



A Vision of Supporting our Members Through Major Life Transitions

We write this paper to claim and announce our vision of supporting individuals in our communities as they age, develop dementia, or are dying. We want to do so by first addressing the needs of the individual with an intellectual disability; yet this must be done within context. We live in a society that often marginalizes people who have an intellectual disability, people who are older, and people who are dying. Therefore persons with an intellectual disability who are aging or dying are at particular risk of being devalued. For this reason, we need to clearly articulate our core values in this area. We are in dialogue with others who are doing similar work today. This work is rooted in both the need and the opportunity before us.

When we first welcomed people with disabilities to our communities twenty or thirty years ago, we offered them 'a home for life'. At the time, we did not imagine what the situation would be in 30 years. Many of the people we first welcomed are now elderly; others are 'aging' prematurely. We have also welcomed younger people with complex medical, emotional and physical needs. L'Arche communities have had to face the limits of our ability to provide care in front of such compelling and complex needs.

We have had the privilege of walking with many in our L'Arche communities through loss and death. We have done this in diverse ways as we have tried to balance the needs of ill or dying individuals with those of others in their homes and L'Arche communities. We have been able to support some of these people in their homes or in other L'Arche homes; we have supported other individuals in hospital, long-term care facilities, or in a free standing hospice.

What has been important for us is to find a way for individuals to receive quality care while maintaining our relationship with them wherever they are living. We have recognized the importance of creating support circles around the person, involving friends and family as appropriate. Our collaboration with professionals has increased our competence while giving us the opportunity to share our gifts. There have been significant challenges and significant blessings. We have been called to look at and deepen our identity and mission as L'Arche communities.

We have discovered that relationships of mutuality between those with a label of disability and those who support them can become even deeper as they age, experience dementia, or are dying. We know these relationships are lived not only with considerable pain but also with considerable personal transformation. They can be a tremendous witness to the healing power of love revealed in the vulnerability of loss. This witness has deeply touched the lives of our communities, families, friends, and many in the wider community.

Core Values in Supporting Members with Intellectual Disability as they Age and Die

- ✧ Our communities are built on **relationships** of mutuality, forgiveness and celebration. We commit to maintaining these relationships throughout a member's life until death whether the member is living in a L'Arche home or in another facility.
- ✧ All of our support, planning and decision-making is **holistic and "person-centered"** - building on the physical, emotional and spiritual strengths, needs and desires of the individual. We want individuals to have as much choice as possible in their lives.
- ✧ "**Circles of Support**" including family, friends, professionals, and community members, help insure that the individual's wishes and desires are central to all decisions.
- ✧ **Home** is a key value and cornerstone to our identity and mission. Our first goal is to provide for changing needs of individuals within their homes if they desire this. If it is not possible for individuals to remain in their own homes, they often experience significant loss and they need to grieve. Moves can also lead to new opportunities.
- ✧ Sometimes, due to personal choice (e.g. a quieter setting), concern for the other members of the home, or the limits of our ability to provide appropriate care, **the individual might need to move** to another home or a care setting outside the L'Arche community. Leaders must make these decisions with care, listening to all who are directly involved.
- ✧ We will be creative and proactive in order to **develop appropriate resources** (both human and material) in order to respond to the changing needs of members. We know we cannot meet every need, and we must be wise stewards of the resources we are given.
- ✧ We will **collaborate** with others in the developmental services sector, health (including C.C.A.C. and Long Term Care), counsellors and ministers, hospices, etc. We want to use generic services (those available to all) whenever possible.
- ✧ We will **advocate** for resources and access to services not only for our members, but also for other vulnerable people in need.
- ✧ We will give **emotional and spiritual support** not only to individuals, but also to those around them who are grieving the many losses involved. The grief of people with intellectual disabilities is often discounted, and we do not want them to be alone when confronting the many, sometimes overwhelming, losses they experience.
- ✧ Loss and pain are opportunities for **transformation**; we will support individuals and their communities to discover and celebrate life in all phases of the journey. Walking with loss and death is changing us. We are committed to be open to the new life that is given as we remain faithful to our most vulnerable members.