



“What are you doing?”

Francine B.

## **Introduction**

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For some time now, a certain reality has been imposing itself on us, and it is beginning to have a significant impact on our community life, especially life in our homes. This reality is the aging and loss of autonomy of L'Arche's core members, people with intellectual disabilities. More specifically, research clearly shows that a significant percentage of people who have Down's Syndrome develop Alzheimer's and suffer the cognitive impairment it brings. But beyond the numbers, the statistics, and the studies are people – men and women we know, and with whom we have meaningful relationships. And there is everyday life and the efforts that L'Arche assistants make, to the best of their abilities, to accompany core members. Some time ago, as the Community Leader of l'Arche Agapè, I was privileged to know Francine, a woman of great gentleness, warmth, and vulnerability. Little by little, we watched as Francine changed, as she lost her abilities. Then the diagnosis came: She was developing Alzheimer's Disease. While we tried to accompany Francine, we felt the need for more training, the need to learn, to understand, and to develop new ways of supporting her. We were thus better able to “walk with her” until her death, to be present to her, to be supportive and loving.

The idea for this guide grew out of that experience and our reflection on it. Three people met and shared their knowledge and experience in order to create a document that would be useful and simple to read, a document addressed to L'Arche assistants, in particular those in our homes, who live side-by-side with people suffering from Alzheimer's. Laurence Lendomy is an assistant at l'Arche Agapè. During Francine's final months, Laurence was the person closest to her. Nancy Lamothe, Community Leader of l'Arche Agapè, brought to this task the experience she gained working at the Alzheimer's Society's Carpe Diem house in the Mauricie region of Quebec. The third contributor was Marie-Claude Savard, Coordinator for Carpe Diem (Alzheimer resource centre in the Mauricie region) member of L'Arche for almost 15 years. I would like to thank them most sincerely for their time and dedication to this project. I hope you will appreciate the material that follows. I especially hope that the tips, the “how-to” ideas, and the other information in the guide will help you to live even more deeply your relationship with the person you are accompanying and to discover all that is beautiful and holy in that special companionship.

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## **Intellectual Disabilities**

**and**

## **Alzheimer's Disease**

The majority of our members with intellectual disabilities were welcomed in their thirties and have now been in our communities for over 30 years. Today, they are slowing down; they seem less able—simply put, they are aging.

Sometimes, their health suffers. They are changing and may develop a variety of illnesses.

This manual is intended to be a guide for caregivers in homes, whatever your age or experience (or lack thereof) working with the aged. We hope to provide tools you can use as you embark on what will become your daily experience: accompanying a person who has an intellectual disability and is developing Alzheimer's Disease.

Our suggestions and comments are grounded in our research and experience with people who are aging. However, this guide does not pretend to be a scientific manual. Every individual is unique, and the disease may take many different forms from one person to another. You will also certainly do your own analysis on the basis of your experiences, and that will also enrich your understanding.

Written by Laurence Lendormy  
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## Aging and Alzheimer's Disease

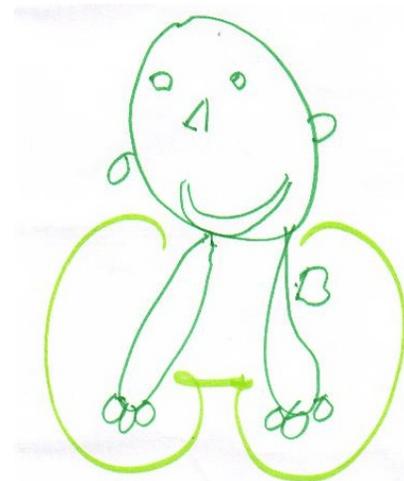
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The first signs of Alzheimer's Disease are no different from the normal signs of aging.

- declining, slowing down
- forgetting little things, having to search for words, losing things
- confusion

It's important not to overreact to these signs. They are common to all people as they age. A person with an intellectual disability may demonstrate these same signs earlier or more intensely than other people do. In addition, keep in mind that these signs can seem more amplified when someone is suffering from an infection of some kind.

When accompanying an aging person, it is critical to take the time to objectively observe the individual. Write down your observations every day – what is going well; what is not? This will enable you, over time, to develop an accurate sense of the changes in the individual's general state.



Francine in a wheelchair – drawn by Bernard

## Alzheimer's Disease: Definition, Signs, Treatment

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**Definition:** Alzheimer's Disease is a degenerative disease which causes lesions to develop in the brain. The disease may affect all aspects of an individual's life, that is to say, his or her thoughts, emotions, moods, temper, behaviour, and physical capacities. Alzheimer's affects every person differently.

