Treating Caregivers Well
A Shared Responsibility!

Facilitation guide for an awareness workshop on the mistreatment of caregivers for caseworkers and healthcare providers

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UNIVERSITÉ LAVAL

RANQ
Regroupement des aidants naturels du Québec

PARTNERING RESEARCH ORGANIZATIONS

This guide was produced as part of an action research project carried out by an academic/community partnership.

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WEB INTERFACE FOR THE DOCUMENT

Regroupement des aidants naturels du Québec:
www.rang.qc.ca

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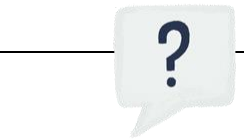
Table of Contents



Introduction to the Facilitation Guide

This facilitation guide was produced as part of an action research project carried out in partnership with the *Regroupement des aidants naturels du Québec* (RANQ), researcher Sophie Éthier (Université Laval) and co-researcher Marie Beaulieu (Université de Sherbrooke and Research Chair on Mistreatment of Older Adults). The research brought together caregiver organizations, organizations for older adults, and family caregivers, caseworkers and researchers, focusing on the following objective: *to deepen the knowledge and raise awareness about, and prevent the mistreatment of, caregivers.* At least 433 caregivers and caseworkers in the 11 administrative regions of Québec were involved. The guide has been made possible with funding from the Government of Québec, through the program *Québec ami des aînés* (QADA).

The action research gave rise to the design of an awareness toolbox consisting of a poster, three leaflets adapted for different sectors of the public, and narrated PowerPoint presentations. Instead of providing static material for distribution, with this facilitation guide we wished to make these tools true springboards to open the discussion about the problematic phenomenon that while still a taboo subject, is nonetheless very real.

For more information about this research, please visit the RANQ Web site: www.ranq.qc.ca

Origin of the action research project on the mistreatment of caregivers

- The *Regroupement des aidants naturels du Québec* (RANQ) has for many years been concerned about situations of mistreatment.
- In 2016, RANQ and the *Carrefour des proches aidants de Québec* (CPAQ) sollicited the help of Sophie Éthier, from Université Laval, to explore this issue.
- In 2017, a World Café (collective consultation activity) was held in Québec with 27 caregivers, caseworkers, researchers and students.
- In 2018, RANQ, Sophie Éthier (Université Laval) and Marie Beaulieu (Université de Sherbrooke) obtained a grant from the Government of *Québec, through the program Québec ami des aînés* (QADA), to carry out action research on this overlooked and poorly documented phenomenon: the mistreatment of elderly caregivers[1] and of caregivers for the elderly[2].

[1] In the framework of our research, this expression refers to people **50 years of age and older who look after another person of any age who has a disability**. For example, it may mean a 74-year-old man who is the caregiver for his wife of the same age, or it may mean a 53-year-old woman who looks after her mentally ill adult son. The threshold of 50 years of age was used by collaborating organizations for older adults that have people aged 50 and over in their clientele. This helps to identify a larger number of caregivers.

[2] In the framework of our research, this expression refers to anyone, regardless of age, who **cares for someone aged 65 and older** with a disability. Once again, this may mean a 74-year-old man who is the caregiver for his wife of the same age, or it may mean a 19-year-old granddaughter caring for her 77-year-old grandfather. 65 years of age was used because it is the threshold for old age in Canada (Old Age Security pension) and in Québec (services offered to the elderly).

Using the facilitation guide

What are the guide's objectives?

This guide is meant as a versatile tool with two objectives:

- Encourage discussions on the taboo subject of mistreatment towards caregivers by using, in the framework of an awareness workshop, the poster *Treating Caregivers Well: a shared responsibility* and the leaflets.
- Obtain advice on how to facilitate an awareness workshop and provide information about the available resources offering help.

The workshop may take the form of a group intervention at conferences, coffee meetings, support or discussion groups or even serve as training sessions. It may also be used as a family or individual intervention aid with caregivers, caseworkers and those being cared for, as well as their entourage (family).

To whom is this guide addressed?

