

# Freedom of choice : Accommodating the refusal of care

In an effort to be caring and empowering, L'Antr'Aidant wishes to inform you that this tool may raise various reactions and emotions. If you are experiencing such a situation, we invite you to discuss it with someone you trust.

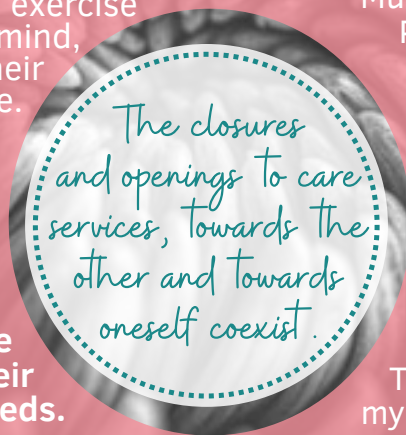
The concept of denial of care involves all types of assistance or services provided by a family caregiver or professional such as hygiene care, assistance with eating, transportation, relocation to an adapted living environment, moral support, etc.

Like the flower, the movement that is present throughout the Caregiver's journey represents the perpetual and delicate cycle of opening and closing to the other and to oneself in a relationship.

## WHAT IS THE FREEDOM OF CHOICE?

Consent is the basis of freedom of choice. Our concept is to recognize that all people, regardless of their situation or their level of autonomy, their right to exercise their power to act, to change their mind, to doubt, to question, to take their time, to accept or refuse care.

Having the responsibility to provide care or other services to someone does not mean deciding everything for them, but rather to use one's power to act to make decisions that best represent their wishes and needs.



## WHY IS IT SOMETIMES DIFFICULT TO ACCEPT THAT A PERSON REFUSES CERTAIN CARE?

Multiple griefs;  
 Personal values, opinions, personal beliefs;  
 The will on the other's life (e.g.: I want him or her to live at home as long as possible)  
 Fear of judgment;  
 Fear of the consequences, of the impacts on my quality of life;  
 Fears and difficulties in accepting my emotions;  
 The fear of suffering, the fear that my loved one suffers, etc.

There is so much going on inside us... Do I give myself the time to welcome them?

*I accept the person I am accompanying in what they are and what they want or don't want ... and a petal opens.*

*I recognize what the refusal of care of the person I am accompanying makes me experience... and a petal opens.*

“

## A Caregiver's Voice

*"Julian refuses to wash, it's very difficult to accept because he has always been a proud man and I don't like to see him like that. I'm also afraid that people will think I'm not taking good care of him. When I stop and take a step back a transformation begins..."*

Petals open in the relationship... New possibilities appear...

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# Freedom of choice : Accommodating the refusal of care

Like a flower, when we open ourselves to the other and to ourselves we allow the relationship to blossom. When we welcome our limitations we allow ourselves to grow together in a continuous process.

## Let's evaluate the risk together

Are there imminent risks to refusal of care?

- For me?
- For the person being helped?
- Objectively, what are the consequences of refusing care?

In the event that your security, your integrity or that of your loved one is compromised in the immediate, contact a health professional or call 911 quickly.

Observation is an internal position without judgment that allows us to observe and recognize things as they are.

## Points for reflection:

### HOW TO SUPPORT THE REFUSAL IN THE WELFARE?

- Take stock: identify what I agree to do and live;
- Clearly identify my inability or discomfort to perform certain actions (providing hygiene care, handling a lift, administering certain medications, etc.) in my role as a caregiver.
- Share the responsibility of caring for the person I am accompanying;
- Question and/or decode the deep reasons for refusing care;
- Decrease our expectations regarding the care proposal;
- Focus on a common goal and consider alternative solutions that could be satisfactory for you and the person being cared for (e.g., accept that a friend come to the house once a week, that hygiene care be provided by another person, etc.);
- Confide in someone to reduce the tensions that I may be experiencing inside myself.

### OBSERVING THE MOVEMENTS OF OPENING AND CLOSING IN THE OTHER PERSON AND IN YOURSELF

Observation is an internal position without judgment that allows us to observe and recognize things as they are.

*"My daughter Josée reacts when I use the lift for her hygiene and dressing. She refuses to let me touch her and put her in the chair. She screams, she agitates herself.*

*I don't know what to do. I have to use my strength to make sure that the straps are well put. I lose my patience. I am exhausted from experiencing this situation every morning for the past 3 weeks. According to the occupational therapist at the CLSC, I have to use it for my daughter's safety and my own. We have both lost these moments of closeness."*

#### Movement of opening...

*"I can see that she doesn't like this new device, that she resists and refuses to use it. This situation is upsetting to her, but it's also hard for me to see her like this."*

**I can accept the refusal without accepting and taking upon myself the consequences of this refusal.**

### FOSTERING COLLABORATION

How can I, in my position, maintain and optimize relationships towards a common goal?

*"Considering that I had identified the reasons why my daughter was reacting the way she was, I contacted the occupational therapist at the CLSC to adapt the braces so that they would stop hurting her and to make her more comfortable during manipulations."*

#### Fostering collaboration...

*"Since I have been using the cushioned braces suggested by the occupational therapist and because I'm always near her when using the lift, she is less reactive and more collaborative. This change allows me to be more calm and to enjoy these moments."*

### UNDERSTANDING, OPENING TO THE REALITY OF THE OTHER ALLOWS YOU TO BE EMPATHIC

I question myself, I am interested in myself and others. I develop my curiosity and my listening skills. The awareness is made on two levels: emotional and psychological. When I allow myself to be by what I understand or what touches me, then a world of possibilities opens up...

*"Maybe she's afraid when I lift her up and she's in the air. I'm not near her at that moment to reassure her, because I have to be careful with the maneuvers I have to do. Maybe the ties are hurting her and she has pain when they tighten on her skin."*

#### Understanding, opening up to the reality of the other...

*After verification, the fasteners leave a "red trace" at the on the intergluteal area. I decided to put some towels to avoid rubbing on her skin. The next morning, I got closer to her during the maneuvers of the lift to reassure her. She reacted much less. She was more calm. I was able to decode her message. Basically, she wasn't refusing to use the lift. She just couldn't put it into words. She was using her body to show me her discomfort and pain.*

### POSITIONING YOURSELF

In light of what I observe and understand, I make choices and take action. These choices may involve my relationship with the person I am supporting, but also with the professionals around us.

*"It was clear to me that my daughter was refusing to use the lift and that I had to find the reasons why she was resisting. The inability for her to express herself raised the level of difficulty. By her attitude and behaviors, I realized how much this new way of doing things did not suit her. However, for my safety, my daughter's safety and to keep her at home as long as possible, I had to work with the occupational therapist to prevent other similar situations. Since then, the occupational therapist regularly contacts me to check if I am experiencing discomfort maneuvering the lift and how my daughter and I are coping with this new reality."*