, the ward clerk in the TB unit worked there with his mask because there were so many papers coming and going.

By far the greatest fear among health professionals was the fear of bringing SARS home to family. What could be worse than infecting the people you love the most? As one health worker said:

I was more frightened of taking it to my family. I did not see anybody, did not touch anybody for almost two months. It was the hardest. You do not realize what it is to look at people's faces and to shake hands and to touch. You do not realize until you do not have it ... for instance, we were not to go to any stores, so we could not go to a store, we could not go anywhere, and yet we were working in quarantine. So you go home, and work, home and work, you do not go anywhere, no social life, nothing, nothing, nothing ...

I have two grandchildren that are very, very young. My daughter would pass with them on the front sidewalk when I was home so that I could see them ... I did not want to infect anyone. I was terrified of infecting somebody else.

Another doctor described for the Commission how hard it was to deal with precautions and protective equipment. Those treating SARS patients or suspected SARS patients started by using a surgical mask, gloves and a gown. Later the mask was replaced by the N95 respirator, headaddress and goggles when examining or treating patients:

... And we realized how difficult it was to maintain those precautions, so once you came out of the room, and you disrobed, what happened then? Should you take your mask off? What happens with contact with your hands? I mean doorknobs, hand railings, how about charts, paper, pens, I mean everything and anything. It was so hard to know exactly what to do. So, again eventually we simply donned another gown, started keeping the mask on, we didn't wear gloves ... but that was a huge question. We were more certain what to do at bedside ... But the big questions, even to this day continues to be is what should the team members do when they leave the room? You know, they are still on the same floor, you know, the rooms of the patients are 10 feet away, what do you do at the nursing station, I still think that is a big issue.

Like others who treated SARS patients, he experienced fear from friends and acquaintances, in one case months after the SARS wave had ended:

I was in a restaurant. We were having a gathering. There could have been 14, 15, or 16 people. It was someone's birthday. A close friend of mine ... we were sitting relatively close together ... By mistake, they gave him mine [food dish], and I got his, well, I didn't realize this so I took a

morsel, a single morsel off his plate, with one of the vegetables, and you should have seen the reaction when I said, "Here's your plate." His wife and his sister said, "You can't touch that."

I just looked aghast, I said what are you crazy? It's a month later, you know my wife, my kids, my mother, a lot of friends ... I've shaken hands, I've hugged, I've kissed, you know, it's not a big deal, it's gone, forget it, and you know what? He, he would have been okay had it just been him and me, but I think it was everybody else around him. It was a silly little thing, but I couldn't believe that eight or nine months later I was still a bit of an outcast ... I think if had I used my fingers, I would have understood, but with a fork?

Another nurse became ill with SARS after she looked after a patient in her hospital's SARS unit. The illness played havoc with her personal life and she still suffers some effects. Although her story has a terrible beginning, it does have a happy ending.

She was saving up to go to the Philippines to be married when the illness struck. As she told the Commission:

We planned to get married there, to have the ceremony there, since our family and my husband's family are all there. We planned to have the ceremony in 2003, the summer 2003, but since I got sick, we changed our plans. We let him come here, use his visa, but I wasn't recovering well yet, so instead of coming here to Toronto, he went to Vancouver for a month so that his visa would not expire. But at that time it was so sad because I had SARS so we have a problem with his family, of course I cannot blame his family, they were discouraging him from coming over because they learned that I was sick. [They feared that] he might get infected too.

I was so scared that the wedding would not be realized. But he really proved to them that he loves me and no matter what he said he would still come to marry me. He actually wanted to come to look after me because even though I was sick already ... My mom was the one doing the household chores for me since I was so sick. I was always tired, so that's why he wanted to come over. I asked him to stay in Vancouver for one month, because I needed some time. Then in August 2003, he came [to Toronto] and then we got married on September 25th.

The couple waited two years to have a child because she was prescribed the anti-viral drug ribavirin, which is deemed to be unsafe during pregnancy:

So, to make it safe, we did it after two years. I got pregnant after two years. It was so scary still. Maybe I was just paranoid, but I know that I had that medication, I was sick. I don't know what the long-term effect of that will be. Even now, I have severe headaches. Sometimes I am so short of breath and still last year, my blood was not normal. And when I got pregnant and I had my ultrasound, ...they said that I am carrying a Downs syndrome baby. So it scared me ... but when I gave birth, [the baby] was healthy

When a health worker gets sick, the effects on his or her family can be profound. One nurse worked at a Toronto hospital but lived in a city out of Toronto. She became infected while helping to admit a patient. The hospital did not know he had SARS.

She was admitted to a Toronto hospital and her husband and her three school-age children had to go into quarantine in their home city. She recalled her experience in an interview with the Commission, explaining what was going through her mind:

Just the dread of possibly infecting my family was the first thing that went through my mind. This fear for my family and then just the anxiety of not knowing whether or not I was going to have it ... And it's very tense trying to explain it to my husband and my kids. Wondering how it could happen. I don't think that kind of feeling, that kind of resentment hit until I was actually hospitalized.

The husband set up school for the children at home. As she told the Commission:

You know they would sit in our family room and he would ring the school bell and sit them down to do their homework from nine o'clock and then they would have recess when they usually had recess and lunch when they usually had lunch and then at three o'clock they were allowed to watch cartoons like usual.

The neighbourhood kids were not so understanding:

There were some kids that were just targeting the house. You know teenagers, what else is there to do, I guess. So they were throwing bottles at the house and trash on the lawn and stuff like that.

For the most part I truly believe most had no idea what was going on. Locally it wasn't big news so I guess most people, if they heard about it, didn't really associate it with something [there]. I had one neighbour who was very, very helpful who brought supplies to the family.

She said her husband faced some shunning after his quarantine:

He went into the bank and they were covering their faces or some silly thing like that. You have to expect that kind of thing because people are not sure what to do and they want to protect themselves so I didn't really hold that against them. It wasn't that bad.

The nightmare of passing SARS on to family came true for one doctor who contracted SARS and infected his 15-year-old daughter. Both survived. The dramatic impact on the family was relived on the first anniversary of the Toronto SARS outbreak on the TV Ontario program *Studio 2*.<sup>813</sup>

The doctor noted that anesthetists sometimes resuscitate people and this has never been a problem for him, even when he had to try to resuscitate a woman with leprosy using the mouth-to-mouth method. But SARS was different:

We had an elderly man who was quite ill in the intensive care unit whose breathing was getting quite distressed. I happened to be the first available anesthetist that morning that entered hospital so I was asked to go and help out in the situation. And you have to bend down and look within a few inches of the patient's mouth. And even just that few seconds it took to do that I guess I was right in the stream of the virus being breathed in and out and I got quite a wallop of it. So even with the mask I had and that, I got I guess enough of it around the edges of the mask to become ill myself.

It happened so fast. I guess I was more like one of the sort of front-line border troops in a war that just got sort of mowed over by the initial blitz.

When symptoms appeared, he went to the emergency department. Several other medical staff were showing up with similar symptoms and all were sent to a newly

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813. TVOntario transcript, *Studio 2*, March 15, 2004.

opened SARS ward at another hospital. He lost 20 to 25 pounds and became jaundiced from the side effects of the drugs, and anemic. He became extremely weak. As he said:

And it got worse when I found out my 15-year-old daughter had gotten sick and was admitted and probably had SARS as well.

When she got sick, I really felt somehow that maybe I should have, you know, immediately just put myself into isolation as soon as that – as soon as I was in contact with that patient. So yes, I certainly did feel a lot of guilt there.

His daughter also spoke on the TV program:

I never was angry. I was never upset at him. I didn't want him to feel guilty. It made me sad that he felt that way.

It all happened in a matter of hours. I started to feel really fluey, got into the shower and within half an hour I was feeling really bad. It was like a flu but it was, I would say, ten times worse. When you breathe, you feel pain in your chest and when you try to cough it's just like fire coming out your throat.

The ambulance came and all of a sudden these guys come out in these outfits that looked like space suits and it sounded like Darth Vader and it was like the scene from *E.T.* when the people come in and take him away. It was like that. And just the sound, everything was really strange and really scary and frightening. I could not stop crying.

There were a few moments when I thought to myself, I'm gonna die. I knew that it was really serious and there was a woman down the hall from me in the isolation ward and she was really sick, and she was screaming and really disoriented and crying. And then I found out a few days later that she died.<sup>814</sup>

The daughter recovered and was in quarantine for about two months and, of course, missed two months of school but she said the experience changed her:

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814. TVOntario transcript, *Studio 2*, March 15, 2004.

I was just sitting in my room alone and didn't know what was going to happen. I had a lot of time to reflect and to think about the way I was living previous to this. I had really, really negative self-esteem, really bad image. And throughout that time, I just only had myself and God and just my thoughts and I had to sort everything out. And I came out feeling just completely more connected with myself and had this really good relationship with myself. I was really happy. I was really positive. I thought, wow, I'm really a survivor of something this dangerous, this scary.

It was a wake-up call. Whether or not you admit it, everybody takes everybody for granted, you know. Your family is always there. When somebody almost dies or somebody is really sick, when you get better you're that much more thankful for it.

What gives me comfort is to know that believe it or not you cannot control many things. And sometimes you just have to take it a day at a time and see what happens. Just live your life and follow your goals and dreams.<sup>815</sup>

The doctor also fully recovered. As he said:

I was lucky. I got over the physical stuff pretty promptly. By the time the quarantine was over I was actually basically sick of being sick. I found that first going out, even just walking, it felt like a walk around the block was a several-mile brisk hike. But within a month I was right back to where I had been before.<sup>816</sup>

But his daughter worried about her dad when he went back to work:

I thought that maybe new diseases would come back. If something like that happens, well, what else? There are probably millions of other diseases we don't know about.<sup>817</sup>

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815. TVOntario transcript, *Studio 2*, March 15, 2004.

816. TVOntario transcript, *Studio 2*, March 15, 2004.

817. TVOntario transcript, *Studio 2*, March 15, 2004.



## The Case of Dr. X

Early in SARS a nasty public controversy erupted over whether a health professional knowingly put hundreds of people at risk when he attended a funeral while sick with SARS-like symptoms. An estimated 150 people were quarantined because of what a public health official painted as an irresponsible action that could possibly spread SARS throughout the community. The media jumped on the story and many people became anxious that the SARS outbreak, already a terrifying situation, was about to get worse.

Dr. Hanif Kassam, acting York Regional Medical Officer of Health when SARS broke out in the spring of 2003, revealed this potential exposure at a news conference the day after Easter. He said the health professional had put “hundreds of individuals at risk” by exercising bad judgment. He went so far as to threaten to have the person charged by police if he did not stay isolated. The *Toronto Star* reported:

He should have known about the symptoms and taken the necessary measures to ensure that other people were not put at risk, Dr. Kassam told the news conference. He clearly doesn't know the gravity of the situation.<sup>818</sup>

This scathing denouncement was made publicly despite the doctor's evidence that he had no symptoms before the funeral.

