



Grief Support Group Backgrounder



by Jane Powell
L'Arche Toronto | 2013

This and the other two documents that it accompanies (the *Grief Support Group Manual* and *My Grief Support Group Journal*) are made available by L'Arche Canada (www.larche.ca) on its Aging and Disability website: www.aging-and-disability.org/grief_support_kit

The Manual sets out basic principles and ground rules, suggestions for getting started, our goals week by week, and also a detailed plan and worksheets for each meeting. The Manual integrates learning from our initial group and from our subsequent experiences.

L'Arche Canada is part of the International Federation of L'Arche. In L'Arche communities, people with and without intellectual disabilities share life together in households and creative day programs.

Acknowledgments

Thank you to the members of L'Arche Toronto's grief support groups and to my L'Arche colleagues—Lydia Banducci, April MacConnell, Mary Jane Kelley, and John Guido. Thank you to Diane Marshall, M.ED., RMFT, for reading our material on grief support groups. Also, thanks to Greg Lannan for his artwork. Thank you to Beth Porter for her editorial work and to Christine Higdon for her design.

—Jane Powell

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Photo of Greg Lannan
by Marion de Couto

A note about Greg Lannan's cover artwork

"The clouds and rain are a symbol for being sad in your heart.

The sun represents the light of God and choosing to be open to new things as well as sad.

The heart reminds of being loved and listening.

The tree can be a sign of protection, spending time together, and forgiveness.

The flower invites us to be light and love for others and reminds us we cannot do it alone."

Greg Lannan is a member of L'Arche Toronto

Grief Support Groups with People Who Have an Intellectual Disability

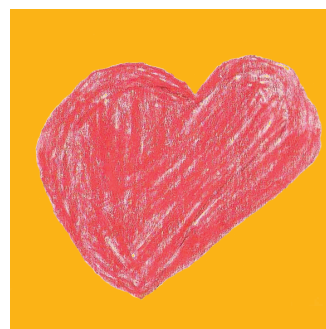
The Experience of L'Arche Toronto

A backgrounder to the *Grief Support Group Manual*
and the *My Grief Support Group Journal*

by Jane Powell

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Introduction: The need

Persons with intellectual disabilities, because of their intellectual impairment, have often been denied the right to grieve. Well-meaning individuals may say, “He does not understand!” Or, “Do not tell her—it will upset her too much.” In this way they have been disenfranchised. Such responses tell much more about those who make them than about the capacity of the individual with a disability to grieve and integrate a loss and move on! If grief work is not done, maladapted behaviours can emerge because of the person’s difficulty integrating the loss.

—*Toinette Parisio, Community Leader, L’Arche London*

Grief work after a significant loss can provide an opportunity for growth and integration of an important part of our lives that should not be lost. This is as true for someone with an intellectual disability as for someone without. This document describes the grief support work of L’Arche Toronto. We present this material hoping that others will recognize the importance of grief support groups for people with intellectual disabilities and will feel more confident to lead such groups.

Our Preparation

Before we began this work, one of the co-facilitators participated in a 10-week training session on Bereavement Group Facilitation at a local hospice. She had already also completed a Certificate in Grief and Bereavement at King’s College, Western University, in London, Ontario.

Our Limitations

Our experience is with conducting groups for people who have at least some verbal ability. We would need further expertise to conduct a group where people do not use language at all. There are some very helpful resources, however, especially the books by Baroness Sheila Hollins et al., listed in Resources, that might be employed in such a group.

Our experience with grief support groups

Our first group

A few years ago, based on our learning and our sense of the needs in L'Arche Toronto, we decided to run a basic 7-week closed grief-support group for 6 to 8 people with intellectual disabilities, led by 2 facilitators. We decided we would invite people who had some verbal ability even if quite limited. We required that group members make a commitment to attending all 7 meetings.

The persons we invited for our first group were all people with an intellectual disability who had lost either a family member or a close friend to death. Criteria for inviting individuals to join the group were either the person's having experienced a loss in recent years or our sense from knowing the person well that they had experienced losses that were unresolved. The time since the loss varied from six months to ten years. All but one person accepted the invitation.

