



Making an End of Life Plan¹

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Conscious that several of their members with developmental disabilities and some of their older assistants were likely to die in the coming few years, the people of L'Arche Vancouver asked its coordinating team to develop a process to help everyone in the community think about their stage in life and to make an end of life plan that would express their wishes for their care, their estate and their funeral and burial. Here is a description from two of the team members.

“The weather,” was Gwenda’s response when I asked her what they talked about at the Seasons of our Lives meeting. Gwenda has Down syndrome, and I wondered whether she had been able to follow the content of the meeting, which I knew was to be about ageing and dying. But, I also knew she had lost important family members in recent years. Maybe, like many other people, she just didn’t want to talk about death.

– Marni, a friend of Gwenda, in L'Arche Vancouver

We encouraged everyone to choose a friend or family member to talk with in making decisions. We developed a **three-stage process**, with three large meetings to initiate the stages. The meetings were for all of us in L'Arche, people with disabilities and the longer-term assistants especially, and any family members and friends who wished to join in.

The **first meeting**, which we called “Seasons of Our Lives,” inaugurated a phase of looking at where each of us is in our particular life journey. We spoke very simply about the life cycle, drawing parallels with the seasons in nature. We spoke about some of our friends or family members who had died, and about the fact that we will all die one day. At the meeting, each person received a one-page summary of the “Seasons of Our Lives.” Some identified themselves as in the spring or summertime of life, and others were able to recognize that they were in the autumn of old age. Just as important and sometimes more difficult, the process helped some of us come to terms with the fact that our parents were

1. *More Than Inclusion: Honouring the Contributions of People with Developmental Disabilities*



approaching death. The fact that we were all sharing in these conversations together seemed to help those who had difficulty with this topic.

At the **second meeting**, we introduced the topic of planning for old age and death. We invited a speaker from a funeral home to tell us what happens to people's bodies when they die and what the options are – a closed or open casket, for instance, whether to be buried or to be cremated and where one might be buried or have one's ashes placed. The speaker talked simply and sensitively, and people could ask questions. Her presentation seemed not macabre but quite natural. Most of us, disabled or not, realized that we didn't know much about what happens at death.

Bill Collins, a man with a mild disability who was one of the founders of L'Arche Vancouver, agreed to be the first person actually to make an end of life plan. Bill was suffering from Parkinson's disease and was conscious that his health was failing quickly. In the ensuing several weeks, we worked with Bill and he helped us figure out the parts of a decision-making package that everyone could be offered.

The **third meeting** was a celebration of Bill and of the completion of his plan and also the inauguration of end of life planning for the rest of the community. It helped that Bill, who was respected as a leader, had made his plan. He lifted it up proudly and told others that it was a good thing to do. At the end of that meeting everyone received the package we had prepared. At this time, we also encouraged people to join a memorial society, since doing so offers substantial financial savings.

Completion of the plan can take some months as the plan has several phases – preparing a living will, choosing a power of attorney, preparing a last will and testament, deciding on and purchasing a burial site and prearranging the funeral. People often want to indicate their preferences for visitation and the funeral service – listing songs and readings and people they would like to speak.