The health professional, Dr. X, was a resident doctor at a Toronto hospital at the time and vigorously denied the accusation. He had admitted himself into hospital with SARS-like symptoms after the funeral but protested that he had been symptom free before going to the funeral home and a church. At the time that Dr. Kassam made the accusations, the doctor had been isolated in hospital for almost two days.

Dr. X responded to the public attack and the two doctors fired back and forth at each other in the media, leaving the public trying to sort out the facts. There is much more to this story than contained in this brief summary and the Commission cannot make a finding of fact in this particular case. It can, however, note that the incident is an example of how easily things can escalate in times of crisis. It shows the need for those

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818. York Health says he spread SARS, *Toronto Star*, April 22, 2003.

in authority to keep a cool head and measure their response when emergencies occur. Provocative personal attacks by those in authority are not helpful.

The public fight between Dr. Kassam and Dr. X was unfortunate and unnecessary. It caused considerable apprehension among the public, who were left with the impression that even the medical community, their best defence against SARS, was slipshod. If anything was learned from the incident it is the need for reasoned approaches and calm communication by those in positions of authority during times of public crisis. What was missing in this case was a measure of official restraint and non-provocative language, especially when the battleground of the dispute was the news media.

## The Wider Impact

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The stories of SARS victims, their families and friends are as plentiful as they are painful and are told in detail in this report. There were other victims who did not contract the disease but who nonetheless suffered from its spin-off effects. These are the hidden SARS victims, those who suffered stress and emotional pain resulting from disruptions in health care, and from the systemic lack of preparation, policies and simple systems to encourage consistent and fair handling of those who needed access to their sick relatives. These systemic failures resulted in great stress and anxiety.

Many hidden victims were members of vulnerable populations: the elderly, the physically and mentally impaired, and those who could not speak English. They had difficulty navigating through a health care environment that is complicated at the best of times but was especially confusing and frightening during SARS. Hidden victims were those who stood by as people close to them died alone because of visiting restrictions. They were people forbidden from accompanying a relative or friend to medical assessments or treatments. In some cases they were people who needed treatments but had to wait because SARS had turned the system upside down.

It is easy now to forget just how disrupted and confused the health care system was during the SARS outbreak. This was a new disease, and the system was unsure how it was spread, how it might be controlled and, in fact, whether it could be controlled completely. It was highly infectious and deadly and it seemed reasonable at the time that health care facilities and their staff do whatever was needed to stop it.

Most people understood the seriousness of SARS and the need for precautions at hospitals and other health care facilities. Many of the hidden victims felt, however, that the health care system was too rigid, cold and uncaring to people struggling with life and death issues. The daughter of a cancer patient, noting a no-visitor policy at a cancer treatment hospital, put it this way:

I know that this was all for safety precautions. I understand all that but you know when someone in your family is all alone there, then you feel angry at a certain point. You would wait outside and you don't know what he's doing in there.

There were many stories of people being handled with less sensitivity than might be expected. However, in these cases it wasn't simply health care staff being uncaring or mean. Systemic failures, not individual care facilities or staff, are behind what went wrong in the stories of the hidden victims. Lurking in the background of each case are signs of lack of preparedness, lack of policies and lack of simple administrative machinery that could have helped to avoid these horror stories.

The lessons from these stories are: Be better prepared for infectious outbreaks, build better systems to handle effectively all aspects of the crisis, be clear about who is in charge, and above all, communicate regularly and clearly with those affected.

Here are some of the hidden victim stories as told to the Commission.

## **A Case of Inconsistent Rules**

Ms. K recalled how her elderly father became a bystander victim in the management of SARS. He was a patient at a Toronto hospital where he spent five weeks isolated from his family because of visiting restrictions introduced to curb the potential spread of SARS. He was paralyzed from the neck down with ALS, Lou Gehrig's disease. His physician refused the family visiting rights on the basis of hospital policy. The family tried to appeal the no-visitor decision. They called the hospital CEO and its Chief Medical Officer but did not hear back from either. They tried contacting Dr. Colin D'Cunha, Ontario's Chief Medical Officer of Health, and Dr. Sheela Basrur, the Toronto Medical Officer of Health. These offices referred them back to the father's physician, who had refused visiting permission in the first place. Ms. K said:

I was at the end of my tether. Nobody had explained to us why we couldn't see my father. It was like living in a pressure cooker. I could not

believe I was still living in Canada. It seemed as if [the hospital] and its physicians had become a law unto itself.<sup>819</sup>

The daughter turned to the media for help. She emailed the *Toronto Star* begging for assistance. A reporter called the hospital community relations department and on May 5 the patient's wife received permission to see her husband. She had not seen him for 40 days. He died two weeks later.

As Ms. K told the Commission:

I should not have had to depend on the media call to see my father. My own call should have been enough.<sup>820</sup>

She said her mother still is unable to handle the fact of not having been with her husband in the final weeks before his death:

She is still traumatized that she could not fulfill her cultural and religious obligations to the full.

She is haunted by the memories of those five weeks and what she saw as the cold indifference of physicians in power. She says this cruelty must never happen again.<sup>821</sup>

What was missing was a system through which families who felt unfairly dealt with could appeal to a senior hospital official or team of senior staff. Different health care staff had different views about access or visiting during SARS. Patients and their families should have had recourse to review such decisions without going to the news media.

## The Man Who Died Alone

Similarly, a 96-year-old man who had been living with his disabled grandson was taken to a hospital in the Greater Toronto Area, where he was diagnosed as requiring chronic care. The man's daughter and his grandson visited regularly but one day

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819. SARS Commission Public Hearings, November 17, 2003.

820. SARS Commission Public Hearings, November 17, 2003.

821. SARS Commission Public Hearings, November 17, 2003.

arrived to find the hospital closed because of SARS. The elderly man's condition was classified as chronic, but not critical; still he was not permitted visitors. The daughter tried unsuccessfully to have her dad's condition changed to critical from chronic so visits could resume; however, calls to the attending physician and the man's family doctor were not returned. The hospital said that when the man's condition became grave they would call her and she could visit just before he died. The only call she received was that her father had passed away.

## **Fifteen Minutes Too Late**

One man told of trying to visit his 56-year-old mother at hospital outside the Toronto area. She was admitted just after Mother's Day, right at the height of the spring 2003 outbreak. She needed surgery on some toes affected by diabetes and he went to visit her before the operation. He told the Commission he was physically removed from the hospital by security staff despite his understanding that his mother had placed his name on a list of visitors and that this was all that was required to secure a visit.

Later he received a call from a nurse saying he should come to the hospital because his mother had had a heart attack. When he arrived he was allowed to go to the intensive care unit without any SARS screening. He talked with a doctor who said he was 15 minutes too late. His mother had passed away.

He described himself as "emotionally wrecked."

This is one more example of the misunderstandings that can lead so easily to a tragic sense of loss when there is no preparedness and no systems to ensure reasonable policies and sensitive communications.

## **High Anxiety and Nightmares**

Enforced separations also created anxiety and pain for people in long-term chronic care facilities and their families. One woman told the Commission how she could not visit and care for her disabled mother for 29 days during the SARS crisis. The facility did not have any SARS cases but imposed visitor bans as a precaution. The mother had suffered a serious brain injury more than two decades earlier. She had been in long-term care since, receiving almost daily care from the daughter:

I promised her that I would remain at her side for as long as she needed me ... I have managed to be at her bedside every day or second day for the last 21 years. I am there to give my mother her personal care, to feed her, to assess her health and to advocate on her behalf.

The visitor bans caused her mother much distress because “I could not prepare her for the sight of staff in their space suits hidden behind their visors, goggles, masks, gowns and gloves.” The daughter said:

My mother will never be able to tell me what her experience was of those 29 days. For me there was high anxiety, nightmares.

The daughter told the Commission that she watched with interest as the Hospital for Sick Children<sup>822</sup> allowed one family member to be with each patient during SARS. A parent was allowed to be with a sick kid, but adult children were not allowed to be with their parent at this long-term care facility:

I and others feel that we are the parent and our loved ones the child, regardless of our blood relationship.

The daughter also said that the facility used the SARS experience to impose what she called greatly altered, reduced and awkward split visiting hours.

She said:

The administration has, by their actions, said that we were not needed during the crisis and that we are needed even less now, post-SARS. Of course, if our loved ones could, they would tell them differently. To me it feels like a hijacking. A hijacking of mine and my mother’s rights or as if Big Brother has come along and taken over and only when Big Brother says I can will I see my dear mother.

She said long-term care facilities should distinguish between visitors and hands-on family caregivers when deciding visiting hours.

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822. The Commission is not saying or suggesting that the Hospital for Sick Children did anything wrong. They were following the directives and allowing parents to accompany ill children, as the directives permitted. The point is not that they did anything wrong, but that consideration ought to have been given for the needs of elderly patients.

This woman's criticism of her mother's long-term care facility is understandable. So are the restrictions placed by the home, when seen from an infection control perspective. The key is that these facilities should work with families so that policies blend the need for infection control and the needs of patients and their families. There is need here for discussion and explanation, not simply arbitrary restrictions. Perhaps there is something in the Hospital for Sick Children's approach that could be applied to other facilities.

## Impact on the Elderly

Another woman told of how her family suffered trauma when access to her father was denied at both a hospital and his long-term care home. The 81-year-old father lived in a long-term care facility where visiting was restricted then cancelled because of SARS. She said:

This had a devastating impact on all seniors, both emotionally as well as physically. They might as well have been in prison. Tuck shops were closed. All activities run by the volunteers were suspended.

The father was suffering foot infections related to diabetes and was admitted to hospital. Doctors decided that his legs must be amputated. The day of the scheduled surgery the daughter arrived at the hospital and was denied entrance. The hospital had been closed to visitors because of SARS. She and her sister sat from 6:30 a.m. to 4:00 p.m. in the space between two sets of doors at the hospital main entrance. The father suffered amputations that were more extensive than planned without seeing his family before surgery or after. Both legs were removed at mid-thigh.

He returned to his long-term care home, where he coped but had trouble sitting in a wheelchair without legs as a counterbalance. He developed an infected bedsore. He was admitted to hospital again, this time another one, which was closed because of SARS a few days after he arrived. He was discharged after eight days, but he and his family were put into quarantine because of their connection with the hospital, which had active SARS patients. He had to cope without family help, and when his daughter telephoned a nurse to ask her to look in on him, she was told:

We are trying to go into his room as little as possible as we are afraid of catching something and spreading it to the other residents.



The daughter told the nurse the quarantine was only a precaution and nurses at the home had been issued protective equipment in the form of masks, gowns and gloves.

The father died unexpectedly on June 22. His daughter said that the next time hospitals are shut down by a medical emergency, seniors should be given the same considerations as children:

Seniors are much like children. Any change in routine causes extreme anxiety, stress and confusion. Seniors need to be able to have someone there with them during peak times of 7:30 a.m. and 9:00 p.m. Someone to speak for them when needed, to help understand medical diagnosis and treatment, and to help with medical histories. Someone to help them with the simplest task like raising or lowering their bed, with their meals, their personal hygiene and to reassure them, just to be there with them. These are all the things a family member would have been doing for them. To deny seniors this basic right is simply wrong.

