

Broken Promises: A Family in Crisis

This is the story of one family – a ‘chosen family’ of Chris, Dick and Ruth – who are willing to put a ‘human face’ on the healthcare crisis which is impacting thousands of families in Alberta.

We are willing to risk speaking out, because we know we are not alone in our experiences, that there are so many other individuals, families and healthcare professionals who are for various reasons unable to tell their story and need someone to advocate for them, to hold the government of Alberta accountable for the decisions it has made and continues to make.

Why now? Because there is an election and healthcare needs to be addressed as a crisis situation and concrete help for immediate concerns to be addressed as part of clear programs for a long term solutions.

This is a story about caring for some of the most vulnerable citizens of this province and those who are trying, sometimes desperately, to care for them. It is also a challenge to all of us to decide what type of society we are, how we value all human beings, and how we want to see our resources spent.

I met Ruth in 1982 (over 25 years ago) when I was a newly ordained minister in the United Church, and I was called to come and care for her when her husband died suddenly of a massive heart attack. He had just walked outside their home.

True to who she is, all of Ruth’s energy, at that time, went into caring for others, and there were so many. Family, friends and a huge number of former students, whose lives Ruth and her husband had touched in so many ways, and in many cares changed their lives – giving them a chance, sometimes a home, believing in them, encouraging them to follow their dreams and sometimes helping financially to make that possible. Through Ruth’s almost 40 years of teaching and her husband’s many involvements, they had given so much.

At that time, it was my primary role to care for Ruth through her grieving process; but as Ruth and I began to spend many hours together, we developed one of those ‘once in a lifetime’ friendships, based on mutual caring, support, encouragement and commitment. We have always known we could trust one another.

Since then, we have shared all of life’s “ups and downs”, and I promised Ruth that I would always be there for her. She had no children so I became her friend, her confidante, her ‘adopted daughter’. Ruth has always “been there for me”, too – we were soul mates.

I am sharing this with you – a very personal glimpse into our lives and our relationship – to set in context my experiences now as Ruth’s primary caregiver and legal guardian. As her health, physically and cognitively, becomes more fragile and her need for me ever deeper, I try to remember the Ruth I have always known. Seniors are real people, with so many stories, who have lived full lives and often given so much. They deserve our respect and compassion and the care they need.

In November 2005, Ruth came to live with Dick and I in our home in Sherwood Park. She was extremely ill, worn out and weak after trying for too long to care for all the needs of her second husband. He had been hospitalized and would be moved to a long term care facility. Ruth could no longer manage where she was – the lodge could no longer provide the level of care she needed. For the past 4 years, we had travelled regularly first to their home – 1 ½ hours' drive – to spend time with them, care for them when one was hospitalized and the other couldn't be alone, and trying to help arrange proper medical and home care. When they had moved to the lodge, we made 2 ½ hour trips, usually monthly and more often when there was a crisis. Ruth and I spoke on the phone daily so I could have some idea how they were doing and to fulfill my responsibilities for Ruth's care.

I remember so clearly being with her again as she tried to understand what the doctor was telling her about her husband's situation and as she faced the uncertainty of her own future. Sitting beside her, on her bed at the lodge, I put my arm around her as we talked and asked her if she would now like to come and live with us, share our home. She looked at me and said, "Oh yes, that would be like heaven".

Thus began, for Dick and I, a long process of nursing Ruth back to health and providing for long-standing needs. Everything from finding a good doctor for her, and later a geriatric specialist, to getting new hearing aids, new dentures, arranging cataract surgery, setting up financial and legal support, getting the 'aids for daily living' she required, as well as all the personal care and basic personal items and furniture she needed. We made a home for her with us; and after several months, she made quite an amazing recovery. We've been able to share such special times together.

At first it seemed that the system for elder care was there for us to be able to care for Ruth. We had an excellent homecare nurse who helped with many things and visited and phoned regularly to see how Ruth was doing. An occupational therapist and physiotherapist came to our home to evaluate Ruth's needs and help us get all the things that were required for her. Everything, over time, was set up for Ruth to be in our home. I became her legal guardian.

