

HOW MUCH IS A KISS OR SONG WORTH?
Homecare for Late-stage Alheimers Patients
My Email to the LHIN 20110624 – No reply received

A number of articles have appeared in the media concerning getting seniors out of hospitals into homecare. Most seem to relate to seniors who are able to cope with varying amounts of support by CCAC and other support services. So far, what I have been seeing is not addressing getting late stage bedridden Alheimers patients home.

My husband was hospitalized at the Queensway Carleton Hospital in Sep 2004 and remained there for 4 ½ months, after which he was discharged, with a doctor stating that he had about 2 weeks to live. I managed to keep him alive until May 2011 with minimal PSW support (15 hours a week later reduced to 10 hours a week) and Carefor visits as required. During that time he was re-hospitalized twice – 14 days for UTI and about 23 days, the latter being end of life care.

At the time, QCH automatically assumed that he would go into a long-term care facility. The length of his stay was increased because of treatment policies in effect at the time. I had to fight to get him home. Based on my experiences, I have identified a great many things which would have helped to prevent the problems we encountered. The major problems were as follows:

1. Medication – Antibiotics were administered for a UTI soon after the surgery (33 hour wait time), resulting in CDIF. This UTI/CDIF cycle was repeated several times. When at home, several UTIs were treated by antibiotics plus Florastor, a probiotic recommended by the local pharmacy, and costing about \$30. QCH had informed me that probiotics were expensive (\$120 range). I provided the probiotics for his 14 day hospital stay. We had no re-occurrence of CDIF. QCH also had a problem with an Alheimers patient wandering into the room during CDIF episodes
2. Diet – my husband was provided with a soft diet, with large quantities of normal food. Nurses could not take the time to feed him, or if they did, they didn't give the most nutritious foods first, and he didn't receive enough nutrition to prevent skin deterioration and breakdown. At home, I designed his diet to provide the minimum amount that could deliver the highest nutritional value
3. Physio and Physio Equipment – we were informed that Alheimers patients were not entitled to physio, except for minor exercises. I researched walkers and found that standing walkers were available on the market which would provide support. When I asked QCH physio about this, they indicated that they had one walker and arranged for him to use it. Initial attempts indicated that he probably would have been able to use it, but because he had already been bedridden for some time and because QCH wouldn't allow the walker to be used during CDIF occurrences, this did not prove to be viable. If the walker had been available immediately after treatment, the outcome might have been different.
4. Homecare Assessment – Because QCH assumed he required too much care to be at home and because seniors were automatically placed on the LTC waiting lists, I had to do the assessment as to whether I could handle homecare. In Oct 2004 I prepared a report which identified my floor plans (the hospital room was exactly the same size as my master bedroom with the bed moved back against the wall), physician support available (I had a doctor who would provide home visits), and many other matters. This report was provided to QCH with a request to take him home. I was required to meet with a team (doctor, head nurse, physio, OT, social worker) to discuss the feasibility of homecare. This was approved based on the condition that he not have CDIF or a UTI or other problem requiring hospitalization, and that I work shifts with the nurses for a week to ensure that I could provide the required care (I just assisted but was not

- being trained). I had also been assisting the nurses whenever possible throughout his stay. No training was provided using a homecare bed – positioning is much more difficult with only one person and would be the main limiting factor in one person being able to cope with homecare
5. Caregiver Information and Training - this was my responsibility and I undertook research on all aspects of his care, including how to recognize when death would be imminent, how to prevent bedsores, what therapeutic equipment was available, dietary requirements, etc. I also read the bulletin boards where QCH had posted information for training the nurses
 6. Homecare Equipment – QCH was not involved in advising on, or providing, the equipment required, except for a wheelchair. My initial assessment was that “I can’t afford it” and I initially took no action because of this. I found the hospital environment extremely stressful (could they not put a sign on the bed when they take him to x-ray? I thought he had died) and felt that if he remained in QCH or LTC that I would have major health problems too. My son told me to think about “how could I get him home?”. This resulted in the Report in #4. Things then fell into place – a newspaper ad for a hospital bed (\$1500), a lift available (\$375). QCH provided the wheelchair (\$5000, my share \$1000). I also needed furniture moved from the master bedroom to downstairs (\$80). I later had to replace the bedrails (\$400) and the mattress (\$800). This total just over \$4000 – a considerable expense for senior’s with limited income. All of this depended on my research and money
 7. Health Care Staff Shifts and Turnover – the QCH practice of rotating staff resulted, on occasion, in problems. Staff were not always aware of his problems and requirements, despite signs and records nearby.
Alzheimers patients require continuity – having multiple persons and constant turnover adds to their medical problems and stress
 8. Restriction of Patients – getting the staff to use wheelchair safety straps and bed rails was an ongoing battle. Falls or near-falls resulted with other patients
 9. PSW Training – PSW’s were not trained in all aspects of care and were not allowed to feed him due to choking risk. This was also an issue during the hospitalizations
 10. In-home Medical Treatment – QCH required hospitalization because the drugs required to treat the UTIs required IV rather than pills. Use of IV in the home would have been possible if caregiver training and been provided or if nurses or PSWs had been able to provide this. After the 14 day hospital stay, QCH provided a hydration IV (identified by the dietician) administered via abdominal wall which facilitated the earlier release. CCAC rented the pump, which was said to be very expensive, and only one Carefor nurse had been trained in this procedure. The doctors were not always aware of services provided by Carefor and CCAC