Our experience with this first group was that everyone found it helpful, though in differing ways. Some had never had an opportunity to talk about their loss. Some had questions they had not been able to ask. Some had long carried confusing misconceptions. Having a closed group (no new members were added after it began) and the regularity of meetings allowed trust and intimacy to grow week by week.

The accompanying Manual provides an outline of the content and our objectives week by week and also a detailed plan and worksheets for each meeting. This Manual integrates learning from this initial group and from our subsequent experiences.

An on-going monthly support group

After our first group, we started a group that has met monthly for four years. The purpose was originally to prepare participants for the death of a parent. The group was a response to some L'Arche community members who expressed much anxiety around the topic of death, especially as they saw their parents aging. The community was concerned about how these individuals would cope with their parent's death. This group welcomed two people from our first 7-week group and an assistant. Sharing has become quite deep. Members sometimes bring a prayer or other item to share, and in various other ways they have taken ownership for these meetings:

- In a brainstorming session they named many topics they wanted to learn about.
- They decided to have individual sharing followed by 15 minutes of input on a topic at each meeting.
- Information is kept simple. Input may include an activity animated by a member.
- Before ending, the group decides on the next topic. The meeting ends with a prayer and members commit to thinking of one another during the coming month.
- Every six months they evaluate together their satisfaction with the group.

Topics include

- Relaxation and stress-reduction techniques (e.g. deep breathing and guided meditation exercises)
- How death or loss can change one's relationship with God (e.g., feeling angry with God or closer to God)
- How our strengths and gifts can help when we experience a loss
- How personal growth and new life can come from loss
- Coping with holidays, such as Christmas, which may be very different after a loss

The group discusses ways that learning can be transferred to deal with other changes and losses. For example

- Aging and changes in one's body
- Turnover of support persons
- Dementia in housemates
- Job loss, retirement, moving

A second basic grief support group

More recently, we ran another closed 7-week basic grief support group. It included two assistants who were grieving. The sharing in this integrated group was very rich. All members were aware of their common humanity and of mutually supporting one another.

At the same time we recognize that a grief support group may be a place where such integration brings with it a certain loss for the persons who have intellectual disabilities: While the presence of the assistants who were grieving may have brought a sense of security, there may have been less opportunity for the voices of the people with disabilities to be heard fully and for them to support one another in the unique way that can happen in a non-integrated group.

The value of ritual

Rituals may be customs within the group or public rituals (wakes, funerals). Usually, everyone can be involved in a ritual. Rituals can symbolically express experiences and feelings and help achieve clarity. Participants have become more ready to support their friends at public rituals. Each person knows that they can count on others being with them when they experience a loss. After a member loses a loved one, the group joins them in an activity (e.g., planting a rosebush in memory of their loved one).

Benefits of grief support groups

- Members say: “I know more what will happen when my parent dies. I know people will be there for me.” “I feel I am getting the garbage out.” “I am listening.” “People understand I need to talk and then I can try and let it go.”
- Outsiders note that participants are more supportive of others when they experience a death loss. Some are better able to express emotions. Some have become leaders or advocates for others. Some have grown in ability to speak publicly. As facilitators, we have been touched by the attentiveness and empathy members show one another.

Resources

L’Arche Canada’s website on Aging and Disability (www.aging-and-disability.org/) includes a section on Grieving with short videos by members of a Grief Support Group. The website’s Resources and Links section includes many resources related to grieving.

Professor the Baroness Sheila Hollins has prepared small books with evocative drawings by Beth Webb and with various co-authors. We have found these books, prepared out of Dr. Hollins’ experience treating people with intellectual disabilities, are very helpful. *When Dad Died*, *When Mum Died*, *Ron’s Feeling Blue*, and other titles are obtainable from Books Beyond Words, www.booksbeyondwords.co.uk.

Ruggs, Sharon, et al. *Memories Live Forever*. ISBN 0-9652410-0-9. This little grief workbook written for children can readily be adapted for adults with intellectual disabilities. It may be obtained for \$5.00 (USD) from www.compassionbooks.com

Worden, W.J. *Grief Counseling and Grief Therapy, A Handbook for the Mental Health Practitioner*, 4th ed. ISBN-13: 978-0826101204, Springer Publishing Company, LLC, 2009.