The progress of Alzheimer's Disease can generally be described as comprising three phases

<b>Phase 1:</b>	Small lapses of memory about recent events, often passing unnoticed, but causing stress nonetheless.
<b>Phase 2:</b>	Loss of short-term and medium-term memory. Difficulty doing certain daily activities that require organization.
<b>Phase 3:</b>	Significant loss of memory Great difficulty – even the inability - to do daily tasks. Confusion, disorientation, incontinence.

**Signs:** At first, just,  
**LISTEN** to the people who interact every day with the person.

- *"It takes him more time to..."*  
- *"She's not doing as well as before..."*  
- *"He loved going there..."*  
- *"She always seems to be ill..."*

Comments like these should make you start to think. They tell you that the person now dresses more slowly and that it will take the person longer to get their things together. Other observations can indicate a loss of confidence or motivation.

Small, daily changes like these can often go unrecognized when we live with someone, because we tend to adapt to them without thinking about it.

So, **WRITE DOWN** your observations, considering the comments of relatives, friends, teachers, etc. who know the person well.

**Treatment:** There is currently no cure for Alzheimer's Disease, nor any treatment that can stop its evolution. There are, however, a number of medications that can slow down certain symptoms of the disease and delay its progress. Talk to the doctor about them. The best way to accompany people suffering from Alzheimer's is still to continue to stimulate their senses and to involve them in activities that call on their strong points and capacities, even if it takes longer for them to do things. Activities like these will be gratifying and can improve their quality of life.

*Remember, it is up to you to adapt to the person and not the reverse.*

## Key Observations: What should we pay attention to? What are the symptoms? When should we consult the doctor?

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To distinguish the symptoms of Alzheimer's Disease in an aging person, think about what he or she is like today. The symptoms consist of a series of clearly observable difficulties related to the following:

### - **Changes in behaviour**

(disorientation, agitation ...)

Spatial disorientation (*a person who has trouble finding obvious places in the house – e.g., his room, despite having lived there for a number of years*), temporal disorientation (*a person who changes into it's pyjamas at 1 o'clock in the afternoon*)

Signs of hesitation when walking, especially if the colour of the floors changes.

The person gets upset when they no longer knows how to express their emotions and wishes.

**NB:** Don't confuse agitation with aggression. Just because she makes violent gestures or is frustrated, that doesn't mean she is aggressive. Be aware that the illness doesn't change an individual's personality.

- **More radical mood swings.** (*For example, bursting into laughter at an inappropriate moment, or being inconsiderate and embarrassing others*)

- **Memory lapses** (searching for words, losing possessions ...)

*The person puts things in the wrong place: for example, they puts cookies in the dresser. They may hide things and forget where they put them. They may put clothes on in the wrong order – e.g., put pants on first and then underwear, or wear several pair of underwear at the same time.*

- **Impaired judgment** (*the person puts three desserts in their lunch bag; they cross the street without looking or stopping, wants to eat soup with a fork, etc.*).

- **Lack of interest** in what is going on around them, in things that have always brought them joy.

- **Anxiety** (fear of falling, fear of darkness, etc.). At such moments, you may note significant restlessness. They can't sit still. Their anxiety indicates that they feel a need they can't express verbally and clearly.

- **Signs of depression.** (*withdrawal, crying ...*)

Just keep making notes of your observation, and the observations of the team, of the person's relatives and friends. Don't try to sort out anything for the moment – just continue to write it all down.

During the annual medical check-up, share your observations with the doctor. Ask the doctor to do a complete check-up in order to eliminate certain obvious things:

- Check eyes, hearing, teeth, gastrointestinal problems, heart, blood tests, thyroid, etc. There are also tests that can refine the diagnosis of Alzheimer's Disease, such as **MOSES** (a test that uses a specific method of observing people with Down's Syndrome), et le **DSDS** (Dementia Scale for Down Syndrome). Talk to the doctor about them.

# The Importance of Knowing “How to Be” and “What to Do” When Accompanying a person who has Alzheimer’s Disease.

## Knowing How to Be: Humility, Patience, Generosity,

Follow the “Accompaniment Code”:

**Competence** will develop over time

**Compassion** means “putting yourself in the other person’s shoes”.

**Coherence:** There needs to be coherence between your words and your actions.

**Consistency** in the physical and human environment is important. Establish routines.

**Calm** and peaceful, serene and reassuring environment.

Respect the individual, listen to them and to those around them.

Accept the disease and the small losses (of capacity, of memory, etc.) that must be lived every day

Reassure the person and their circle of family and friends.

Be very gentle and calm.

Knowing “how to be” includes knowing how to care for oneself.

Know how to pace yourself and conserve your energies. It’s important to create a place where you can safely talk about your feelings and share your emotions - a circle of support for you and the other members of the house.

### Know-How:

Establish a plan of action with the team and close friends, the community, and the family.

### Have a verbal and non-verbal communication plan.

Signal when you approach – let them know that you want to talk to them.

Eliminate distractions (e.g., radio/TV).