This facilitation guide is addressed to anyone (healthcare providers, caseworkers, volunteers) who facilitates awareness activities related to the mistreatment of caregivers, whatever their target audience – caregivers and those being cared for, caseworkers, healthcare providers or the general public.

What's in this guide?

The first section of this facilitation guide gives a definition of mistreatment of caregivers, including its sources and its manifestations. The second section offers the foundations and guiding principles of the poster that serves to drive the facilitation. The third section offers concrete avenues to help facilitators prepare activities for greater awareness of mistreatment of caregivers. The appendices provide advice for less experienced presenters to facilitate (Appendix 1), plan (Appendix 2) and evaluate (Appendix 3) an awareness workshop.

How to use this guide

This guide suggests awareness interventions adapted to the different actors involved in a mistreatment situation: caregivers and those being cared for, members of the entourage and caseworkers or healthcare providers, using a poster that encourages conversations.

⚠ ATTENTION

This guide does not offer solutions for intervening in a context of mistreatment. Aid organizations for caregivers and in the field of mistreatment may help you in these situations, in particular:

Elder Mistreatment Helpline (Ligne AAA) **1 888 489-2287**
Caregiver Support **1 855 852-7784**
Info-Social Line **811**

The poster and its facilitation guide remain the awareness tools for this phenomenon as their aim is to recommend favourable conditions for holding workshops for group discussions or family or individual contexts. The way the workshop is run is quite flexible in order to allow each agent to include their own ideas in facilitating the workshop. It is up to them to include the actions most relevant to their specific context.

The awareness poster and the three leaflets for healthcare providers, the entourage and caregivers are available for printing on the RANQ Web site:

www.ranq.qc.ca/bientraitance

We believe that awareness is an effective means of intervention for preventing a problematic phenomenon.

SECTION 1:
Definition of mistreatment of caregivers[1]

In Québec, there is still no official definition of mistreatment of caregivers. Our action research has brought to light the sources of this mistreatment, very specific manifestations that distinguish the mistreatment of other people (older adults, children, etc.), which has led to the establishment of a definition.

There are four different sources of mistreatment of caregivers:

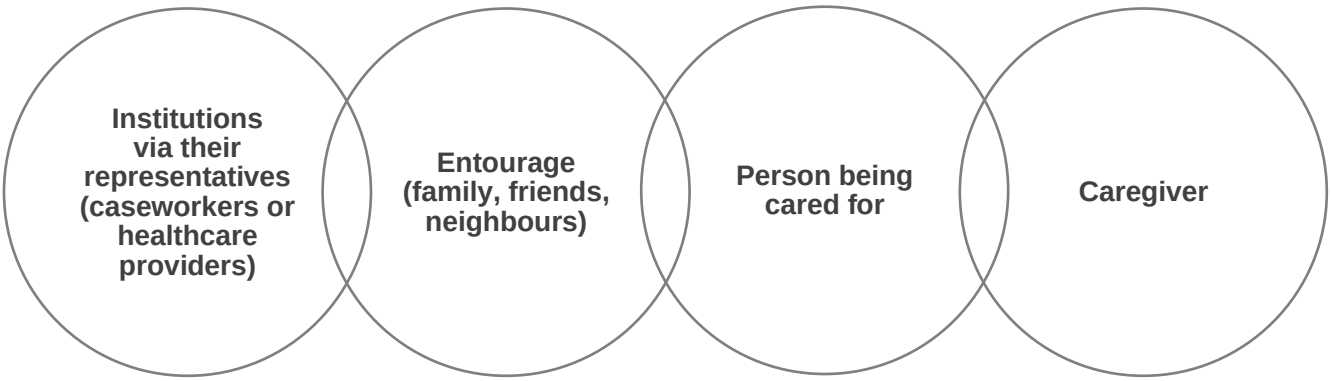


FIGURE 1: Sources of mistreatment of caregivers

Whatever the source of the mistreatment, its manifestations can be grouped into seven categories, representing examples of mistreatment towards caregivers.