Another case involving the elderly shows how SARS impacted the quality of life of many older citizens who came into contact with it. One gentleman went into hospital for a hip operation, contracted SARS, and infected his wife. Rehabilitation exercises are critical in recovering from hip surgery, but he could not complete his rehabilitation program because of SARS. Now he has difficulty walking.

The family was interviewed by the Commission. His daughter described what happened:

When you have a hip replacement, you've got to be up the next day. Well, he was. I remember the phone call after the hip replacement because he was about four days with therapy. He was so excited that he could walk so much better now, and I remember they were making him do the stairs and he was so happy. And then he got taken with SARS to another hospital and that was it for the therapy. For five weeks he lay in the bed with no therapy.

No therapist would go in with nobody knowing anything about SARS, nobody would even go in the room except the doctor. And even though he was well after one week, they wouldn't take him out of isolation because, well, they would release him to me but I'm untrained. But even if he went home, I tried two different nursing companies, private nurses, nursing companies and the second I said he's going to be in quarantine from SARS, that was it. They said no.

So I said to the hospital, if trained professionals won't come in because they don't know anything about SARS, I certainly am not a medical professional and able to protect myself or my daughter for him to come into my home or my brother's home. You know, they have children. And they said that's our only option. And it was a big fight with administration.

The daughter enlisted her MPP to get her father released to another facility, where he finished his quarantine in a private room. But it was too late for rehab.

The system, unprepared, could not cope with this man's pressing medical need. A system better prepared is required to prevent this kind of medical damage.

## Shifting Policies and Practices

The Commission heard much about the lack of consistency and clarity of rules and restrictions put into place during SARS. A woman told the Commission her family's story of trying to navigate conflicting hospital policies and practices. On March 27, 2003, her father was in such pain from cancer that his wife and son brought him to a hospital in Greater Toronto Area. Only his wife was allowed to accompany him into the emergency department.

The next day, the wife went to visit him but was told by a nurse that visits were not allowed because of SARS. Later, the hospital said they would allow one visitor for one hour per day. Then they said someone would have to telephone ahead and provide the name of the visitor.

Said the daughter:

And so it went. Each day the rules seemed to change with respect to visitors. Not only with respect to the number of visitors but also when it came to washing our hands, having our temperatures taken or completing the sign-in sheet on the door where my father was staying. Sometimes these tasks were monitored and other times they seemed to be forgotten. It also seemed that some staff members seemed to enforce the rules more than others.

Four days after the man's admittance, the family was told that patient visits were suspended. The family called the hospital ombudsman, their MPP and some other

public officials. On April 1, the hospital said it would allow one visitor a day if the name was provided in advance. This policy created a problem when the man's 91-year-old mother wanted to visit. She was blind and hearing impaired and needed someone in the family to escort her through the hospital. The hospital at first allowed this, then changed its mind. The elderly woman had to find her way own way to her dying son's room. Later the man asked to be discharged so he could die at home.

His daughter told the Commission:

I truly believe that the quality of my father's life during his final days was affected by being kept isolated from his family. He needed our support and we were not allowed to be with him.

What difference would it have made if there was more than one visitor at a time? Or if the visitor stayed for more than one hour per day? Would that really put the hospital at greater risk? I don't think the health care administrators thought about the impact of those restrictions on patients in palliative care. Patients who had nothing left to hang on for, except seeing their loved ones.

Once again it is hard to fault the individual hospital and its staff. They were forced to make up visiting policies as they went along. The health system must understand the vital human importance of visits to the sick. Advance planning is needed to create systems and policies to ensure a safe, humane and sensitive health system during infectious outbreaks.

## Hospitals Under Stress

Another woman's story illustrates the tension among hospital staff during SARS and how it reduced quality of care for patients who did not contract SARS. Her story is another example of the tremendous stress under which hospital staff, from doctors and nurses to cleaners and security staff, had to labour.

She told of how her father was in a Toronto-area hospital for hernia surgery in May 2003. The man was 85 years old and did not do well after the surgery, and his stay was extended. At first the family was allowed to visit frequently, then two SARS patients were brought to the hospital and visits were limited to one person at a time for five minutes:

This [admission of SARS patients] seemed to put the fear of death into the staff. Nurses didn't want to discuss the fact that two SARS patients were in their unit.

The father died in that hospital during the second week of June. Visiting was restricted when he died. His son and a granddaughter who had travelled from overseas were not allowed in to see him before he passed away. The daughter said:

For the last 17 days of Dad's life he never felt human contact. For a man who always reached for someone's hand to hold, whether it was his daughter's or one of his 10 grandchildren, all he got was a latex glove. The grandchildren are left with this awful image of not being allowed to be with their precious grandfather for the last week of his life.

The coroner's office ordered an autopsy. The daughter told the Commission that five months after the autopsy they still did not have the results, although they had been told he did not die of SARS:

We still don't have closure. A lifetime of love and caring that ended with neglect and loneliness.

## **Quarantine: Confusion, Controversy and Hardships**

There had been no widespread use of quarantine in Ontario for 50 years, so it is not surprising that quarantine during SARS caused confusion, controversy and stress. By one official estimate, 15,000 to 20,000 Ontarians entered quarantine during the outbreak.<sup>823</sup> But there is some confusion about how many people were under home quarantine, how many under work quarantine, how many were actually contacted by public health and how many quarantined themselves voluntarily without ever speaking to public health authorities.

It is likely that somewhere around 30,000 people observed quarantine during the outbreak in Ontario. Virtually all of those entered quarantine voluntarily. Sixty-five persons were issued Section 22 orders during SARS; one was served with a Section 35 order, and the latter was a matter of some controversy. Section 22 of Ontario's *Health Protection and Promotion Act* allows a medical officer of health to require a person to

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823. SARS Commission Public Hearings, September 29, 2003.

take (or refrain from taking) any action specified in the order regarding a communicable disease. Action under the order can include directing a person to remain at home while a danger to others. Section 35, used for people who refuse to comply, allows the Ontario Court of Justice to issue an order directing compliance, and may also require police to help to enforce it by taking the person into custody and admitting the person involuntarily to hospital.

The glaring inadequacy of Ontario's antiquated *Health Protection and Promotion Act* is described in the Commission's Second Interim Report.<sup>824</sup>

The term "quarantine" is often misconstrued, and sometimes confused with isolation. Both are defences during infectious disease outbreaks. Public health officials must have the power to isolate those who are infected, and to quarantine those who might have been exposed to infection and might be infectious to others. The U.S. Centers for Disease Control and Prevention defines both:

Isolation refers to the separation of persons who have a specific infectious illness from those who are healthy and the restriction of their movement to stop the spread of that illness. Isolation allows for the focused delivery of specialized health care to people who are ill, and it protects healthy people from getting sick. People in isolation may be cared for in their homes, in hospitals, or in designated healthcare facilities.

Quarantine refers to the separation and restriction of movement of persons who, while not yet ill, have been exposed to an infectious agent and therefore may become infectious. Quarantine of exposed persons is a public health strategy, like isolation, that is intended to stop the spread of infectious disease.<sup>825</sup>

Ontario was not the only jurisdiction to use quarantine during the 2003 outbreak period. China, Taiwan, Singapore and Hong Kong were the main areas of Asia affected by SARS and they also responded with quarantine. However, the approaches to quarantine in Asia and Ontario were quite different. Some Asian jurisdictions set up police checkpoints, cordoned off entire villages, and even threatened to execute anyone who broke quarantine.<sup>826</sup> In Ontario, public authorities used voluntary quar-

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824. For more analysis of the legislation and the problems that arose during SARS, see the SARS Commission, second interim report.

825. CDC *Isolation and Quarantine (SARS)*, [www.cdc.gov/ncidod/sars/isolationquarantine.htm](http://www.cdc.gov/ncidod/sars/isolationquarantine.htm).

826. Article by Brian Friel, National Journal Group Inc, October 21, 2005.

antine and in some cases provided food and supplies needed during isolation.

Ontario's quarantine involved staying at home for 10 days, after which the risk of having been infected was considered over. Quarantined individuals slept separately from other people in the home, wore masks when near others and were not to share personal items.

Toronto used work quarantine for health workers exposed to SARS but who remained healthy. These health workers continued at their jobs but stayed in home quarantine after working hours. They were expected to travel to work in isolation (i.e., not using public transit) and were asked to closely monitor themselves for signs and symptoms of SARS, including twice daily temperature checks. The idea of work quarantine was to ensure that there were enough health care workers available. If every health worker exposed to SARS had to remain in home quarantine, there would have been a tremendous, and perhaps impossible, strain on health facilities because of worker shortages.

Quarantine was discussed in the Commission's interim reports. The purpose of raising it here is to illustrate how quarantine disrupted the working and home lives of thousands of Ontarians who suffered considerable emotional and psychological strain because of SARS.

Public hearings and private interviews produced many individual stories of the hardships and stress caused by quarantine. People told the Commission of the stress of being isolated from family and friends, plus the anxiety they developed from fear that they might have SARS and pass it on to their children or other family members.

The Ontario Nurses' Association presented this collage of quotations from nurses who were quarantined because of possible contact with SARS at work:

Quarantine was very difficult. Not being near my family, not being able to touch them.

I was sleepless, stressed, feeling despair every time I went to work. I felt depressed, angry at how it was mishandled, especially isolated, suffered from insomnia and had a tremendous fear of bringing a deadly disease home to my children. The babysitter refused to babysit my child. Friends, family and parents of my child's classmates did not want their kids to play or contact my family.

I had several vivid nightmares during outbreaks that my children were ill with SARS. One night I woke and ran to the bed of my youngest who was clutching her forehead, convinced she was burning with a high fever. My youngest child was teased and isolated by her peers because her mother was a nurse at a SARS hospital.

My husband and children moved out for 12 days. Grandparents changed schedules to care for the children. There was stigma from friends outside of work. I suffered nightmares.

I was very much isolated from loved ones. My family thought I was going to die.

Just last week a number of ONA members who developed SARS after caring for SARS patients told me they continue to suffer severe emotional and physical repercussions of a disease that we still don't know that much about.<sup>827</sup>

Roughly 7,000 persons were sent into home or work quarantine because they had a connection to North York General Hospital, the epicentre of the SARS II outbreak. Some 4,000 were hospital staff. Bonnie Adamson, president and CEO of the hospital, told the public hearings of the tremendous hardships caused by quarantine:

For many of them the situation made them feel like pariahs in their own community. We heard reports of neighbours crossing the street to avoid houses where our staff lived and even an eviction notice to one of our staff members by nervous roommates ... Many were unable to attend important family milestones: weddings, graduations and even the funeral of parents, and these are events that could never, ever come back.<sup>828</sup>

Many of the stories of hardships during quarantine are anecdotal. However, hard evidence of the effects is found in a study by researchers in Toronto and New York. It found that of 129 quarantined persons studied, 28.9 per cent showed symptoms of

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827. SARS Commission Public Hearings, September 29, 2003.