Face the person, stand or sit so that you can look each other in the eye. Maintain strong eye contact.

Speak gently and clearly.

Give short and simple instructions, one at a time.

Use names and first names rather than pronouns in the conversation (e.g., say “Mary” rather than “you”, “she” or “her,”

etc.)

Phrase your questions so that they can be answered with a “yes” or “no” response.

Point to things when speaking about them.

Verbally guide the person through a task; you may eventually need to mime the action before them, or possibly guide their hands to execute the action.

Give them a limited number of choices (e.g., between two things).

“Doing something with someone” becomes more significant here. Never do it **instead of** them

**T**ouch the individual ... to get their attention, to reassure or calm them, etc..

**T**ake your time

Encourage them to talk about their memories; about photos ... This is their world now

### Prevention of agitation: Watch out for:

- fatigue
- pain
- hydration, constipation, the need to urinate
- allow him or her to move about freely.
- inaccurate interpretation of events:  
*cupboard doors are not closed. = There are people here*  
*stuff is all over the place. = I saw a dog in the shadows*

If someone is agitated, ask yourself three questions:

1- What is he or she doing when behaving this way?

2- In what circumstances does this

3- Does this behaviour have consequences? What kind? For whom? Knowing the person's family history and life story well may provide answers to these questions. *For example, when they were little, their house caught on fire; now they are afraid of candles .....*

#### Minimize stimuli

- Lower the volume of the telephone's ringer, the TV, and the radio.

- Clear space, get rid of furniture that is not being used and is in the way.

Keep in mind that the house is everyone's home. Don't turn it into a hospital

#### Prevention of Disorientation

- Establish concrete reference points in time and space. Respect for routines

behaviour manifest itself?

should determine the daily schedule. Don't tell the person about activities until the last minute.

Use photographs of the person to identify their place at the table, their room, a picture that identifies the bathroom ... Always keep the person's furniture and other things organized the same way.

Always close the curtains or blinds at dusk.

- Disorientation with respect to people: Identify yourself when you speak to the person. If they don't remember first names, use Miss, Ms., Mrs., and Mr. instead.

Remember that the emotional memory is still intact. Even if the person makes a mistake in your name, they remember you as someone who has helped them. Reassure them that you would never do anything that they don't like because you know them. Being a caregiver is your strength because you have lived with the person for a long time ...

#### The Eleven Absolutes:

Don't DEBATE; EXPLAIN instead  
Don't REASON; DISTRACT instead  
Don't SHAME; DIVERT instead  
Don't PREACH; REASSURE instead  
Don't REMIND; TELL instead  
Don't say "I TOLD YOU THIS"; REPEAT instead  
Don't say "YOU CANNOT"; say "DO WHAT YOU CAN" instead  
Don't ORDER; ASK instead  
Don't DEMEAN; ENCOURAGE instead  
Don't FORCE; REINFORCE, COMPLIMENT instead  
Don't INTERRUPT, WAIT instead.

## Maintaining creativity in our interventions in an effort to preserve the individual's dignity.

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The goal of the information in this chapter is to help you preserve the dignity of the person affected by Alzheimer's Disease. Your job is to accompany the person where they are, and to walk with them through their daily life. In the case of a person affected by Alzheimer's, it is important to keep in mind that you are managing a decline. So, forget about educational interventions; they are now beside the point.

### **Beware of Making Changes!!**

Here are some basic tips:

- **Respect** the person's routine: bathing at the same time(s) every day, etc...
  - **Don't** turn your back on the person when you are together.
  - **Continue** to include the person in the house's routines, even if only to have them be with others.
  - **Don't** hesitate to increase your "trial and error" efforts. They will help you learn quickly and be more at ease in accompanying the person.
  - **Keep** in mind that "what works today" may not work tomorrow.
  - **Ask** yourself good questions: *(To what need are we responding? Where are we trying to go with this? How can we do this thing with the person? ...)*
  - **Emphasize** the abilities and tastes of the individual. Give priority to what the person likes and is capable of doing ...  
*For example: Put on the music the person likes, bring out a small ball, and play with it in the living room; put significant photos (of people, past or upcoming events...); identify the person's environment clearly by using a particular colour, by putting a photo on the dinner table, by having a carpet or rug that lays out the route from one place to another.*
  - **Minimize** stimuli or things that get in her way *(use a plain place mat and a single plate at the person's place...)*
- Ask yourself the following questions: Is**

*there too much noise? Are there too many people, too many distractions? Is the table too crowded? Is the lighting adequate? Does the person seem stressed? Hurried? Are the others impatient with him or her?)*

- **Speak** to the person often *(but not too much – we all sometimes need moments of silence. We don't talk constantly in other situations and shouldn't do so here either).*