[1] Although the research was funded by the program *Québec ami des aînés* (QADA) and the data were reviewed and collected with a focus on elderly caregivers and caregivers for the elderly, the tools designed are intended to be universal to apply to caregivers generally. From this perspective, the term “caregiver” will be used throughout the rest of the document.

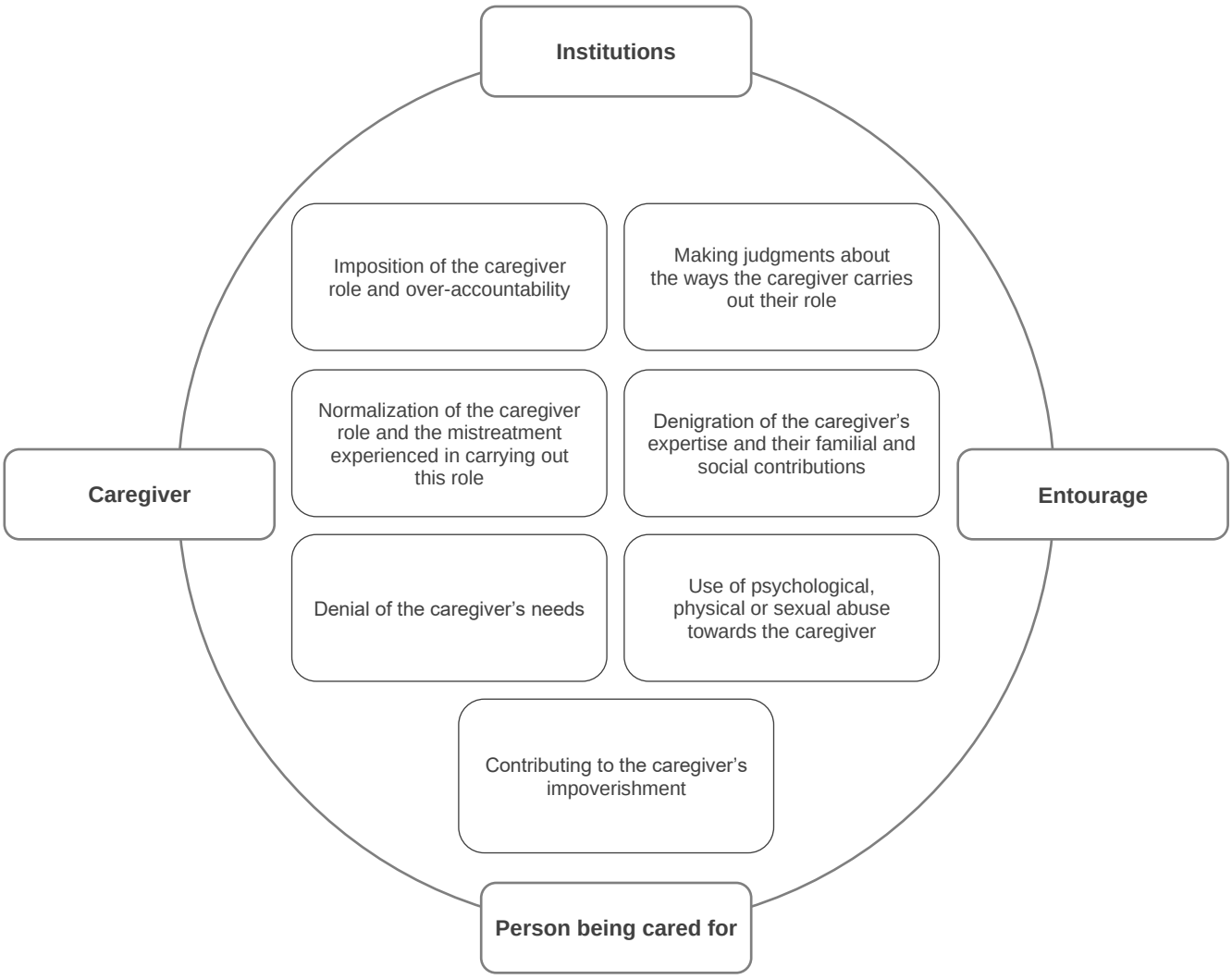


FIGURE 2: Manifestations of mistreatment of caregivers

When reading these manifestations, it is pertinent to ask questions such as, "what does denial by the entourage of the caregiver's skills consist of in concrete terms?" or "how may a caregiver contribute to their own mistreatment?". Table 1 offers a few concrete examples of these seven manifestations according to the four sources of mistreatment.

