



Circles of Support and Decision Making

Around Seriously Ill People with Disabilities

**Compiled by
Jane Powell**

INTRODUCTION

The following was created in response to the questions of when, how and who decides if a person with a disability needs to move from a L'Arche home to long term care, hospice or other alternative settings. It has been a very difficult question for us as it has been for families.

When we welcomed people with disabilities years ago we were offering them a home for life. This was also the understanding of their families. So this process needs to be done with much sensitivity and in dialogue with the family.

It would very helpful if we were able to have a checklist, where, if you said yes to eight out of ten questions, you moved. But we know that that is not the reality as each person and situation is unique.

We created this package to help communities¹ look at a number of different factors that need to be considered. Once this information is gathered it may be possible to have a clearer sense of direction.

This material could be helpful and inspiring as well to other organizations as they search for ways to support people with disabilities and teams through these difficult questions.

More and more we will find ourselves in front of the situation of needing to make decisions around the types of support we are able to offer people as they age and die. We hope that with some people we will be able to support them in their home until they die. With others we will become aware that what we are able to offer no longer meets their needs. For this reason we need to continue sharing information and “best practices”.

Let us continue to walk together and hold each other in our hearts, particularly those who are most fragile and dying.

¹ L'Arche communities are places of belonging where “differently-abled” people share their lives

CONSIDERING MOVING TO LONG TERM CARE/HOSPICE FROM A HOME

Principles and Assumptions

- 1) Each individual is unique and has unique gifts and needs.
- 2) The desire or choice of a person, although one of the main considerations in making such an important choice, is not the only one.
- 3) Key persons affected by the decision will be involved as much as possible at the appropriate level.
- 4) This is a decision that touches very fundamental values so it is difficult and often painful. While people involved will do their best, it is possible they may hurt each other in this process.
- 5) It is a decision that puts many people in touch with issues of loss and grief.
- 6) Treatable medical conditions will be, as much as possible, ruled out as the possible cause of the deterioration of the disabled person's health.
- 7) Pastoral support should be in place at many levels during this process and available after the person has moved to long term care.
- 8) Outside resource people with knowledge of the ill person's condition should be consulted if at all possible.
- 9) An outside facilitator might also be helpful.

Suggestions for a Process- Use What Seems Helpful

- 1) Have different people gather or share information on the different factors that are listed on the following page. Use the suggested tools to do so if that is helpful.
- 2) The following options will be considered in the following order of priority:
 - a. Making adaptations/adding resources to the home the person presently lives in. The composition of the team may need to change.
 - b. Seeing if a different home would be helpful
 - c. Looking at Long Term Care /Hospice Options

- 3) A circle will be created around the person. It will serve as a “wisdom body” for the Leadership Team² who will make the decision in the end. There is an attached Circle appendix. The circle would meet (the number of times would vary) and their recommendations would be presented to the Leadership Team. A representative from the Leadership Team should be present at the circle meeting. This would most likely be a Homes/Residence Coordinator.
- 4) The Leadership Team would look at the recommendations, take steps to clarify if necessary, and make a decision that would then need to go to the Community Council³ and the Board for approval.
- 5) Once the decision is finalized it would need to be presented to the person, their circle, and their team and housemates. It should be presented in the clearest and most compassionate way possible. There will be a need for much consideration, sensitivity and creativity in processing this with all involved.
- 6) The Leadership Team would then work with the circle to develop an action plan that would include a person and timeline for each step. This would be either the process for admission to Long Term Care or another plan of action to continue to support the person with a disability in the community.

Factors that need to be considered in the process

- 1) The health status and prognosis of the person with a disability
- 2) Desires of the person with a disability
- 3) Physical environment
- 4) Team considerations
- 5) The impact on other people with disabilities
- 6) Financial resources
- 7) External Resources
- 8) Are there other people in the L’Arche community (organization or residence) that will need similar care?
- 9) What is the “emotional” health of the community? What other losses (actual or anticipated) are community members in front of?

