

Palliative Care in the Context of Co-Housing: Insights

I. Our introduction

New to co housing, sharing morning coffee was how my friendship with Joyce Jones unfolded in late 2007. We would review happenings in our community including council meetings and other occurrences and slowly over time Joyce would ask me to help her out with more challenging tasks like how to operate her new computer. At 82, her friends had convinced her that a computer was a great way to share photos and messages with friends both near and far. As a visual artist she took delight in being able to see other artists new works as well to share with them news of her life including discovering meditation and having a new boyfriend! When she asked me mid summer 2012 to drive her to her doctors, never did I envision that I was beginning with her the last chapter of her life. Soon I was involved with a small circle of her friends who were taking on the challenge of helping her deal with myriad medical challenges in a storm of confusion where we were not sure what was unfolding and how we should proceed. In this endeavor we did the best we could. We did not necessarily understand the consequences of how we organized ourselves, nor did we have the luxury of time. Joyce's illness moved very quickly. We were trying to be loving and supportive friends to a neighbor in distress but we were also challenged to respond effectively and calmly to a situation for which we had no roadmap.

The motivation for writing a piece on the experience was inspired from two wells. The first was to help me in saying a final personal good bye while the second was to somehow honor Joyce's wish that others might learn from her experience. At one of our last coffee klatches Joyce took great delight in thinking that others might learn from her and her friends experience.

I have posted the full text of my reflections about this experience on the public website of Creekside Commons under the section of "What's New". The topics range from better ways to have organized ourselves to how we helped those living in the community respond to Joyce's dying. Go to creeksidecommons.net for the rest of the text.

II. Getting Started: The Care Circle

At one of our coffee breaks Joyce had asked me how she could involve some people in her care while not hurting the feelings of others who might also want to be involved. From my social work training I shared with her the idea of the care circle where you deliberately invite a few people to be involved in your care while saying to others I don't think I need any more assistance at this time but if my needs change I may call upon you. She appreciated the idea and set out to slowly identify who she thought she might need and what support that they might be able to offer. Within a few weeks the circle was formed and we leapt into our task with enthusiasm. We never formally met at the

beginning to reflect on who was doing what and what were things that we should all be mindful of.

In hindsight, it would have been ideal if we could have identified and divided the various care need/responsibilities up front, but we didn't, and we didn't know what we were in for. Having had the year to reflect, the following is what I would propose to help a care circle maintain focus and to keep its members healthy in the face of overwhelming stress. There was also one electronic tool that served us well and a few unexpected insights which I will attempt to describe.

III. Better Focused Roles

1. Wise Counsellor:

In the TV series Star Trek there was the character Ginan who ostensibly had no active role on the starship but was there in the background if and when someone needed to reflect and or debrief. I don't think any of us up front anticipated this need but towards the end of our caregiving when we were running on empty its need became more readily apparent to me. My recommendation would be for a group of doers to have at least one person who is available to step back and just be there for debriefing, counsel and nurturance. This person might also be able to identify gaps in the services being offered and propose remedies such as seeking out new volunteers.

2. The person accompanying you to medical visits should always be the same.

It never occurred to me that having different people each week driving Joyce and accompanying her would lead to confusion amongst the professionals providing care to her and leave those of us in the care circle bereft of helpful information what we could share with each other. This became obvious during a medical crisis in the hospital where the surgeon and nursing staff did not know who among us to talk to, nor did they feel an obligation to inform. The computerized hospital record indicated that one of us was "next of kin" as Joyce had no living family members but there was no completed advanced care directive indicating who the medical team should formally consult with if Joyce was unable to direct her medical care. When pushed for information the staff were uncertain who was who and why we were asking. We had the appearance of "visitors" and the staff was not certain who the "designated" person was.

From the point of view of those of us in the care circle understanding what was unfolding over several weeks we each only had little snippets of information and were unable to see or understand the big picture so we literally did not know if we were coming or going.

3. Pharmacy Volunteer

We were always running out of medications at the most inopportune times including the last hours of Joyce's life. In the last two weeks of life, Joyce's prescriptions were changing daily. Even the doctor would forget what had been prescribed the previous day! What would have assisted us immensely would have been to ask one person in the care circle to act as the pharmacy volunteer. This person could have dedicated themselves to monitor supplies and ensure the proper arrangements were made for refills. The pharmacy volunteer could be responsible for keeping the prescription list updated, thus avoiding duplicate prescriptions.