828. SARS Commission Public Hearings, September 30, 2003.

post-traumatic stress disorder (PTSD). Symptoms of depression were observed in 31.2 per cent.<sup>829</sup>

All respondents described a sense of isolation. The mandated lack of social and, especially, the lack of any physical contact with family members were identified as particularly difficult. Confinement within the home or between work and home, not being able to see friends, not being able to shop for basic necessities of everyday life, and not being able to purchase thermometers and prescribed medications enhanced their feeling of distance from the outside world. Infection control measures imposed not only the physical discomfort of having to wear a mask but also significantly contributed to the sense of isolation.

This study said that just making temperature checks caused anxiety in some people. It quoted two people as illustrations:

Taking temperatures was mentally difficult, said one.

Said another:

Taking my temperature made my heart feel like it was going to pound out of my chest each time.

Following quarantine, 51 per cent of respondents had experiences that made them feel that people were reacting differently to them: avoiding them, 29 per cent; not calling them, 8 per cent; not inviting them to events, 8 per cent; and not inviting their families to events, 8 per cent.<sup>830</sup>

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829. Laura Hawryluk et al., "SARS Control and Psychological Effects of Quarantine", *Emerging Infectious Diseases*, Vol. 10, No. 7, July 2004 (Hawryluk et al., "SARS Control and Psychological Effects of Quarantine")

830. Hawryluk et al, "SARS Control and Psychological Effects of Quarantine".



### *Individual Stories*

One of the most serious effects of quarantine was that it kept people apart when they needed to be near family and friends. In so many cases, a family member was ill, or dying of SARS, and those close to him or her were unable to provide normal care and comfort to the patient or each other.

Said one man who lost both parents to SARS:

Nobody could see each other. Finally I was able to get permission to go visit Mom because she was dying but I couldn't go next door to visit my sister or two doors down to visit the girls [his nieces].

When a death did occur, some people were not able to pay their last respects or attend funeral services because they were under quarantine. More is said about this under the section on funerals.

Quarantine affected many people who had no risk of exposure to SARS until they had to visit a medical facility for treatment of an existing condition, or for examination and tests. A kidney dialysis patient told of how he had to take treatment three times a week at a hospital. He complained about confusion over SARS quarantine. After one treatment, public health authorities called him and said he must be in quarantine, which included wearing a mask at home and not sleeping with his wife. Other dialysis patients told him they were not quarantined. However, every time he went for dialysis he was placed under a new ten-day quarantine. He complained to public health that he could be in quarantine for the rest of his life and maintained that only people sick with SARS should have been quarantined.

Shunning of people possibly exposed to SARS in some cases continued after a person ended the quarantine period and was symptom free. One woman told of how her adult son gave up a business connection, partly because the people with whom he worked found out he had been in quarantine:

... when this happened [quarantine] he had to stay home and he chose not to tell the other people in the office why he was home because people were very skeptical about being around people and whatever. When his time was finished with the isolation [quarantine] he did tell them why he had been off and things didn't go very well. They almost threw him out and said how could you do that when there was other people at risk who

had families that he worked with and it just got worse and worse ... I'm not saying that this was a whole result of this but this was kind of the icing on the cake ... they were very irate.

One woman whose family suffered three SARS deaths told of the effects on her children. Their father was in hospital desperately ill with SARS and they were quarantined at home:

My daughter missed her play, the school play that they've been working on all year, and I couldn't get the school to put it off for a week. She missed it. My kids were just so isolated and the school wasn't doing anything, and they were sending homework home. That's what they were doing, they were sending homework and leaving it on the porch.

To help ease the strain and break the boredom, the mother called friends and asked them to bring children over to hold signs, sing and perform skits while the quarantined kids watched from inside:

And they did and it made such a difference. I was so angry that my children's mental health was left to me. Like, where are all, where's public health, where are the schools, where's the school boards, you've got mental health issues going on here in quarantined homes, and nothing, nothing in the system.

The problems did not end when quarantine did. A daughter was not allowed to return to her high school after quarantine. She missed her Grade 11 final exams and was penalized 30 per cent of her marks for not being able to take the exams. Her mother said:

That's what my daughter's dealing with now. So, in Grade 12, she has to maintain an average over and above, aside from the fact that they didn't make up the materials she missed, they kept her out of school for a fair bit of that last term.

The schools didn't know how to respond or react, they had parents panicking ... The absurdity became that my kids, although not in quarantine, weren't in school, they were at the mall, because they weren't quarantined anymore ...

Another woman had to get public health to help her fight a principal who banned her daughter from school. No one in the family was ill or quarantined but the principal had heard that the woman's mother worked at an infected hospital. She said:

I knew the principal quite well at the school and he tried to ban my child going to school and then again I had to phone public health and she ... phoned over to the school and also faxed a letter to him that he could not do that.

Some schools were closed and students and staff ordered into home quarantine when officials feared students had been exposed to SARS. Quarantine affected 1,700 students at one school in the Greater Toronto Area.

One student told the media he was upset because he missed his girlfriend's prom night because he was in quarantine:

It's so hard for me right now, because I'm 19 years old, and whenever I'm not in school, I'm out. So for me to be stuck in my house is the hardest thing.

Mixed in with all the stories of hardships caused by quarantine were some stories of human kindness. Like the friends who gathered outside the home of the quarantined kids to perform skits, and the people who assembled outside a hospital to cheer on the work-quarantined staff.

Toronto Emergency Medical Services told this story to the public hearings:

We got a phone call from someone who said "my nine-year-old son's birthday is Friday. My whole family is in quarantine. Can someone please go buy a birthday present for my son?" And we took care of that ...<sup>831</sup>

This last story is so typical of those health workers who went the extra mile to help the sick. The story of SARS quarantine, with all its problems, is the story of magnificent work by health workers and magnificent voluntary support from the public. As noted in the Commission's interim reports, systems are required to support and encourage this magnificent cooperation by health workers and the public.

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831. SARS Commission Public Hearings, September 29, 2003.

## No Chance to Provide Support

One woman told of the difficulties of not being with her companion when he went for cancer treatments. On April 8, 2003, she took him to a cancer clinic. She was not allowed to enter the hospital and sat between the double doors at the entrance while he sat in the waiting room for three hours. Another time he had a doctor's appointment and the results were expected to be grim, but she was not allowed in to give him support. In May he was very sick and she took him to hospital, where she was told she would have to wait in the car. She went home and eight hours later the hospital called and told her to come and pick up her companion. The man succumbed to his cancer not long after.

## Critical Treatment Delays

One doctor told the Commission of a study her hospital did of cancer patients requiring treatment during SARS. The study showed that when SARS screening measures were first introduced, there was confusion because "we didn't know what we were doing":

We were dealing with sobbing patients, husbands threatening to bomb us because we wouldn't allow them in with their wives [newly diagnosed with cancer].

The doctor said directives relating to SARS were so frequent that information didn't get passed along in a timely fashion to staff and patients. One man was told he could bring his wife when he came for his treatment. When they got there she was turned away and had to wait in the car. Another man diagnosed with cancer was scheduled for treatment as SARS began. The treatment was delayed three months and of course he was distressed because the delay could give the cancer more time to spread.

SARS made hospital visits especially difficult for new patients. They were already traumatized by recent cancer diagnosis and were confused and even frightened by hospital systems and routine.

Said one patient:

For me my experience is so scary because the first day you come to hospital you know the diagnosis was cancer and there was no visitor with me.

That is something missing, the support. When I step into the hospital and I just get crying.

Said another whose husband had a brain tumour:

There is no reason a spouse can't be with them. He was unable to go anywhere without me. I could not leave him at all so why can't I come? There's no difference in SARS exposure information for either of us.

Her point is understandable considering that some brain injury patients are unable to record properly what doctors are telling them. Some are unable to take notes, like many patients do. Even patients without any brain impairment have difficulty absorbing and accurately recording what health care professionals tell them about diagnosis and treatment.

What is required is a system that plans ahead to minimize as much as possible the collateral impact of infectious outbreaks on necessary medical treatments.

## Common Threads

A common thread in all these stories is the lack of someone to turn to for appeal. Most of these hidden victims could have found comfort in being able to approach one person at a hospital or other care facility who could have provided facts and explanations, and even overturned any access decisions that might have been made in the heat of battle. SARS was confusing and health workers under extreme stress made judgment calls that they thought best. In the absence of preparedness and consistent policies, they were often forced to make it up as they went along. For the hidden victims there was no one to turn to for explanation or discussion of those judgment calls. No person should have had to turn to the daily newspaper to gain access to a dying relative, as did the woman in the first story related above.

These stories also show what was seen in other aspects of the SARS outbreak: not being prepared. The health system needed simple policies and practices to meet the needs of not only victims, but family and friends and other innocent bystanders. Bad things always happen in times of crisis. That is part of life. However, policies thought out in advance, strengthened through staff training and applied consistently, would have prevented at least some of the grief suffered by these hidden victims.

## Impact on the Chinese and Southeast Asian Communities

No ethnic group was more affected by the SARS outbreak than Toronto's 400,000-strong Canadian Chinese and Southeast Asian community. It was widely reported that the outbreak originated in Asia. The stigma was immediate, especially in those parts of the Greater Toronto Area where Chinese and other Asian restaurants and businesses are concentrated.

Citizens and tourists avoided people of Chinese background for fear that they carried the new disease. They avoided them on the streets, at work and at their places of business. Normally jammed with customers, these areas were deserted. Not only did tourists and restaurant customers stay away, but the Chinese Canadian residents stayed home as well.

The Chinese-Canadian National Council (CCNC) estimated the loss of income to businesses in the "Chinatown" areas at 40 per cent to 80 per cent, depending on the type and location of the business. The loss was substantially worse than that suffered generally by businesses across Toronto.

Politicians and public officials took notice of Chinatown's plight. Prime Minister Jean Chrétien and Ontario's Lieutenant Governor James K. Bartleman made photo-op dining visits to Chinese restaurants. Some Chinese Canadians said these gestures did not make a big difference, but others applauded the intervention.

The impact of SARS on individual Chinese and Southeast Asians Canadians went beyond business loss. Many service workers, including live-in caregivers and restaurant waiters, lost their jobs.

Members of the Chinese and Southeast Asian communities felt they were stigmatized unfairly, and were wrongly blamed for the emergence of SARS. They felt racism was at play. The Chinese-Canadian National Council's report blames the media, which always raises the spectre of the "shoot the messenger" exercise. But the problem was widely recognized and as noted earlier, public health stressed to the public that it was not easy to contract SARS and that race had nothing to do with getting it.<sup>832</sup>

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832. SARS news conference, April 5, 2003.

