

In 2020, governments prevented families from visiting their loved ones in hospitals and care homes. With a mother in long-term care, it was a mandate we realised was terribly wrong. We knew isolation, neglect and medical mismanagement as a result of measures imposed for COVID19 would be a far greater threat than any virus. Like others who saw it too, we fought back. But no one listened. Throughout 2020, we received frantic calls from desperate families who sat in hospital car parks while loved ones suffered and died, no one allowed in for support or to advocate on their behalf. Virtual visits were offered up as a poor substitute for in-person access. Ask anyone in poor health which they need more - holding a phone or your hand, seeing you on a screen or touching your face. There is no substitute for in-person interaction, especially when life hangs in the balance. We were told it was for their safety, for our safety, for everyone's safety, to trust government and experts, and to put the lives of those we loved in the hands of those who knew best. Hindsight indeed is 2020. Those policies, a deviation from tried, tested and trusted medical practice, were criminal acts and led to untold harm. Never again can this be allowed to happen..

Our healthcare system is under more pressure than ever since COVID protocols came into effect. This week, one of our family discharged herself from hospital after waiting for three hours for her IV to be removed after antibiotic infusion treatment, not once being seen by the doctor on duty. She called the physician in charge of emerg who apologized, removed the IV that same evening in a revisit and assured her that he will be addressing the issue in a staff meeting. Next, our local pharmacy is struggling to fill prescriptions promptly - citing supply and staffing shortages. My urgent script had to be sent to another pharmacy who were able to dispense it right away. Lastly, and most disturbingly, a 48-year-old man and family friend, coughing uncontrollably for over a week. This patient is a heavy smoker who has suffered a heart attack in the past. His doctor did not perform a physical exam or order any tests but diagnosed him with a viral infection. He was sent home with an inhaler but continued to deteriorate. He returned to his doctor who refused to even listen to his chest to reassess. Fortunately, he asked a good friend to be available by phone if needed for the appointment. Finally, with both the patient's persistence and friend's support, antibiotics were prescribed, and a chest x-ray was ordered. It's an all too familiar story I've heard in the last three years. Hopefully now he is on the road to recovery. Each one of these situations required action prompted by the patient or advocacy from a concerned friend to get appropriate care. If you are the decision maker for the health of someone else, your child, your parent or other dependant, it is even more important for you to be a strong and informed advocate.

We still receive messages from families who are not receiving the quality care every Albertan deserves. And this is before we hit winter. A senior healthcare professional in the province told us recently to avoid hospitals for anything other than critical care. Another visitor who was dealing with substandard care for his father was told by a healthcare professional that this was what he should expect from the system now. These statements are shocking and unacceptable. Patients and providers have to push for better from our government.

So what can we do to prepare for a health event to ensure the best possible outcome? From first-hand experience as an advocate for others, these are my thoughts. I hope they are helpful.

1. Find a trusted family member or friend to support you either to prepare for medical appointments or to be there with you. Choose someone who is aware of and supports your healthcare choices. Do not be

intimidated by or afraid to ask your healthcare providers any questions or concerns you may have about a diagnosis or treatment. Ask for details on tests, test results, drugs or therapies, surgical procedures, and all possible outcomes. It is every healthcare professional's job to provide you with all the risk/benefits of any treatment.

2. When a health crisis occurs, even the strongest of us are at our most vulnerable. Keep a health diary. Document everything in writing (times, dates, providers, treatment, results). Contemporaneous notes (that means notes made at the time) from phone calls and medical visits are always useful for review (and for the record if needed). After my mum suffered a life altering stroke in 2012, we charted every step of her journey to the present day. It has been an excellent resource for all who have supported her rehabilitation (staff, family and friends) and an invaluable reference when we have had to address issues with her care.

3. Make sure the healthcare team are fully aware of a patient's prior medical history. This is especially important for those with complex pre-existing conditions. David has his medical history with him on a double-sided sheet of paper at all times. It is pinned to our notice board at home and in the glove box of our car. It is also accessible on his cel phone. If he suffers a health emergency, critical care providers have his complete medical history in point form including his current medications, allergies and drug reactions immediately on hand. In a crisis, almost all of us will panic and forget important details. Even medics trained for this make mistakes. We have been thanked many times by his healthcare providers for this short form summary of his health. It makes medical appointments less stressful for everyone involved. And to be fair, no provider has the time to read the long form version for David!!

4. There is NO SUBSTITUTE for in-person support for anyone who finds themselves in hospital. Oversight by vigilant family members or friends is critical to ensure quality patient care - whether it is for a short stay procedure or end of life. If a hospital/care home declares an outbreak, especially as winter approaches, it is MORE important not LESS that there is an in-person advocate present. For three years, too many families have been discouraged or outright denied access to loved ones in crisis. This was a dangerously misguided policy predicated on unjustifiable fear which resulted in unnecessary suffering and death. It can never be allowed to happen again.

5. As an advocate, if your concerns on behalf of your loved one are not acted upon immediately and to your satisfaction, escalate to a more senior healthcare professional, for example, a charge nurse, on the unit. Make sure your concerns target a person who can address the issues. Understand that those at certain levels are limited in what they can say or do. Find the right person to answer your questions.

6. If you are still not satisfied with the care provided, call or submit a formal complaint to Patient Relations or the relevant College. Remember your advocacy may well result in changes that protect the next person faced with a health crisis.

Lastly, keep in mind that a pro-active rather than reactive response puts you in a position of strength at a time when you or a loved one are most vulnerable. And might just save a life. Never again must patients and families relinquish control in health decisions. Never again should procedures be endorsed or enforced without fully informed consent. And never again should anyone be denied an advocate in a health crisis.