However, I soon became aware of problems within the healthcare system which threatened Ruth's well-being as well as ours.

1. Soon after Ruth came to us, she had to be hospitalized for various health problems and an assessment of her medical needs. The experience around her admission turned into a nightmare and it was only resolved hours later after my continuing insistence that they follow through with the admission and care we had been promised for her. The lack of proper communication left me frustrated and exhausted. Despite repeated requests and promises I never received a discharge report and assessment so that I, as her primary caregiver and legal agent would know what her true health condition was and what level of care she needed. There was also a mix-up regarding her follow-up care.

2. Next we experienced the first of many budget cuts, when we lost our excellent homecare nurse. We were assigned to another one who visited us once in a whole year.

3. The request for an assessment for Ruth's long term care needs has taken the system two years, despite my repeated requests. And, I still do not have a copy of it, even though I am legally responsible for all her medical care and personal and housing needs.

4. The problems with homecare, which has been largely privatized and is dramatically underfunded, now means that Ruth receives about 10 minutes of morning care (a sponge bath, help dressing, etc.) Monday to Friday, and one bath a week. They stopped providing us with even one afternoon of 'respite care', where someone would stay with Ruth so we could go out. They will not provide any evening care for someone to be with Ruth, although she cannot be left alone.

The workers who come are kind and very good with Ruth, but how much can they do when they have 18 to 20 clients to care for in a morning? They are also very limited in what they are allowed to do. Proper training and courses for 'homecare assistants' (the titles keep changing as services are downgraded) have been cut severely and almost no one is even applying for the courses because the wages are so poor. We are paying these crucial patient care assistants less than Tim Hortons! Our two workers are obviously committed and caring, yet I fear if they will be able to continue as they are so underpaid and overworked.

This is another Broken Promise. The Government tells us that they will help seniors stay in their homes and their community. The Reality is that the crucial people resources and financial needs are so underfunded that families and friends are being asked to provide levels of care far beyond their means. How many can provide long term care 24/7?

5. We were told that if we needed 'additional' care for Ruth, beyond what homecare provides, we would have to arrange and pay for private care. Not many families have those resources. We do occasionally get private care for Ruth – if we can even find someone. The agency has almost no staff available to provide this care. We have made private arrangements and occasionally relied on friends; however, Ruth now really needs trained people to be with her because of safety concerns. This is what we are told by her medical caregivers, yet where do we find affordable, competent help? We do not leave her alone, yet how long can caregivers manage almost without a break providing 24/7 care, no matter how much you love a person?

This has been yet another Broken Promise for us, and tremendous pressure on our health and daily lives.

6. In many ways the final straw for us has been the Broken Promise regarding Respite Care to help families care for their family members of all ages who are ill, disabled, and needing qualified care in an appropriate care facility while they have some respite time.

Last October my health was deteriorating further (I am already on Long Term Disability myself because of severe health problems). Our family doctor, who is also Ruth's doctor and thus is aware of our total situation, told me that Dick and I must have one week per month for Respite Care arranged for Ruth. Her health needs were increasing and our resources diminishing. This "break" was crucial for us to continue to care for Ruth.

When I called CAPS (the Central Assessment and Placement Service of Capital Health) to arrange for respite care, I discovered another area where our healthcare system is in crisis. I was informed that due to staff shortages the respite care beds in Strathcona County, including Sherwood Park, had been closed indefinitely. I was shocked. No one else in the healthcare system seemed to know – not our doctor, the Seniors Clinic and geriatric specialist, or the homecare and other programs. The whole thing was being hidden until families requested Respite Care. Only the families directly involved were becoming aware of the severe crisis of adequate and appropriate staffing for long term care residents and those in facilities providing other levels of care, including rehab care and, of course, as it has now come out, acute care in hospitals. Beds and whole wings of all levels of care facilities are being closed.