Chinese Canadians noted that people moved away from them on subway trains and their children were sometimes shunned at school.

Hospitality workers felt the effects most directly. When customers avoided Chinese restaurants, waiters were sent home. Live-in caregivers caring for children and the elderly were especially vulnerable. About 70 to 80 per cent of them come from the Philippines under a government program. SARS had a great impact on their lives since, unlike health professionals, they have few guaranteed rights and little job protection.

Coco Diaz of Intercede, an organization for the live-ins, told the CCNC researchers:

There were many cases of unfair termination of employment during SARS. They were dismissed as if they were already carriers of the disease. Employers were most concerned with the elderly or children in the family and yet showed little concern for their employees.

She told of a live-in who contracted SARS by taking the elderly person in her care to the hospital. The live-in spent three months in a coma and had to undergo many months of rehabilitation.

Ms. Diaz reported that unfair dismissals intensified in April 2003 when the media reported the links of several new SARS cases to members of a Filipino Catholic group:

Immediately, some employers started to think that just because the workers are Filipino, then no, they cannot come and work.

Some who employed live-ins worried that their employees would get exposed to SARS during their days off and bring it back to the household. In some cases, live-in employees were quarantined for 10 days after returning from their days off, then were dismissed anyway when the quarantine ended.

To a live-in caregiver, the loss of a job also means the loss of a home, since they usually live with their employers. To lose a job is to jeopardize immigration status.

The Metro Toronto Chinese and Southeast Asian Legal Clinic told the Commission's public hearings that, ironically, Chinese and Filipino Canadians were the ones who fought on the front line as nurses, doctors, and other health care workers. Nursing is one of the few professions where Asians, particularly people of Chinese and Filipino descent, are well represented, the clinic said:

So while Asian Canadians on the street were being targeted, Asian Canadian health care workers were risking their lives for the people who were inflicted, inflicted with the disease. It is not a coincidence that the two nurses and the doctor who died from SARS, were persons of either Chinese or Filipino descent.<sup>833</sup>

The clinic noted that anti-Chinese sentiment has always been present in Canada, notably when Chinese labourers were brought to Canada to build the early railways. When the SARS outbreak occurred and was reported to have originated from Asia, racism based on fear of Chinese carrying the disease emerged again:

Images of Chinese Canadians wearing masks began to appear in mainstream media reports and this new fear the Chinese Canadian Community, while never spoken was certainly felt by members of the Canadian public ... It was also around that time that our clinic began to receive calls from individuals who became the casualty of SARS, although not in the medical sense.

While some workers lost their jobs in restaurants and other workplaces from the economic impact of SARS, others reported discrimination based on the idea that SARS was a Chinese or Asian illness:

We received a number of complaints from tenants who got kicked out by their landlord because they were Chinese. Some of them were new immigrants or recent immigrants from China but one of these tenants who called us was, in fact, a Canadian-born Chinese who had never set foot in China or in Hong Kong and who actually lived in Guelph outside of the epidemic centre of SARS. She was told by her landlord to move out ...

The clinic also heard from many workers of Chinese descent who were terminated or told to say home because of perceived fear from their non-Chinese colleagues:

There was a nursing home which served primarily Chinese Canadian seniors where some nurses refused to work because of a totally unfounded rumour that the nursing home residents had contacted SARS.

Hundreds of workers were left out in the cold. Especially hard hit were “undocumented workers,” workers in Canada illegally.

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833. SARS Commission Public Hearings, November 18, 2003.



While they were out of a job, they had no access to unemployment insurance or other governmental benefits. They also could not or would not complain to the authority when their rights were being violated.

The clinic filed a formal complaint against the Immigration and Refugee Board, where staff started wearing masks at hearings for Chinese or other Asian claimants. These claimants had been in Canada for at least a year, since that is how long it takes for a claim to heard, and were not recent arrivals. The practice was dropped after the protest.

Such experiences left many Chinese and Southeast Asians stigmatized and humiliated. This simply should not happen. Communication and education are the keys to avoiding such stigmatization. Intelligent people who have been communicated the real facts know better than to participate in such shameful shunning. Time and again the Commission has seen that preparation in communicating clearly and effectively could have avoided many of the problems that arose during SARS.<sup>834</sup>

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834. SARS Commission Public Hearings, November 18, 2003.

## Funerals and the Suffering of the Families

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The case histories of families who lost members to SARS are horror stories. Losing someone is bad enough, but with SARS there was fear of contagion throughout the entire family. There was the shocking reality of loss and the prospect of more losses. The bereaved were faced with trying to make funeral arrangements while they worried how deeply the virus had penetrated their family. Who would come down with the illness next?

Here is the recollection of one person who buried a family member who died of SARS:

They opened the casket just for the immediate family. We had to wear masks and gloves. Nobody came to the funeral home or the funeral; a lot of people were scared.

Another story illustrates the extreme ugliness of the SARS outbreak.

A man in his 70s experienced heart irregularities in early March and went to hospital. It was his wife's birthday. He was released the next day and when he got home he began having flu-like symptoms. He became sicker and his family doctor diagnosed double pneumonia. Eight days after first being released from hospital he was returned by ambulance.

While he was in hospital on a respirator, his wife was not feeling well. She was taken to the emergency department but nothing serious was diagnosed. The man died two weeks after his first visit to the hospital. The day after his death, the widow was admitted to hospital. Soon after, a daughter was admitted with flu-like symptoms. The family originally had been told the father had atypical pneumonia, some type of mysterious illness. The son told the Commission:

For the first two weeks we weren't allowed to see my mother ... The hospitals were all closed down.

Everybody was in quarantine. I had my sister's youngest, she's 14 years old, and was staying alone in my parents' house because her mom was in the hospital.

The family learned their father died of SARS when they went to the funeral home to make arrangements. While they were discussing the arrangements at the funeral home, Toronto Public Health called. After the call, the funeral director gave the family the news that SARS had killed their father. Toronto Public Health also had advised the funeral home personnel that the family should leave the building and enter into quarantine.

The funeral home held the body for 48 hours, then took the body to the cemetery for a graveside service. Public Health had told the family there could be no public funeral service. Only a half a dozen people attended the burial of a man who had hundreds of friends. More than 500 people attended a memorial service a couple of months later.

Various family members who either had the virus or were thought to have it recovered, except for the mother. She died three weeks after the father. She also had a graveside funeral, which meant bypassing many of her Jewish faith rituals, including sitting shiva and tahara, traditional washing of the body. The bodies of both the father and the mother were left sealed in plastic bags in their coffins. The son said:

... it was a real horror story. One of our Jewish rituals is sitting shiva, which is like a mourning period. We weren't able to do that for my dad. We barely had enough pallbearers at the funeral to bury him. We had to drive ourselves to the cemetery.

The son also recalled the desperation of trying to find out what was happening to his family:

My two nieces, this was my older sister who was in hospital with SARS, her two older daughters were taken to [the hospital] and when they took them in there it was almost impossible for me to keep track of what was going on. I've lost both my parents and you've got my sisters and my nieces here ... I need to know what's going on ...

Another nightmare involved a widow whose husband was shipped out for autopsy and cremation without her involvement. She had visited him in hospital one night but then she had to go into quarantine for 10 days. When she finished quarantine the

hospital was closed to visitors. Her husband died and was cremated without her knowledge, and she never got to say goodbye.

## Importance of Funerals

The end of a life, although shocking, also is the start of a grieving and healing process in which the living begin to accept their loss and the need to carry on. With SARS, however, this process was often short-circuited, and in some cases completely blocked. Relatives and friends were denied normal bereavement and spiritual comfort because of fears about the spread of the disease. Some of these fears were based on misinformation or simple lack of information because our public health systems were overwhelmed. They had no prepared plan to deal with funerals and burials, and were unable to respond quickly and decisively.

Funeral homes, where comfort and healing is supposed to begin, found themselves disconnected from the public health and health care systems. More will be said later about the organization of the funeral industry and its role in public emergencies. The industry struggled with the effects of quarantines, contradictory information from government and the additional anguish of families unable to achieve proper closure. Quarantined families found it difficult to make funeral arrangements from home. Funerals were delayed, sometimes cancelled, and burials were conducted without mourners.

As one senior public health official told the Commission:

There were so many tragedies in this outbreak.

One heartbreaking image from the SARS outbreak was a burial scene in which a lone limousine delivered a victim's coffin to an open grave attended by two cemetery workers in "space suits," the term a funeral director used for the protective gear worn by the grave handlers. Another is the scene of family members standing afar in another section of the cemetery as a coffin is lowered into its grave. One cemetery manager told a funeral director the family would not be permitted to attend the burial because they had had contact with the deceased during his illness, but the director ignored this.

Throughout history, pandemics and epidemics have set up conflicts between dealing with the dead and protecting the living from the spread of disease. The need to restrict public gatherings often clashes with the human desire to pay final respects to

the dead. In the 1664–1665 Great Plague of London, city officials tried to stop public funerals, but people refused to obey and flocked to graveside services by the dozens.

Widespread deadly outbreaks also strain society's services for handling the dead. During the Spanish flu pandemic of 1918, which killed 50,000 Canadians, one Toronto undertaker reported stacking 23 bodies in his garage because there was no room inside the funeral home and help was difficult to get because of fear of the disease.<sup>835</sup>

In a health emergency such as SARS, funeral rites obviously must carry lower priority than the need to contain the virulent public health threat. However, there is evidence that more planning and much better communication could ensure that fighting a pandemic and burying the dead with dignity can be carried out without one seriously compromising the other. Fixing some underlying problems of where the funeral industry fits in the health care and public health systems and how it is regulated also would help funeral directors better carry out their important role. More will be said about that later.

SARS deaths confirmed the importance of the funeral process in our society. A death brings out high emotions. The rituals and ceremonies of funerals help people support each other and try to deal with those emotions. Visitations and body viewing bring reality and some comfort to mourners.<sup>836</sup>

The Ontario Funeral Service Association reinforced for the Commission this view of the importance of funerals and, for those who choose it, the viewing of the body:

It has been proven time and time again by psychologists and grief counsellors that having an opportunity to see the deceased is a big part of the grieving process. The embalming and the visiting play such a huge part in the process though it might be a small issue. In the SARS situation many

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835. "More Deadly Than War Itself", *Legion Magazine*, January/February 2001.

836. The powerful need for a funeral process is dramatically illustrated by a bizarre Ontario historical event, the death of landscape painter Tom Thomson. Thomson drowned mysteriously in Algonquin Park in 1917. His body was found after nine days in the water and because it was decomposing, his friends buried him immediately. When the Thomson family in Owen Sound was informed, they ordered the body exhumed and shipped home for another funeral and burial. This caused much controversy and added to the mystery surrounding the death. However, the fact was that the Thomson family felt it could not accept the death and grieve properly without witnessing a funeral and burial themselves.

families were not allowed in the hospital. The concept of seeing the body for many people shows them that the person is dead.