It was also a huge challenge to figure out when and how to record to administer the range of drugs. Some of the pain medications were given every six hours while others were every eight. Some of them had to be with food while others without food. After several drafting attempts we developed a spread sheet that was organized by themes and columns for times during the day. The theme headings were: pain, appetite, bowels, breathing, sleep. The time columns were organized by both time and notes such as one hour after lunch meal. This organization helped us all, including Joyce, to understand and remember the purposes of the different medications that she was taking. There was also room for additional observations such as "did not keep the pills down and not re-administered."

4. Community Contact Volunteer

Joyce had envisioned that any one of us in the care circle could receive offers of support and or fill people in on how she was doing. We just found that this turned out to be unwieldy and hard to do. In hindsight, I would suggest that it would have been better for the community to have been told to contact one or two people whose sole responsibility would have been to share information and to sort offers of assistance.

5. External Communications Volunteer

Having lived in several places for long periods of time, Joyce had friendship networks which included France, England and the Gulf Islands of BC. She had the intent of wanting to stay in touch with everyone in one way or another but as Joyce became sicker, I could see that she did not have the energy to do this and I knew that it would be courteous to let people know what was unfolding so that could "prepare themselves." I was faced with the task of determining when and what to communicate to others, striking the balance between privacy and human needs. Joyce was an extremely private individual and expected us to respect her privacy -- particularly the privacy of her medical information and required time to craft communications mindful of her specified parameters. What worked was biweekly communications with the care circle, Joyce's friendship circle and, the members of our co-housing community. The level of detail was tailored to the need for specificity. I found it hard that community members did not

seem cognizant of the privacy restrictions that were placed on those of us tasked to relay information. We shared what we could and what we knew which often was very little!

III. Electronic Tools that Helped

6. The Electronic Communications Book

Traditionally in palliative care a “communication book” is created and kept at the door for home care staff and volunteers to record and reflect on the day’s events. Practically speaking, this wouldn’t have worked for us as not all members of the care circle had easy access to it when they left the community to attend to family events outside of the community and off the island. What worked for me was to go home, pour a glass of wine or a cup of tea, and write an e-mail in the solitude of my own home enabling reflection and contemplation. It was comforting to know that I was sharing not just details, but the weight of this profound responsibility with all of the care circle, all at the same time.

In hindsight I wish that all of us in the care circle had taken advantage of this possibility. Although not totally conversant in what is out there, tools like Yahoo Groups, Facebook or, g-mail circles support this type of activity.

IV. Surprises!

7) Accept that you don’t have to organize everything!

Day to day, people would say they wanted to do something to assist Joyce and her care circle members. It was bewildering how to respond appreciatively and meaningfully. Initially I had thought we would need a food coordinator to ensure that meals were available. I noticed however, that in fact each day, food was arriving from several corners of the community. The most practical thing that spontaneously occurred was people were sharing left overs. I often marvelled at the fact that you don’t need to organize everything.

V. Closure for the Co-housing Community

As Joyce’s death approached there was yet another challenge: to meet community members’ shared need “to do something” when there was little more to do. To assist in filling this need I suggested that people create a flower garden of mums in autumn colors that could sit outside her patio doors in view of her hospice bed just inside. She was delighted to awaken to a forest of sixteen bouquets! This small gesture allowed

those who were outside the care circle to feel part of the “inner story”, while keeping Joyce’s environs quiet and peaceful.

A celebration of life was held one month after Joyce’s death. The challenge to those organizing it was to meet the variety of expressed desires by community members that it be informal, not too religious, celebratory, and be honoring of Joyce’s life beyond the co-housing community. To strike this balance, in our Common House we set aside a room for quiet reflection with an altar highlighting epic moments of her life. In the hall, her photo albums and treasures from travel, as well as numerous protest posters from the seventies that she had hand painted, were displayed. We held the celebration with food and music from members of the community, and provided opportunities for people to speak, in our dining hall.

Joyce had asked us to make sure that gestures of thanks were created. Her friends purchased and arranged for planting of a beautiful oak tree in front of the patio doors of the Creekside Common house. In addition her estate and US friends contributed to the commissioning of a stained glass window that is now placed above the fireplace in our Common House sitting area.

VI. Afterwards

It has taken a good rest and a long time to reflect and to make sense of these ideas. I do not pretend that it is a comprehensive list but it describes the highlights of our experience of caring for Joyce in our new co housing community. In the end, we were able to say with satisfaction, “we did it”. Tired and wiser, I hope others are able to do it with less stress and wasted energy. This is my final tribute to Joyce and I hope a worthy final gift from her life.

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