Thus for us began an exhausting and heartbreaking struggle to find the Respite Care we so desperately needed. Space was eventually found in a facility in Edmonton; however their staff shortages and the poor level of training for even basic care did not make me feel secure in leaving Ruth. This anxiety for me increased when I discovered that the paperwork was outdated and missing; there were mix-ups over medication lists and despite my efforts to provide detailed notes, the staff were unable to even put Ruth's hearing aids on for her! Ruth tried to cope, we tried to cope; the staff seemed frustrated and overwhelmed.

In December things came to a head for us, when Ruth was in Respite Care in this Edmonton facility and had a terrible fall. At that time we discovered another huge problem – substandard equipment which would not even be allowed in our home and was not replaced because the maintenance budgets for these facilities had been drastically cut.

Ruth has experienced a severe set-back – physically, emotionally and mentally – since the fall. It has been documented and we deal with it each day. She has been frightened to go back into Respite Care and I have become increasingly concerned and exhausted with this lack of healthcare.

Thankfully Strathcona Care Centre was able to find staff to re-open a respite bed for Ruth in January. Ruth is familiar with this facility as she attends a wonderful Day Program there twice a week, and they were willing to help with her respite care, thus easing some of the facility staffing problem. Ruth was able to return there for Respite Care in February, although we did not know until the last moment whether there would be staff for Respite Care beds. They are always the first to be closed as permanent residents must have priority. Because of Ruth's needs and our concerns, I have decided that I will only agree to Respite Care at Strathcona Care Centre because after discussions with her medical caregivers it is clear to all of us that she cannot manage being moved from one facility to another which is unfamiliar to her. Our crucially needed Respite Care remains a huge uncertainty for us as it is for so many families.

Government promises of new beds ring very hollow, when we know beds are being closed and there is inadequate staff to cover the present needs. Proper programs are not in place to deal with the staffing crisis, training and adequate wages, maintenance needs for the facilities – the list goes on and on.

In this wealthy province we have burned-out, undervalued staff and exhausted, anxious families who do not know how to care for those they love. Families are now being asked to shoulder an increasing degree of care for their family members whether they are still 'at home' or in a care facility. Funding does not cover even the basic needs for so many, so they are going without. There is no excuse.

I have kept my promise to Ruth, with help from my husband Dick and some wonderful caregivers. The question is how long can we continue like this? There is a one-year waiting list for long term care beds in Strathcona County. This situation is the same throughout the province. Our story is one of hundreds, or more likely thousands. Although we may be focusing on care for vulnerable seniors, the problem is as great or worse for children and adults and their families trying to care for them; for those who are disabled or may suddenly need help due to illness or accident.

As the citizens of this province we need to know that this is a manufactured crisis in healthcare. It is based on government ideology for increased privatization of many areas of healthcare, the deliberate decision not to fund training for doctors, nurses and other healthcare professionals and to "blame" those who become ill and need care – our most vulnerable citizens. It is going to affect all of us if it isn't already.

I have been described as a "strong advocate" for Ruth. I fear for what happens to those who do not have someone to speak for them and oversee their care. As a "baby boomer" I do not believe I am part of the problem; I am part of "the solution" right now – paying taxes and caring for those in need. I don't have time to worry about my future (as an increasing number are). I am too worried about our present, caring for family and friends now.

This is a systemic problem. Individuals should not be made to feel guilty because they become ill or disabled, or aged; they should not have to worry about being a burden to others, and be afraid to talk about their situation. People, all people, deserve to be treated with respect and basic human decency. People like Ruth, and Dick and I, simply want a decent quality of life.

We are asking for a government that will finally take its citizens' needs seriously as part of their programs, by listening to us and our stories, consulting with us, treating us with dignity and fulfilling its promises. The financial resources belong to us; and we need to examine who we value, so we, as citizens, have a proper say in how the money is used.

No more Broken Promises. I've watched and experienced too many of the consequences on human lives. We are the face of thousands more.

Chris Swaren
Sherwood Park
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