**Tell** what you are about to do, or what you are doing. Talk about what's going on around the person. Use humour

**Buy** clothes for the person that are easy to slip on or do up



Francine playing a harmonica ... drawn by Julienne

## How to manage the environment, prevent falls and pacing back-and-forth?

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Here too, be very creative

Think about the **4 S Rule**

**Security** – prevent falls and pacing back-and-forth.

**Simplicity** – get rid of what isn't needed. Clear out the clutter.

**Stability** – Don't keep changing the furniture around.

**Structure** – it's essential to maintain a family environment and a constant routine.

### Inside the home:

**The bedroom:** Arrange the person's bedroom so that it's pleasant and safe. Use strong colours (red, orange, yellow) that can be easily seen. Remember that white is invisible to people with Alzheimer's and that dark colours appear to them as "holes". Clearly identify spaces: use stickers on the drawers and closets, put up photos of things that are inside, etc. ...

If the person is waking up more easily at night, leave a nightlight on near their bed, and leave their bathroom light on.

**The bathroom:** With the help of an occupational therapist (check with your local or regional public health authority, to find out how to access the services of an occupational therapist), you can identify modifications and assistive devices that will help make the bathroom a safer place to use (*Support bars, transfer bench, raised toilet seat, portable toilet, etc.*)

Obviously, all cleaning or similar products should be removed from the

bathroom. Move the garbage pail if it might be confused with the toilet seat!

Remove the lock if necessary!

**Taking a Bath:** This is an intimate act; be very respectful.

When accompanying someone with Alzheimer's, it may be useful to learn about the person's youth or childhood. How did they take their bath? Alone? With their mother? How often? Once a week? This kind of information will give you clues that may make it easier to handle the situation if the person refuses to go into the bathroom.

Prepare the bath: Have the room at a comfortable temperature; make sure the water is not too hot or too cold. Bring the towel, soap, and anything else you'll need for the person's routine. You might want to put the towel into the clothes dryer for a few minutes to make it softer and warmer. Take your time. Be calm and relaxed.

If the person is afraid, try to figure out why. *Is it fear of falling? Fear of washing their hair? Fear of the noise of the water, of the soap, of the facecloth? etc.* Washing the person's hair may become a problem. We suggest washing hair at a sink (rather than the bathtub) as hairdressers do.

**Living Room:** Choose a chair that has firm cushions and solid armrests... Make that the person's regular place to sit ...

**Prevent falls:** Falls are significant accidents that can often be avoided. Some things - for example, low tables, telephone tables, chairs, etc. that are often in halls or passageways - may be nice to have, but they may be more in the way than they are useful. Use a barrier at the top of staircases. Make sure floors aren't too slippery. Pay attention to the corners of tables and other pieces of furniture. Sometimes we think there's enough room to get around them, but we can in fact end up banging into them.

**Preventing pacing:** In most cases, this reflects the individual's anxiety – anxiety the person can no longer describe or talk about.

*For example: the need to go to the bathroom or to look for something; someone is annoying the person; or the person sees boots and coats which suggests an outing.*

1- Is the restlessness telling you that the person needs to be more active, to move? Set up a program of regular exercise:

*walking, dancing, playing ball, etc. Ask the person to help you with chores around the house*

2- Is the pacing a sign that the person wants to leave, to go out? Make note of the specific circumstances of the pacing.

*It's possible that the person doesn't recognize the environment any longer, or that there is too much noise or too many people around at the same time.*

**Remember** that someone affected by Alzheimer's may become more disoriented as night approaches.

*Camouflage the doors leading outside – put curtains over them. Hide boots and coats.*



Francine with Alzheimer ...

by **Julienne**

## **The Importance of Communicating with Family, Peers, and the Person Himself.**

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Talk openly about the daily losses. How are they affecting the life of others in the house?

With the family, be clear about what the individual can still do and what they can no longer do. The fact that they don't live day-to-day with the person with a disability makes it difficult for them to comprehend the extent of the illness.

Talk about the possibility that placement in a facility may eventually become necessary. How do we bring up the question of the person's death? With those in the home/residence? With the family? ...

## **Useful Links**

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- Check with your local or regional public health authority to see about a consultation with an occupational therapist.
- The Alzheimer's Society. Borrow their books and videos. Visit their Internet site: [www.alzheimer.ca](http://www.alzheimer.ca)
- The Alzheimer's Society regularly publishes informative leaflets on issues related to daily life. See <http://www.alzheimer.ca/english/care/dailyliving-intro.htm>
- International Alzheimer Society, [www.alz.co.uk](http://www.alz.co.uk)
- A very informative web site on the subject of Alzheimer's Disease is this one: [www.passeportsante.net/fr/Maux/Problemes/Fiche.aspx?doc=alzheimer\\_pm&xlor=EPR-2](http://www.passeportsante.net/fr/Maux/Problemes/Fiche.aspx?doc=alzheimer_pm&xlor=EPR-2)

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