TABLE 1: Examples of manifestations of caregiver mistreatment according to the source

Imposition of the role	▪ **Person being cared for:** expects the caregiver[2] to be always available, do things properly, make no mistakes, etc. ▪ **Entourage:** expects someone to look after their spouse, mother, etc. ▪ **Institutions:** expects a family member to become the caregiver without asking them, without offering enough support or offering it too late, etc. ▪ **Caregiver:** imposes high, unrealistic standards in performing their role.
Making judgments	▪ **Person being cared for:** is dissatisfied with or criticizes the caregiver, etc. ▪ **Entourage:** judges what the caregiver does and their relationship with the person being cared for, etc. ▪ **Institutions:** blame or reproach the caregiver, make inappropriate remarks, lack empathy and consideration, etc. ▪ **Caregiver:** feels incompetent in their role, etc.
Normalization of the role and of the mistreatment	▪ **Entourage:** tolerates bad behaviour by the person being cared for, does not recognize or acknowledge symptoms, problems, mistreatment, etc. ▪ **Entourage, institutions, person being cared for and caregiver:** excuse the mistreatment and explaining it as being a result of the illness or age of the person being cared for.
Denigration of skills and familial and social contributions	▪ **Entourage, person being cared for and caregiver:** does not acknowledge the scope of the caregiver's role and its importance, its consequences and the diversity of knowledge and skills needed to carry it out. ▪ **Institutions:** minimize the caregiver's skills, leave them out of decision-making, question their decisions, do not acknowledge the role's social contribution, etc.
Denial of needs	▪ **Institutions:** marginalize the caregiver's needs at the expense of those of the person being cared for or through a lack of resources, etc. ▪ **Caregiver:** does not consider their own needs, does not consult a doctor themselves, remains silent about difficult situations, neglects themself, etc. ▪ **Person being cared for:** does not consider the caregiver's needs, etc.

[2] Caregiver: Person caring for someone.

Psychological or sexual abuse of the caregiver	▪ **Person being cared for:** throws objects, hits them, injures them, sexually assaults them or intimidates, injures, threatens the caregiver in private, etc. ▪ **Institutions:** intimidate the caregiver, threaten them, talk down to them, medicate them for sleep problems or anxiety instead of considering the cause of their problems (exhaustion, mistreatment), etc. ▪ **Caregiver:** blames themself, feels responsible for everything, accepts psychological, physical or sexual abuse, etc.
Contribution to impoverishment	▪ **Person being cared for, entourage:** does not acknowledge the financial impact of caregiving, does not repay loans provided by the caregiver, refuses to reimburse certain expenses paid for by the caregiver, etc. ▪ **Caregiver:** agrees to pay certain expenses for the person being cared for, etc. ▪ **Institutions:** require fees for certain support services or respite in order to continue a role carried out free of charge, etc.

Based on the review of the literature and the findings of the data collection, we are proposing the following definition of mistreatment of caregivers:

Performing the role of caregiver involves a risk of mistreatment, which affects the caregiver. This mistreatment can stem from institutions, the entourage, the person being cared for and the caregiver themself. Whether or not the mistreatment is intentional, it manifests itself through a lack of appropriate action, an attitude or a gesture that happens once or is repeated. The mistreatment of caregivers may take one or more of these forms and may change over time:

- imposing the caregiver role and over-accountability;
- normalizing the caregiver role and the mistreatment experienced in performing this role;
- making judgments about the ways the caregiver performs their role;
- denigrating the caregiver's expertise and their familial and social contributions;
- denying the caregiver's needs;
- use of psychological, physical or sexual abuse towards the caregiver;
- contributing to their impoverishment.

The aim of this guide is to help prevent this mistreatment by offering awareness workshops about this phenomenon.

