

Funerals and the Suffering of the Families

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.⁸³⁵

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.⁸³⁶

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

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.⁸³⁷ 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.⁸³⁸

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.

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.⁸³⁹ 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.⁸⁴⁰

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.

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.⁸⁴¹

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

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.