² The leadership team in L’Arche might typically include what, in other organizations would be, the Organization’s Director, Residential Director, Human Resources Director

³ A Community Council in L’Arche would typically include members of the Leadership Team as well as other long term community members. In other organizations this could correspond to an Advisory Board to the Executive Director

1) STATUS AND PROGNOSIS OF THE PERSON WITH A DISABILITY

Obviously this is one of the key factors to be taken into consideration.

The first step would be to ask the doctor for as much information as possible. If there is an association around the condition it is often a good source of information concerning the possible route the illness will take and the prognosis.

The following are some tools that might help to look at the potential risk for the person with a disability as they are being cared for at home.

Delirium: a differential diagnosis from BPSD is a tool that helps to diagnose delirium, as opposed to behavioral and psychological symptoms seen in dementia. This would be particularly helpful if there was a rapid change in a person's condition and you wanted to try and determine if the person was delirious or not. (cagp.ca)

The Mini Nutritional Assessment is a tool to evaluate if someone is at risk of malnourishment.

The **Geriatric Depression Scale (Short Form)** is a tool that can be used to determine if someone who is articulate is depressed or not. Depression may cause a person to look like they are experiencing a greater decline than they are, and is often treatable.

The Braden Risk Assessment Scale is used to determine if a person is at risk for pressure sores. Pressure sores can be a serious medical problem. Prevention requires frequent repositioning during the day and night which can place a significant demand on the team.

Pain control needs to be considered. The **Facial Grimace and Behavior Checklist Flow Charts** may be used as a tool to consider if pain, or pain control, is an issue. Pain can be difficult for the team to be in front of and pain medications can also be quite complicated.

Another major concern is the possibility of falling. The tools are not included but it is certainly something that a physiotherapist or an occupational therapist could be asked to assess.

A decision will also need to be made in each situation as to what medical procedures the team, certain members of the team, or the community medical coordinator or nurse (if there is one), are able to carry out. It is important to keep in mind that the focus of community care would be to teach the team how to do the procedures they are coming in to do. We need to know clearly what we can and cannot agree to do.

2) DESIRES OF THE PERSON WITH A DISABILITY

The choice of where one lives needs as much as possible to be, a personal choice. Some people may be very clear that they would like to stay in their current home if possible and others are clear that they would rather be in a long term care facility or a hospital. It seems best that a long term assistant⁴ who is not immediately involved in the situation does this with the person concerned.

3) THE PHYSICAL ENVIRONMENT

The physical environment is also a major factor to consider in deciding if someone is able to stay in their home or not. The environment can become an issue due to cognitive or physical impairment. Two books from the Canadian Housing and Mortgage Corporation **At Home with Alzheimer's, Maintaining Seniors ' Independence through Home Adaptations and the Safe Living Guide** are available. They may be helpful in pointing out things that may be unsafe and giving suggestions of ways to make the situation safer. www.cmhc-schl.gc.ca/en/co/maho/adse/index.cfm

It would always be important to consider if there is a home in the community, other than where the person lives, that would be a more appropriate physical environment. That does not necessarily mean that the person could move there but it is good to consider the options.

4) TEAM CONSIDERATIONS

It is always very important to determine/discern if the team is able to provide the type of support the person with a disability will need. People need to feel they can choose to be in a situation where they are caring for someone who is more fragile and possibly dying. We cannot automatically expect everyone to choose, or to be well, in this situation.

The leadership is very important. The leader needs to be someone who has a vision around providing this type of care as well as certain competencies in this area.

Communication within the team and with outside people, especially medical people, is extremely important. So there needs to be someone on the team who is able to do this in a professional manner. If the community has a medical reference person they could help with this.

Each community/organization will need to find its way of assessing how the team is doing. An external resource would be helpful for this evaluation.

⁴ « **assistant** » is a term used in L'Arche for a person walking with, supporting, and caring for a person with a disability and may be called a support worker, educator or caregiver in another organization

5) THE IMPACT ON OTHER PEOPLE WITH DISABILITIES IN THE HOME

If we know the people with disabilities well, we are hopefully able to have a sense of how much stress they are experiencing. We usually know what type of behaviors to be looking for. The ill person with a disability is of course not the only contributing factor here.