SECTION 2:
Foundations and guiding principles of the poster

The poster is titled *Treating Caregivers Well: a shared responsibility*. Over the course of the action research, it was sometimes difficult for participants to disassociate the consequences for the caregiver (exhaustion, impoverishment, isolation, etc.) from the manifestations of the mistreatment in the context of caregiving. Starting with that premise, our idea was to **think of the caregiver's journey as a route along which mistreatment could occur.** We have to be mindful of the fact that not all caregivers are mistreated while performing their role. And that mistreatment is perceived differently depending on the people involved and the context. Thus in order to open up the conversation, the situations illustrated on the poster leave room for a variety of interpretations (see figure 2).

FIGURE 2: Awareness poster for mistreatment of caregivers

The poster illustrates a main path, which “maps out” the official path for caregiving that caregivers take. Certain individuals are outside this path while others are trying to get on it. Various situations are illustrated along its route: caseworkers, members of the entourage, the people being cared for and the caregivers themselves, representing the four sources of mistreatment mentioned previously. At the same time, the poster shows potential actors who can help promote good treatment for caregivers.

Taking on the role of caregiver means committing to a journey. This journey may be long or short, intense or restrained: no one can predict the outcome. It may therefore be a marathon, a sprint, an obstacle course, a relay race or even a long walk. Caregivers are clearly identified on the poster by numbered vests. At the top left, the first caregiver is from a CLSC; she is trying with difficulty to return to the main path, running, exhausted and weighed down by a ton of information she has been given. A second caregiver seems perplexed, alone in the middle of the path, not knowing what to do or where to go. This may represent a caregiver who has suddenly been pushed onto this pathway with no preparation, who does not understand their role, their situation or the path to take. Moreover, they seem to be headed in the wrong direction. Perhaps they are questioning the route that is proposed. The third caregiver belongs to the “sandwich” generation, caught between their work and caring for their child and for their mother, all at the same time. In trying to conciliate all these roles (work/family/caregiving), they are heading straight for a dead end. The fourth situation illustrates the denial of the caregiver’s expertise and needs, which seem to be excluded from the discussion that the healthcare providers are having with the person being cared for. An elderly couple also wear vests: it is difficult to be sure which is the caregiver, because the roles may change depending on the circumstances. The woman seems exhausted, impoverished and laden with baggage, while the man seems to be complaining and is threatening with his cane. Is this a mistreated caregiver? Is this a caregiver expressing their anger? Is this an elderly caregiver and an adult child? Next to them, a caregiver is pushing a wheelchair with someone who could be their grandmother; both look enthusiastic. However, they are headed towards an obstacle in the path that they seem to have overlooked. Or perhaps towards sources of help that are being offered to them?

As for the caseworkers, one wants to help but is providing too much information without noticing the caregiver's fatigue and the burden they are carrying; other caseworkers are supportive, encouraging the caregiver, offering them water (or support on their journey). One of the two caseworkers is more outgoing, while the other waits passively for the caregiver to ask for help. Near them is a rest area. Is it easy to access? In the entourage we see family members or friends who are encouraging the caregiver on their journey: they are offering flowers and tokens of love. However, some other members, seated on a bench some distance away, are commenting, observing from afar, without intervening. It is of course possible to interpret their conversation differently. Finally, along the route are other symbols that may be subjects for discussion: a stop sign, signs pointing in different directions announcing sources of help, a hole, obstacles in the path, etc.

The poster can be used in different ways depending on the target audience (caregivers, entourage, caseworkers and healthcare providers, and people being cared for).

- On the one hand, the situations of the individual caregivers can be addressed in turn for discussion about the mistreatment issues that they face, for example, for Monique, Caregiver # 1, etc.; for Pierre, Caregiver # 2, etc.
- On the other hand, this is an opportunity to talk about the various forms of mistreatment: *Where do you see yourself in this image of examples of imposing the role, denigrating your skills, etc.?*

The following section describes the different situations illustrated on the poster. Examples of facilitation questions will help participants describe what they observe, how they feel, what they think. These questions make it easier for the participants to talk about a situation. Examples of responses are also offered to encourage the discussion and help the facilitator.