In SARS some victims entered hospital and were never seen again. Religious rites were bypassed in some cases. Those left behind had no opportunity to confront the reality of death and to honour the life of the deceased. Last wishes could not be fulfilled. The relative of one victim said:

I am very upset over the way the burials were handled ... they seemed to have made it so hard for us to pay our respects.

Said the widow whose husband's SARS-infected body was shipped out for autopsy then cremated without her knowing it:

I went through Hell. If they told me the truth and said he had to be cremated because of the sickness I would say okay, but they never asked me ... they never told me. Nobody asked me nothing.

## Body Transfers

Complications for burying those who died of SARS began with transfers, the process of picking up a body at hospital, taking it to another hospital for autopsy and eventually on to a funeral home. Funeral home staff encountered significant challenges in trying to complete transfers, mainly because hospitals had no standard procedures for removing the bodies of SARS victims. Rules and practices for body transfers during SARS varied from hospital to hospital.

Uncertainties created by lack of preparedness and misinformation, or lack of information, appeared to cause much of the confusion over body transfers. Early on it was not known how SARS was spread or even how long the virus might live after death. Some hospitals therefore became cautious of funeral home transfer people arriving for normal body pickups but who might have picked up SARS bodies from other hospitals.

The uncertainties about whether SARS might be spread by funeral home workers led hospitals to institute some procedures for body pickups, including donning of protective gear. However, because there was no overall prepared plan supported by policies, protocols and memoranda of agreement, the policies and practices varied from hospi-

tal to hospital. There was no consistency, and this made work difficult for the funeral industry.

These inconsistencies included the following:

- Some hospitals screened funeral workers at the front doors before allowing them in. At least one hospital required them to go to the emergency department for screening. However, others refused them entry, and hospital staff delivered paperwork and in some cases bodies for transfer to funeral home staff waiting outside.
- Some hospitals questioned funeral home employees about what other hospitals they had visited. If they had done SARS pickups at other hospitals, they were turned away.
- One hospital required funeral workers to wear protective gear when entering offices where body transfer documentation was to be picked up. For others, screening was enough. For still others, staff delivered paperwork to funeral home workers waiting outside.
- Funeral home workers found procedures used at a hospital on earlier pickups suddenly changed. Procedures for entering the hospital one week were different another week.
- Practices varied, even inside the same hospital. For instance, one funeral worker noted that medical staff wore protective gear but security staff didn't.
- When SARS appeared to be waning, one funeral operation continued to dress its workers in protective gear as a precaution. At least one hospital asked them to remove it.
- Post-SARS, some hospitals still required funeral home personnel to wear masks, while many did not.

One funeral home executive told the Commission:

They were tripping over themselves ... Hospitals started to say that if our personnel were in a SARS hospital to pick up a body then they wouldn't be allowed in other hospitals to pick up bodies.

It took a bit of time but they realized that we would run out of players to come to the hospitals.

In one case a hospital refused a funeral home employee access to pick up a body because the media had reported that someone in contact with SARS had attended a visitation at the funeral home.

Before SARS, the typical pickup procedure involved funeral home staff arriving at the hospital, presenting a permission slip, completing paperwork, obtaining the death certificate and meeting security to collect the body. When SARS arrived, procedures became confused because there were no effective planning or preparation, no standard systems, and no universal precautions for picking up a SARS body. As already mentioned, procedures varied from hospital to hospital and sometimes changed, leaving funeral home workers confused about exactly what they should do. Most hospitals required funeral staff to wear protective gear such as masks, gloves and coats. In one case, paperwork exchanges were done in a tent outside the hospital.

One funeral support service involved in body transfers told the Commission:

The rules changed at nearly every hospital, they were never the same and just when you thought you had the routine down, they changed the rules... . Different hospitals did different things.

Lack of communication helped to create confusing situations. For instance, workers from a funeral home transferred two bodies from one hospital in one day. The next day they heard through the media that the hospital had been closed because of SARS and anyone who had attended the hospital must go into quarantine. The funeral home operators decided to cancel the funerals and to store the bodies until after the quarantine period. They were upset that they had not been told of the closure and quarantine by the hospital or by anyone in authority.

The Toronto and District Funeral Directors Inc., an association of 60 Toronto-area funeral homes, advised its members in a faxed memo that:

Funeral homes will be made aware of SARS deaths from the Medical Officer of Health, prior to family contact.

Although every effort was made to make this happen, some cases inevitably fell through the fingers of a system that was unprepared and overwhelmed.



## Embalming

Once a SARS body was at the funeral home there were other complications. Embalming, because it involved handling SARS-infected fluids, presented possible risks of spreading the disease. Also, the bodies of people suspected of dying of SARS likely would be partially autopsied. The dangers of working with SARS-infected bodies were confirmed later by a study of SARS autopsies that showed the coronavirus continued to live in the dead. Autopsies of 19 patients who succumbed to SARS in Toronto showed the virus was present in the lungs of all of them.<sup>837</sup> It also was found in high percentages of bowel tissues examined.

Opening the body created exposure to airborne pathogens and required what the medical community calls taking universal precautions. In general terms, universal precautions involves using protective gear, including gowns, masks, gloves and shoe covers, to shield workers against spraying blood and gases during embalming. Surgical-type masks normally used by funeral homes were replaced by N95 respirators during the SARS outbreak. However, the Commission's investigations found only one funeral home that actually fit tested the N95 respirator before use.

Advice from public health on embalming was not always clear. One funeral director spoke with a local coroner's office, which advised him that it was okay to embalm as long as universal precautions were used. A letter from Toronto Public Health advised that embalming should be done using full respiratory precautions, including gloves, gowns, masks and goggles. However, the letter added:

Although we have no evidence of risk to staff who are using these precautions, it may be prudent to avoid embalming the body if possible.<sup>838</sup>

Some people in the funeral industry found this advice too vague to be helpful. They thought there should be specifics, especially considering that some other countries prohibited the embalming of SARS victims.

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837. Mazzulli T, Farcas GA, Poutanen SM, Willey BM, Low DE, Butany J, et al. Severe acute respiratory syndrome-associated coronavirus in lung tissue. *Emerg Infect Dis* [serial online], January 2004.

838. April 2, 2003 letter to Toronto and Area Funeral Directors Inc.

## Screening Measures

The risks for funeral home operators and staff did not come only from handling bodies. There also were the risks of contracting the disease from family and friends who had contact with the victim while alive. This latter risk also applied to funeral home visitors.

In one highly publicized case, a doctor who had been working with SARS patients showed up at a funeral home for a visitation and later for the actual funeral. After the funeral he felt unwell, found he had an elevated temperature and admitted himself to hospital, where he was isolated. Controversy erupted when the acting York Region Medical Officer of Health denounced the doctor in scathing terms for attending the funeral despite the doctor's evidence that he was not symptomatic until after the funeral. That controversy is addressed earlier in this report, but the upshot was that 150 people who might have had contact with the doctor were quarantined.

This kind of incident led to funeral screening measures. These measures included questions about possible contact with SARS, posting notices and establishing hand-washing stations. But screening of any sort is never completely effective. The experience of one funeral home illustrates this. One family went to a funeral home and passed the SARS screening tests. A visitation was held in the evening. The next day the family called the funeral home and said they had learned from public health that their relative had died of SARS and that the family was possibly exposed along with anyone at the visitation.

The home had to provide a list of names of everyone who attended the visitation so they could be quarantined. Four funeral home staff were quarantined.

As recounted earlier, one family learned of their father's death from SARS while at the funeral home making arrangements for his service, when public health called and told the operators to get the family out of the building because he had died of SARS:

We were making the arrangements for them and the phone rang. It was the Board of Health. They were saying that it was SARS and to get the family out of the building. They said that the family should be in quarantine and not together.

However, the Coroner's Office understood it was not a SARS death. It took two to three hours to confirm that the death was indeed from SARS. The managing director of the home told of the chaos resulting from the situation:

We had conflicting information from public health and the coroner.  
There were so many phone calls that day. It was the day from Hell.

Three staff had to be quarantined, leaving only two funeral directors to handle the business.

In some cases when funeral directors and families met to make arrangements, everyone wore gloves and masks. In others, arrangements were made over the telephone. In still others, there were no usual arrangements, as bodies were taken directly to a crematorium or cemetery for burial.

## Quarantines

Quarantines disrupted funeral home operations significantly. Staff quarantines required split shifting to prevent overlapping staff from infecting each other, borrowing staff from affiliated homes and in at least one case shutting down operations for a short period.

The same rules did not appear to apply to everyone. The funeral home that made the two normal pickups from a hospital then learned that the hospital was shut down cancelled the two funerals, which did not sit well with one of the families. A competing funeral home was in a similar situation but did not follow quarantine and went ahead with funerals. The family wanted to know why the rules were not applied uniformly.

Other awkward situations were created when funeral homes had to explain surcharges for infectious disease body handling. One family complained to the Board of Funeral Services about extra charges, but the Board held that the charges were proper. Handling the bodies of those who have died of an infectious disease does involve additional costs. Funeral employees must have personal protective equipment (PPE), more time must be spent disinfecting, and bodies sometimes need to be put in special bags. There also is the extra expense of staff time lost to quarantine and the costs for screening measures.

Funeral homes received no government compensation or relief for SARS expenses but the health care industry did. One operator said that quarantine of staff had cost \$14,000.

Funeral directors had the choice of passing on these costs to customers or absorbing

them. One funeral director said he made a deliberate decision not to absorb surcharges to demonstrate that special precautions were being taken. This he hoped would boost public confidence that his operation was doing what it could to prevent any spread of SARS. However, passing along costs risked creating an image of funeral operations profiting from disaster.

Public confidence certainly was an issue, as evidenced by the experience of a funeral home caught in the media spotlight early in the SARS outbreak. Some funeral home staff and people who attended a visitation were quarantined and the case was much reported by the media. A manager at the funeral home told of how the media exposure affected business:

Everyone knows the quarantine period was 10 days. So Canada Post informed us they would not deliver mail for two weeks. Our suppliers were concerned whether or not they should be sending their delivery people out. That's the reaction that we got.

The 2003 SARS outbreak was the first time Ontario had used quarantine in 50 years.<sup>839</sup> A post-SARS study concluded that quarantine can cause considerable psychological distress and depression and that support should be available for persons at risk for adverse psychological and social consequences of quarantine.<sup>840</sup>

Said one man whose family was quarantined after attending the funeral home without knowing his father had died of SARS:

Then the whole thing ... dealing with the whole fear that everybody had.  
We had friends that treated us like we were lepers.

In the end, most funeral homes and their clients simply coped as best they could. They watched television news, surfed the Web and talked to coroners and anyone else who could provide information. Experience gained in handling AIDS deaths was helpful. One of their most important jobs was to maintain public confidence that funeral homes were safe when precautions were being properly followed. As with other parts of the SARS story, impressive individual efforts were what got them through problems that were systemic.

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839. SARS Commission Public Hearings, September 30, 2003.