On my husband’s return to QCH for the 14 days, I was told that he had been the first patient discharged to homecare and that the procedures were being changed. It would have been helpful if I had been presented with options and the hospital had done the assessment and provided the equipment. It would also be useful if potential caregivers could talk to or visit others who are doing it, or if homecare could be simulated in the hospital as part of caregiver training, so potential caregivers know they can do it. I lived in fear the first 2 weeks he was at home, getting up every 2 hours to turn him so the bedsores wouldn’t get worse and thinking he could die at any moment. Once I found that he would live and his diet improved his skin, I rarely had to do this. I look back on my 4 ½ months of hospitalization as a nightmare, brightened only once by a nurse who asked how was I doing. The homecare years were hard, with most of the stress coming from having to deal with PSW service problems, but the good memories far outweigh the bad. I even was able to take him to my son’s wedding in 2009 via private ambulance.

I was able to provide homecare, partly because of a 20 year age difference – it would not have been feasible if my husband had been heavier (he was about 125 lbs), if I had been the same age or if I also had health problems. I was unable to go to a doctor because of the time limitations – having to wait for service rather than being able to schedule an appointment within the short window when I had PSW support. Also, follow-up tests would have been impacted, especially if they were farther away. I also provided caregiver support to my mother who was ambulatory for about 3 years. Having expedited health care services for caregivers, perhaps provided by the hospitals where all testing could be done at once, would have helped. Having labs arrange pickup of urine/stool samples would also have been useful. My local pharmacy's free delivery of medications was a critical service. I still haven't sold my husband's medical equipment – having an organization which could provide and recycle the homecare equipment would be very useful. In addition, the following would be useful:

- Having caregiver respite in-home for short-term needs (less than the week which was required for respite in a LTC)
- Ensuring caregiver respite is part of the PSW service would also be useful.
- Varying the PSW service requirements depending on caregiver needs rather than having fixed service limits – there were times when I could have used more and other times when I needed less hours
- Having the government fund the use of private ambulance services – the 911 ambulance was covered – the return trip home wasn't
- Having the government fund private ambulance services for non-critical hospital visits e.g. UTI problems
- Providing medical and dental checkups and testing services at the hospital periodically, as well as for the caregiver if needed
- Removing parking fees for persons visiting long-term care hospitalized patients
- Removing visiting hour limitations for spouses visiting long-term care hospitalized patients
- Training spouses/potential caregivers in how to help the hospital staff during the hospital stay

I believe that there may be many potential caregivers who could handle the advanced care required for the late-stage cases if the government initiated the assessment and provided the equipment and support services, and made changes in medical treatment and services.

I hope your organization will consider my comments and do everything possible to allow other people to have control over their quality of life with support from the healthcare system. My husband and I enjoyed the time together – he could sing even when he couldn't talk. I knew how he was 24 hours a day and didn't grieve his passing – we celebrated that I had been able to keep him alive so long, how long he had lived and that we had good memories. When hospitalized, doctors had asked why I wanted him to live longer and encouraged passive treatment. My answer – how much is a kiss or a song worth?

I am willing to provide more feedback on my experiences and what is required for caregiver support if your organization is interested.