It would be important though to note if more than one of the people with disabilities in the home was experiencing higher than usual levels of stress.

Are the usual things such as relatively normal meal times, house meetings and usual outings able to happen?

Again having someone from outside the home spend some time listening to each person with a disability might be helpful. Maybe a long term friend from outside the home or a family member could be asked to check in with the person and give feedback as to how they are experiencing the illness of their housemate.

If the person who is ill has dementia using the “What is Dementia Booklet?” www.dsscotland.org to help the other people with disabilities understand what is happening might be helpful. The discussion may also allow for an opportunity to explore the feelings that are evoked in living with someone who has a dementia.

6) FINANCIAL RESOURCES AVAILABLE

Caring for someone who is very ill, or needing 24 hour support because of a dementia, is unfortunately very costly. It would be important for the Board of Directors to assess the financial situation and see what finances they are able to allocate to the situation. People may need adaptive equipment, overnight support, special daytime support or any other number of things, depending on the individual. Exploring the possibilities of special grants or negotiating with the ministry may be options. Finances do need to be considered though.

7) EXTERNAL RESOURCES

We need to investigate what resources and supports are available from outside the community/organization. These would include supports for the individual who is ill, for the team, for other people with disabilities in the home and possible financial resources.

The following are some possible options to explore:

Family, friends, volunteers

Community Care Access Centers (CLSC in Quebec)

- use different therapists available

- they may do a comprehensive assessment of the ill person

Alzheimer's Society, Cancer Society or other network around a particular illness

Palliative care doctor or agency

Pastoral Supports for all involved

Regional Geriatric Assessment Units

8) ARE OTHERS IN THE COMMUNITY/ORGANIZATION NEEDING SIMILAR CARE?

If there is more than one person with a disability in the community/organization where long term care is being considered it might be worth looking at the possibility of creating a setting within the community where that care could be provided. We need to realize though that we are not nursing homes.

Many of the same factors considered in looking at an individual situation would need to be looked at in creating a setting as well.

9) WHAT IS THE EMOTIONAL HEALTH OF THE COMMUNITY? WHAT OTHER LOSSES IS THE COMMUNITY IN FRONT OF?

This would be a very difficult thing for the community to gage for it's self. It would be important to consult with appropriate outside references. These might include the Regional Coordinator, the Pastor, Board President or a therapist who know the community well.

What is important to acknowledge is that when we are in the midst of a difficult situation where we have a lot invested emotionally, it is hard to make an objective decision. We may be wise to ask others for their reading of the situation even though those more directly involved will ultimately make the decision.

APPENDIX

CIRCLES AROUND SOMEONE WHO NEEDS SIGNIFICANTLY MORE SUPPORT OR IS TERMINALLY ILL

Assumptions and Principles

- 1) Each circle will be unique as it is responding to a particular individual.
- 2) The Leadership Team makes the final decisions about how to respond to the person in need. There needs to be close communication between the Circle and the Leadership Team. The Homes Coordinator would normally be this link. If not possible a delegate from the Leadership Team would chair the circle. They would also be the person that ensures the implementation of the recommendations (both short and longer term response).
- 3) These circle meetings are called because of the fragility of the person with a disability and so can be quite emotional at times. Some people who would normally be present at the meetings might find it too difficult. They could give their input in another way, if that seems more appropriate.
- 4) The involvement of family throughout the process is crucial.
- 5) The circle should take time to pray or be peacefully and quietly together.
- 6) When a community has more than one person with a disability, who requires additional special care, an alternative home within the community might be considered in addition to looking at external placement.

Goal of the Circle

- 1) To gather information and make a recommendation to the Leadership Team about providing support in the current situation and what they consider the most appropriate way of responding to the situation long term.
- 2) To be involved in helping to support the person with a disability by making suggestions for a short term response and possibly helping implement these plans until a final decision is clear.

When is a Circle Created?

A member of the Leadership Team, in consultation with the Community Council, will call together and facilitate a circle around a person with a disability when the Leadership Team feels that this is the best way to respond to the disabled person's situation.

