



Walking Together

by Donna Rietschlin

Families and communities supporting people with intellectual disabilities through the aging process and when dying

Death, aging, illness – these realities in our lives can cause us to rise to a higher ground or can drop us into old patterns. Usually such stressors cause both to happen and the responses come in waves. It happens to everyone involved: the Core Member¹, the friends of the person, the team supporting the Core Member in community and the family of the Core Member. How do we walk together in these blessed, fragile and sometimes explosive moments?

This brief writing shares some of the experience in L'Arche Ottawa as we walked with families and Core Members through the Core Member's aging and dying. It is specifically about journeying with families.

To walk with families we first begin with our own families. What is our story? Was our family of origin a place of nurture and support? Was it a place of harm and loneliness? Most of us probably experienced some wonderful gifts as well as some great challenges in our families of origin. To walk with someone else's family it is necessary for us to come to acceptance of our own story, no matter how wonderful, no matter how difficult. If we are unable to bless our story we will not be able to walk into another's history without coloring it with our own subtext. This is crucial work if we are to journey with someone else's family.

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1. Core member is the term used in L'Arche for the person with intellectual disabilities supported by the organization. Other organizations might use the term client or consumer.

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To walk with families, we own our own story and listen to that family's story. Sometimes there is amazing gift and sometimes there is deep hurt. In most families, there is both. Families are complex and my experience is that most people and most families do the best they can in the situation. This does not mean things are perfect. It does mean intentions are usually good and people care for one another as best they can.

In L'Arche Ottawa we have discovered that when walking in painful areas with family members, it helps if we keep the Core Member, the person we all care about, at the center of our circle. . He/she probably loves both the community and the family. We need to work together for the person to be well. From time to time we have had meetings without the Core Member present. At these times, we bring a picture so everyone remembers why we are meeting and that the Core Member is at the center of our gathering.

We need to build relationships with Core Member's families and other loved ones. It is ideal if this building happens before serious health issues emerge or aging has a significant impact in the Core Member's life. Creating a safe place to hear the family's stories builds trust and often opens wonderful, privileged stories. We have met folks in living rooms, coffee shops, over lunch and in hospital cafeterias. Often, when we know someone well, we love him or her more fully. We have found this is true of families as well as individuals.

Create opportunities to celebrate the Core Member together. Birthdays are great! We celebrated one person's 50th birthday early because we were concerned that her dementia might be so progressed that she wouldn't enjoy the celebration by her actual birthday. The family and the community gathered for an afternoon. Most of us wore her favorite color and wore sunglasses, also a favorite. The family was amazed at the number of friends that came to celebrate. One of her brothers told me the next time we met that he no longer felt like it was a tug-of-war between the family and the community. Just like he left his family of origin and created home with his wife and children, his sister left her family of origin and created family in L'Arche.

We have learned that some families want regular phone calls; some want e-mails. Find out what works best for the family and be faithful. If something comes up and you aren't going to call or write at the agreed upon time, let people know in advance.

We have learned that some families want one person in the family to be the liaison with the community. Who is this person? If there are many siblings, it is good to know who the family sees as the person with moral authority. Invite the family and especially that

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person to events in the Core Member's home and in the larger community. Let them know when teams change. Again, create a relationship!

We have walked with families who really needed one person in our community designated to walk with them. Be wise about choosing that person. Our experience is that the person needs to have a gift for creating relationship. The person may or may not already have a relationship with the family, the important piece is that the person is willing to work on the relationship and will be in community for a period of time. The person needs to be able to respond without becoming defensive or reactive. The person needs to be close enough to the Core Member and home to answer the families' questions/concerns. Humility and the ability to say 'I don't know but will get back to you' is important. Follow-up is essential. Often it is good to say, 'I'll get back to you on _____ and name a specific day. If the information is not known or clear by that date, honor the commitment and call the family. Let them know where the process is and set another date for talking about it. The person must be able to talk with the team supporting the Core Member without blaming the team or the family. The person must be able to recognize her own feelings in a tense situation and be able to put them aside to be present to the other(s).

Families have known their son/daughter/brother/sister for many more years than the community has. We need to be humble and recognize that those relationships were there before we were involved and will be there when many Assistants² have moved on. We have found that asking people for their stories and their insights has made us all richer. We come to know the gift of the Core Member more fully through their family's history.

We have walked with a number of families over the past 15 years as their beloved family member, also a beloved Core Member of L'Arche Ottawa, has aged or died. The experiences have varied from person to person, from family to family. It seems the essential bit is to nurture the relationship such that the Core Member is free to love everyone in the circle and knows that he/she is loved.

*Donna Rietschlin
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2. **Assistant** is the term used in L'Arche for the person walking with, supporting, and caring for the person with intellectual disabilities. Other organizations might use the term support worker or caregiver.