840. Centers for Disease Control and Prevention, *Ahead of Print*, Vol. 10, No. 7, July 2000.

## Associations

Funeral homes should be networked reasonably well through regulatory agencies and their own associations. All Ontario funeral establishments are regulated by the Board of Funeral Services, which is governed by the Ministry of Consumer and Business Services. There also are a variety of provincial and regional funeral associations that individual homes can choose to join. None of these connections, however, provided a lot of detailed and clear instructions for operating during the SARS outbreak.

The industry had mixed views on the effectiveness of the Board of Funeral Services (BFS) in its response to the crisis.

The Board of Funeral Services told the Commission that it first learned about SARS through the media. During March, April and May of 2003 it sent four communiqués to funeral establishments. Most of this information concerned universal precautions. The Board said it did not receive any communications from the provincial government, Toronto Public Health or any other health department.

Toronto Public Health provided some direction helpful to funeral establishments, but distributed it through Toronto and District Funeral Directors Inc. Membership in this association is voluntary and therefore only those who belong to the organization received the information.

Leadership seemed to be an issue throughout SARS, with more than one funeral home director saying that there was not enough leadership from the provincial government, public health or the funeral industry professional organizations.

## The Funeral Issues

The SARS outbreak of 2003 killed 44 persons in Ontario. What if it had been a pandemic like the Spanish flu of 1918-19, which killed 20 to 50 million people worldwide, 50,000 in Canada? The 44 SARS fatalities produced enough disturbing stories about after-death care that one has to wonder about the extent of social disruption we would see with thousands of deaths.

Several critical after-death issues have been raised by the SARS experience. They are preparedness, leadership, communication and the role of the funeral industry in epidemics. By studying them, perhaps we can avoid some of the problems encoun-

tered in SARS and be better equipped to deal with the next serious public health threat.

As noted in the Commission's first interim report and other sections of this report, lack of preparedness seriously hampered the fight to contain SARS. Ontario was unprepared to deal with a major infectious outbreak. That failing spread beyond the primary health care system to become an issue in post-mortem arrangements. Better preparation would have helped the funeral industry to do its job without so much unnecessary distress to families who lost relatives to SARS. Better preparation could have helped to alleviate some of the hardship and additional grief suffered by the families and friends of the 44 killed by SARS.

When all is said and done, everyone got through the crisis. SARS was contained. Those who died of SARS were looked after. After-death precautions were taken to avoid spreading the virus. However, it wasn't easy and it wasn't pleasant and it was clearly more difficult than it should have been and produced unnecessary confusion and anguish. Some families will carry forever the scars of not having been able to arrange the proper final arrangements that their deceased relatives deserved.

Throughout its work the Commission heard complaints of lack of strong leadership in the SARS crisis.

One funeral director told the Commission:

There seemed to be no leadership anywhere. The Province was quiet. The Minister was quiet. The Board [of Funeral Services] was quiet. Everybody was quiet. There just was no leadership.

Another funeral service person noted:

There was very limited positive direction from health care. I had to go and seek it out. It was like pulling teeth.

One public health official cited the strong leadership of Bukas Loob Sa Diyos (BLD), the Roman Catholic charismatic group. Toronto Public Health quarantined 500 BLD members over the Easter weekend of 2003 because of SARS exposure.

Easter is their most important religious day and some might have been expected to break quarantine to attend services. However, Easter services were broadcast over cable TV, home delivery of Communion was arranged and one of their religious lead-

ers told them it was their religious duty to stay at home.

Better communication and networking throughout the primary health care system and the funeral industry could have lessened the problems seen in SARS after-death care. The Commission heard story after story of communication failure and of lack of networking that could have made a difference.

A pre-planned response involving the funeral industry, the Ministry of Health, public health, the hospital community, Emergency Measures Ontario and the office of the Chief Coroner, supported by agreed policies, procedures, protocols, memoranda of understanding and tabletop drill exercises would go a long way to prevent the problems that arose during SARS.

One funeral director told of a public health hotline that funeral homes could call for information, but he said that often no one answered and if they did he had no confidence in the information provided:

We had a hotline number to call if we had any concern with a deceased that we were supposed to pick up from the hospital to find out what the protocols were and what we were supposed to do. We were told that it was a 24-hour number but needless to say 90 per cent of the time no one answered.

Another noted that his operation had to turn to the World Health Organization website to get SARS information:

I got most of my information from the WHO website. A lot of what I received we obtained ourselves and disseminated it through Canada. The Health Canada website, I looked at it once.

The following quotation from one director seems to sum up the feelings of many in the industry:

It was frustrating that there was a lack of concrete information and there were a lot of maybes and third-party information and we needed clarity.

One front-line public health worker cited duplicated efforts by various government agencies seriously undermined effective communication:

We were required to provide the same information to four or five people. It drove us crazy.

Workers in health care and the funeral industry cited the case of conflicting information from different agencies. The example most often used was one office saying “don’t embalm” SARS corpses, another saying it is okay. Another was conflicting information on whether coffins should be closed.

Information was communicated during SARS but in many cases it was hedged and sometimes contradicted. Certainly there was not much information from the Province, the Coroner’s Office or medical officers of health that boosted the confidence of people in the funeral industry. As one funeral service director said:

No government stepped up and provided information. I had to watch the news to get information.

There was not enough information that, as one funeral director put it, “you could sink your teeth into.”

Funeral directors needed very specific information from public health authorities, especially early in the crisis, to questions such as: Is embalming allowed and if so under what conditions? Should there be an open or closed casket? Should there be a funeral at all? Should staff be quarantined? One said:

The press releases that went out were frightening. We needed to know how safe we were, how secure the public was, i.e., hand washing, tell us what the real risks are.

The breakdowns in communication resulted in additional stress for the bereaved. Funeral homes trying to cope with miscommunication or lack of communication were not able to supply confident answers to the families of victims. And of course, there were the cases in which lack of proper communication directly affected those trying to deal with a loss. One of the most dramatic of these was the daughter who didn’t know her mother had died of SARS until it was announced in the news media. The family was never told by anyone in the health system.

The Commission heard much from the funeral industry about how it feels it was left out of the loop during SARS. There were concerns that the industry is not well represented in pandemic planning. As the Ontario Funeral Service Association said:

During the SARS outbreak, we were not part of the inner circle and we should be because during a man-made catastrophe we deal with the end result of any epidemic or pandemic.



They told the Commission that anything that happened after death appeared to be an afterthought:

Funeral homes hold an odd place in society. They are ignored and neglected. This has to stop.

The Association said:

We are the first line of defence with doctors and nurses but we are not treated as if we are. Someone could die of pneumonia but the hospital, nursing home, the coroner does not have to tell us that the person had AIDS. Universal precautions are used in an embalming room, but that extra piece of information [knowledge of AIDS] may assist us in keeping our people secure.

Although regulation of the funeral industry is not within the Commission's terms of reference, many in the industry thought that structural problems in funeral home regulation contributed to the problems encountered during SARS. The industry is comprised of independent business people who offer a service to the public. Because of the importance of this service to society and the complications that can arise from it, the industry is regulated by the provincial government.

The ministry responsible for the funeral industry until 1991 was Health, for the obvious reason that many health issues are involved in handling the dead. Then the government placed regulation of the industry under Business and Consumer Services. The Commission heard many recommendations for placing funeral services back under the Ministry of Health because they are so closely linked to health care. One director said the move from Health was the worst thing that had ever happened to the industry and added:

We are in the health care business. We deal with the dead and the living and their health. We are now in an industry of dollars and cents [in reference to being under Business and Consumer Services].

Another funeral director suggested that governments and the health system should re-evaluate the importance of funeral workers. Still another said public health should recognize the funeral industry as a resource.

Some recognition did come later. In August 2004, as Dr. Bonnie Henry, Associate Medical Officer of Health, Toronto Public Health, told the Ontario Standing

Committee on Justice Policy, studying the adequacy of Ontario's emergency management statutes:

The funeral home association was an extremely valuable partner for us in SARS. The care of people who have died from an infectious disease is very tricky, and they're very skilled at assisting us in things like that.<sup>841</sup>

The roles of individual funeral operations and their associations also were raised. Toronto-area funeral homes have 11 associations, including one federal, one provincial and nine district associations, to which they can choose to belong or not. When public health agencies pass along information to these volunteer associations, some funeral homes are likely to miss out because they don't belong to them all.

The only mandatory membership is with the Board of Funeral Services, which regulates funeral homes. Questions about the Board's role and effectiveness were also raised. Because it is a regulator, should it be expected to be an information network provider? Does it have the resources to carry out such a role?

Another issue cited was the fact that individual funeral operations made their own policies for handling SARS complications. There were no set standards for body transfers, body handling, visitations and body viewing. Some in the industry wondered if standards should be set and communicated by one entity within the industry. That way whatever messages had to be delivered to a grieving family – closed casket, no public funeral, no visitations – could be delivered with authority by one agency or association. As one funeral director said:

We need a central agency with authority to educate us and tell us what to do.

One funeral director told the Commission that during SARS:

There needed to be a front-line person with credibility to talk to the front-line people in the funeral end of things, telling them what they know, what they are recommending, and "here is what you go with."

One cited the example of contradictory opinions over whether victims who die of SARS should be embalmed. As noted previously, funeral directors attributed the

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841. Justice Policy Hearings, August 18, 2004.

coroner's office as saying embalming was not a problem while Toronto Public Health said perhaps it was best to avoid embalming. One director said the embalming direction from Toronto Public Health was so vague that he placed several calls for clarification. None were returned.

What funeral directors seemed to need during SARS was recognition of their role in the health crisis and leadership to help guide them through it. They wanted better leadership within their own industry and from their governments, right from the Ministry of Health through to local public health boards.

Certainly many in the industry also feel that they should once again be under the regulation of Health.

## Lessons Learned

Bad experiences usually carry good lessons, and this was the case with SARS. Wrapped within all the things that went wrong are some lessons for next time. Many funeral directors said that because of SARS they are prepared for the next crisis. As one said:

We are well positioned now because of what we went through. We are ready for pandemic influenza.

That is the optimistic view, and optimism is good, but it must be backed by a plan for future outbreaks of infectious disease. There needs to be a plan that will overcome the lack of preparation that made the SARS outbreak of 2003 more difficult and more painful than it should have been. This plan should consider:

- The importance of funerals and how outbreaks can be effectively controlled while the dead are buried with dignity and without compromising either.
- How to include the funeral industry in planning for a pandemic that will require special funeral and burial procedures.
- Special attention to the possibility that the next outbreak might bring deaths far in excess of the 44 deaths in Ontario from SARS in 2003.
- What role funeral directors have or should have in the health care and public health systems.

- How to provide the funeral industry with clear-cut direction, communication and leadership that will help it do its job effectively.
- What procedures are needed for the safe, uncomplicated and efficient transfer of bodies from hospitals and other health care facilities to funeral homes.
- How public health can communicate effectively with the funeral industry and provide one authoritative information point where funeral directors can get answers to questions and concerns quickly and clearly.
- The roles of the Board of Funeral Services and the funeral industry's numerous voluntary associations, and whether their effectiveness in keeping the industry informed can be improved.