Who should be part of the circle?

The following people should be included in the circle if it is at all possible.

- 1) Someone prepared to speak about the desires of the person with a disability in regards to their living situation. The person with a disability may be expressing this verbally or through their behavior. This could be a long-term friend.
- 2) Someone from the person with a disability's family or their substitute decision maker.
- 3) Someone who can speak to the actual medical status of the person with a disability and the probable progression of their condition or conditions. If the community has a medical care coordinator it would most likely be this person.
- 4) Someone, most likely the Head of House, who can speak about the impact the person with a disability's medical condition and changing needs, are having on the other members of the household – people with disabilities and assistants. The rhythm of life in the home may also not be helpful for the person with a disability concerned.
- 5) Someone who has an awareness of what other resources are available in the larger community. Examples could be the Alzheimer's Society, C.C.A.C, Cancer Society, and Palliative care providers.
- 6) Someone from the Leadership Team.
- 7) The person organizing daytime support if this is an issue.

Process Suggestions for arriving at a recommendation to Leadership

N.B - use what is helpful
- all of this should be done prayerfully

- 1) Brainstorming the ideal living situation for the person with a disability concerned and then looking at what parts of this are realistically possible.
- 2) Naming the pros and cons of the ill person with a disability staying in the setting where they presently live or moving to a smaller setting. This applies particularly to people with dementia.
- 3) Naming what changes would need to happen, or resources made available, for the person with a disability to stay in their home or another home in the community.

- 4) The meetings should begin with updates of how things have been for the person with a disability and their household since the last meeting. This way people are on the same page.
- 5) The meeting should end with a clear plan of action of who is doing what and a time line.
- 6) The person with a disability could look at a pictorial booklet called Looking at my Home to help them articulate their desires.
- 7) It might also make sense to simply list major issues/concerns and then do next steps for each.

Possible Agenda for 1st Meeting:

1. Prayer/quiet – centering around the person the circle is for – take a picture.
2. Sharing and agreeing to guidelines (Principles and Assumptions of circle).
3. Introductions if people don't know each other. Brief discussion of circles of support, particularly purpose and clarity that it has a very significant place but is not a decision making group.
4. Listening to each person about what they are seeing, know, or are concerned about. Probably beginning with, but not necessarily, the Head of House and community Leadership Team representative.
5. After listening to each person, what are the issues/concerns that need to be addressed?
6. Are there next steps to take and who can help make sure they happen? There will probably be more information to gather. Keep in mind that there will probably be shorter term and longer term issues to respond to.
7. Set the next date.
8. Brief checkout (2 sentences) from each person.
9. Closing Prayer.

Guidelines of the Circle

1. Try to come with openness to the different perspectives each person will bring. It is a gift.
2. Try to be non-judgmental of the others (use I statements ...)
3. Confidentiality needs to be respected. The group needs to be a safe place for people.
4. We hope that the group will bring unity and a sense of “being in it together”. But we may hurt each other along the way, so may need to ask forgiveness and to forgive each other so we can work together in the person with a disability’s best interest.
5. Agreement on the principle and assumptions of the circle of friends.
6. Trust that people are coming with the best interest of the person with a disability.

WHAT IF SOMEONE HAS A DEMENTIA?

It is difficult to make a plan with/for someone with a dementia because each person is affected so differently.

Many of the factors which need to be considered are the same as one would consider if someone was thinking of moving from a home to long term care, hospice or other alternative setting. Those that might need special emphasis would be when looking at how the team and other people with disabilities in the home are doing. Behavioral and grief issues would need to be given particular emphasis.

With someone with a dementia it might actually be at the stage when the person is experiencing difficult behaviors that it is hardest to support. It may actually be easier to provide care when they are in the end stages of the disease.

We need to remember that almost everyone with a dementia will eventually need “total nursing care”. We need to take this into consideration when planning.

Transition and especially change of environment can be very difficult for someone with a dementia. We need to be aware of this and try to limit the numbers of moves and adjustments we ask someone to make.