One of the best lessons is how people summon their best abilities in times of crisis. Funeral service workers, despite concerns for themselves and their families and the lack of clear information, did a good job of protecting the public while carrying out their duties to grieving families.

One of the difficulties for funeral operations was trying to find out the cause of death. Public health either didn't know immediately or was slow to say. Most funeral homes decided to take precautions no matter what:

We learned that what was prudent was necessary.

Funeral services learned to split their shifts to reduce exposure among all staff. There were extra costs involved, however, said one director:

When things like this happen, competition or not, public safety comes first.

One large funeral operation used red tags on body bags to indicate that a person died of SARS. This helped funeral workers to know they were handling an infected body and remind them of the precautions needed.

## Recommendations

Better preparation and communication obviously are the keys to major improvements in after-death handling during any serious infectious disease outbreak. The funeral industry's problems and concerns during SARS flowed mainly from these two areas.

Although some efforts were made to communicate with the funeral industry, these proved inadequate for lack of a plan agreed to and tested in advance. The funeral industry was largely left out of the loop during the crisis. Funeral directors interviewed by the Commission noted that they still have not been included in post-SARS discussions, and have received no recognition for their efforts during the crisis.

It is not within the Commission's mandate to report on funeral home regulation. It is clear, however, that there are underlying problems with regulation and administration that impact on performance in crisis. The mix of regulatory agencies and volunteer associations that funeral directors deal with needs review, including a reopening of the discussion of what ministry or ministries are best equipped to regulate the industry. Until it is clear exactly how the funeral industry fits into, and is directed by, the health care and public health systems, it will be difficult to plan for a health care crisis that requires special funeral and burial procedures.

Specific recommendations from the funeral industry include the following:

- Hospitals should have documents and bodies together in one place, such as the morgue, so funeral home employees do not have to enter public areas of hospitals.
- Bodies should be red tagged to indicate death from infectious disease. This would let funeral home workers know what they are dealing with during body transfers.

Any planning at any level, especially in public health units and coroners' offices, should involve the funeral industry. The Commission notes that the Canadian Pandemic Influenza Plan recommends that the Funeral Services Association of Canada and/or local funeral directors be involved in any mass fatality planning.

Only if the funeral industry is involved in planning will it be able to properly update its preparedness, which will include what policies and protocols are needed for body

pickups, embalming, visitations and other funeral arrangements, plus universal precautions and protective equipment.

As for communication, the best way to start improving it is to recognize up front that in any crisis it is always cited as a problem. Approaching the crisis acknowledging that is a start at dealing with it.

The industry should have a single voice during a crisis. This voice could play an important role in advising the public about how public health concerns might alter traditional funeral arrangements. A single voice would help strengthen public confidence.

The Commission recommends:

- That the underlying problems of regulation of the funeral industry should be addressed, including the questions of which ministry or ministries are best equipped to deal with the industry, and exactly how the industry fits into and is directed by the health care and public health and safety systems in relation to any public health problem or emergency that engages the need for special procedures for funerals and burials.
- That these problems be addressed by a lead ministry or agency selected by the Ontario government in conjunction with other affected ministries, the industry and local medical officers of health.
- That the funeral industry develop a single voice and communications point for dealing with government organizations such as public health, Emergency Measures Ontario, and the Ministry of Health and Long-Term Care, together with an internal communication system to ensure that one communication from government to one industry communications point will reach all members of the industry immediately.
- That a pre-planned response be developed for any public health or other emergency that engages the need for special procedures for funerals and burials; such planning to include the funeral industry, the Ministry of Health and Long-Term Care, public health, the hospital community, Emergency Measures Ontario and the Office of the Chief Coroner, supported by agreed policies, procedures, protocols,

memoranda of understanding and tabletop drill exercises, would go a long way to prevent the problems that arose during SARS.

- That Emergency Measures Ontario, in consultation with the Chief Medical Officer of Health, assume the initial responsibility as lead ministry for such planning.

## Clergy and Spiritual Leaders

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Spiritual comfort during an outbreak of a potentially fatal disease is an issue that deserves some comment. It was specifically raised by a Protestant clergyman, who asked the Commission:

What is the role of the clergy and spiritual leaders in the health care system of Ontario?

Because the issue is marginal to the Commission's terms of reference and produced only one response, the Commission makes no recommendation other than to say it needs to be addressed by the health system, the chaplaincy community and those it serves.

The clergyman noted that during SARS, clergy were barred from visiting patients in some hospitals, long-term care facilities and nursing homes. One Toronto hospital declared its chaplain non-essential staff during the crisis and sent him home. This was part of the overall attempt to limit SARS exposure and lessen the chances of spreading the virus. Some hospitals did allow clergy visits if precautions were taken, but a clergyman who addressed the Commission complained of inconsistency and different interpretations of rules established by health officials.

He summed up the problem:

There exists a large percentage of the population for whom religious faith is important. They deserve spiritual care at crisis points in their lives and hospital admission is almost always a crisis point.

While it varied from hospital to hospital, during the recent SARS crisis many clergy were denied access to patients. I want to be clear that when professional clergy visit they do so primarily and almost exclusively to people of faith.

He said that throughout the SARS crisis his parish was prevented from bringing the sacraments to a nursing home. He felt there was no reason why professionally trained



clergy cannot follow the same basic hygienic and infection control practices as doctors and nurses.

The clergyman is not alone in his belief that spiritual care is important to medical care. A study at the University of Pennsylvania shows that 45 per cent of a study group reported that religious beliefs would influence their medical decisions if they become gravely ill.<sup>842</sup>

Some medical practitioners feel that patients and the health system benefit from having clergy involved. A doctor writing in the *New England Journal of Medicine* said:

Even as we ponder whether or how we should step inside the religious worlds of our patients, we should also ask whether members of the clergy should enter more deeply into our clinical sphere. There is a great imbalance of power between patient and doctor. Often, I have been insensitive to this imbalance and have taken a patient's silence to represent tacit assent to my recommendations.

A member of the clergy can speak to a doctor at eye level and act as an advocate for a patient who may be intimidated by a physician and reluctant to question or oppose his or her advice. A priest, a rabbi, or an imam can help patients to determine which clinical options are in concert with their religious imperatives and can give the physician the language with which to address the patient's spiritual needs.<sup>843</sup>

Clergy visits have been part of the hospital system since the beginning. Some hospitals have their own chaplains, whom they pay to provide spiritual care to anyone who desires it. Clergy from outside the institution visit when requested by patients, patients' relatives or staff. They sometimes are asked by a hospital chaplain's service to volunteer to handle spiritual matters many hours a week in certain parts of the institution.

Rules and practices related to clergy visits, however, have become confused and inconsistent, mainly because of privacy concerns. It used to be, and still is the case in some hospitals, that visiting clergy are given access to a patients' list that includes religious

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842. Do Patients Want Physicians to Inquire About Their Spiritual or Religious Beliefs If They Become Gravely Ill? *Archives of Internal Medicine*; Vol. 159 No. 15, August 9, 1999.

843. "God at the Bedside", Jerome Groopman, *The New England Journal of Medicine*, March 18, 2004.

denominations. Only clergy who have been pre-screened to ensure they have valid qualifications are allowed to see the list. An Anglican priest, for instance, is allowed to see the Anglican list, then proceeds to a nursing station and asks to visit the Anglican patients whom he or she has noted from the list. The practice, according to this clergyman, is to ask the patient if he or she would like the minister to stay and visit. If the answer is no, then the clergy person leaves:

They are not attempting to evangelize those who are weak and vulnerable but rather seek to bring comfort and support to people of faith.

The information on religious affiliation used to be collected by hospital admitting staff when patients arrive at the hospital. However, this clergyman told the Commission that very often the question of religious affiliation is not asked. Some staff think that asking for religious affiliation is a privacy issue, but he said the people being asked are free to note their religious tradition, or simply to say they have none.

He added:

For some reason the staff in the hospitals feel reluctant to put the question, thereby denying patients access to spiritual care. I would like to see a concerted effort by hospital staff to provide this information to community clergy. It's a question that needs to be thoroughly discussed hospital by hospital.

An Anglican chaplain has noted publicly that in at least one Toronto hospital she is now forced to make "cold calls" on patients, walking door to door in the hospital looking for Anglican patients.<sup>844</sup> Sometimes she relies on sympathetic staff to tell her which patients might wish to see her.

A nurse who contracted SARS on the job and was hospitalized raised the issue of patient privacy before the Commission. She complained that while in hospital she felt abandoned, not having been visited by any managerial staff and the chaplain with whom she had worked closely. Later, when she asked the chaplain why he had not contacted her during her illness, he said he tried but hospital managers cited confidentiality concerns and refused to give him a list of names.

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844. "Privacy laws force chaplains to make 'cold call'", *The Anglican Journal Canada*, April 2004 (The Anglican Journal).

She added:

And that was always something that was so special. that the chaplains were always there for the staff. They knew us. They knew what was going on in our lives.

A clergyman writing in the *Anglican Journal* said there is a concern among Ontario's churches that new privacy legislation will limit pastoral care in hospitals. The article said churches have asked for changes that "clearly state that providing basic information to clergy and religious caregivers is not a violation of the Act."<sup>845</sup> and that chaplaincy be included in the definition of health care providers.

The clergyman who contacted the Commission expressed concerns about a climate of fear and mistrust, which had significant impact on the Toronto Asian community. He also noted that part of the SARS crisis occurred at Easter of 2003 and that warnings against large gatherings reduced church attendance. He said:

Fear is not a positive attitude. Faith can be an antidote to fear. People cut off from their spiritual traditions get unhealthy. People who find faith important find strength that helps them live their lives. We must guard against denying people their religious freedoms.

The Commission notes how one religious group managed to observe quarantine and still bring Easter services to its members. Bukas Loob Sa Diyos (BLD), Roman Catholic charismatic group, had its 500 members quarantined over Easter because of a SARS contact. Although there had been concern that some members might attend church despite the quarantine, the group's leaders arranged to broadcast Easter services over cable TV, and set up home delivery of Communion.

The clergy concerns brought before the Commission raise some sensitive issues that should be addressed. Few people would deny that there is a role for clergy in hospitals in offering spiritual support to those who want it. There are, however, those who resent any religious intrusion on their personal privacy. However, there are no overall policies or protocols that would provide some clarity and consistency to the situation. In order to address this gap, the Commission recommends that the Ministry of Health and Long-Term Care and the Ontario Hospital Association and the chaplaincy community engage in multifaith consultations toward the development of the

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845. *The Anglican Journal*, April 2004.

policies and protocols required to address chaplaincy services during an outbreak of an infectious disease. These consultations could address the difficult questions of how to make chaplaincy service available to those who want it, without intruding on the privacy of those who do not.