SECTION 3:
Awareness workshop on the mistreatment of caregivers

Before setting up an awareness workshop, it is essential that these questions be answered.

What is the suggested composition of the awareness workshop?

As far as possible, the composition of the workshops should be fairly homogenous to facilitate talking about the participants' situations and emotions. Participants can be divided into four separate groups:

- Caregivers
- People being cared for
- Caseworkers and healthcare providers
- General public

What are the objectives of the awareness workshop?

The overall objective of the workshop is to provide awareness of mistreatment of caregivers by means of a poster. Four target objectives are associated with the poster so that by the end of the workshop, participants:

- will be aware of the existence and the consequences of mistreatment of caregivers;
- will be able to identify the various people involved in situations of mistreatment of caregivers;
- will have the tools needed to recognize instances of mistreatment;
- will have had the opportunity to discuss any mistreatment to which they themselves have been subjected or for which they may have been responsible.

What materials are required for an awareness workshop?

Materials for the facilitator	Materials to be given to the participants
▪ Facilitation Guide ▪ Large format cardboard reproduction of the poster ▪ 8½ x 11 reproduction of the various situations (images), with examples of representations and facilitating questions on the reverse Optional: ▪ Attendance sheet (as needed) ▪ PowerPoint presentation (optional) ▪ Laptop and projector (as needed) ▪ White board (or *flipchart*) with markers, *post it* notes and blank paper (optional)	▪ Copy of the poster (8½ x 14, printed in colour) ▪ Leaflet (printed in colour) ▪ Copy of the PowerPoint presentation (as needed) ▪ Evaluation form

What is the proposed agenda for an awareness workshop lasting 90 minutes to 2 hours?

Time	Agenda
Before the workshop	▪ Customize according to the target audience of participants (caregivers, caseworkers, healthcare providers, members of the entourage or people being cared for); ▪ Evaluate the level of awareness needed by the target audience. Needs can vary from one particular group of participants to another; themes can therefore be removed or added; ▪ Plan the workshop according to the needs diagnosed; ▪ Plan co-facilitation, when necessary; ▪ Establish a presentation schedule; ▪ If funding sponsors request it, create an attendance list for statistical purposes and accountability; ▪ Prepare pertinent, adequate documentation to give to participants; ▪ Prepare a collective agreement (according to the group's profile) concerning the notions of benevolence, respect, confidentiality, etc. (see example in Appendix 4); ▪ Determine the best location (according to the group's profile and desired facilities);

	▪ If your resources allow for it, evaluate the needs in terms of replacement caregivers/respite time and transportation for participants who are caregivers; ▪ On site, organize the meeting place and prepare the necessary materials (tables, chairs, snacks, etc.).
Opening the workshop **(20 min)**	Manage the set up and running of the workshop: ▪ Welcome the participants and introduce yourself (name and role); ▪ Have them sign the attendance form (optional); ▪ Distribute the necessary documentation: PowerPoint presentation (optional), copies of the poster and leaflet; ▪ Project the PowerPoint presentation: Section 1: Definition of mistreatment. (optional); ▪ Present the workshop agenda orally or by projection; ▪ Go round the table so that the participants can introduce themselves and briefly explain their reasons for participating in, or their expectations of, the workshop; ▪ Formalize the collective agreement.
During the workshop **(60 to 80 min)**	▪ Present the poster: propose case discussions associated with the situations illustrated (see examples of questions, plan about 15 min per situation).
Concluding the workshop **(10 to 20 min)**	Plan a discussion and question period: ▪ Go over the main points raised in the workshop; ▪ Verify whether the objectives or the participants' level of satisfaction were reached (orally or in writing); ▪ If the evaluation is done in writing: distribute a suitable questionnaire (see example in Appendix 3), allow for a few minutes to complete them, then collect them; ▪ Thank the participants.
After the workshop	▪ As needed, talk with any of the participants for whom the discussion was emotional or brought to mind difficult experiences; ▪ As needed, provide participants with resources for support; ▪ Clean and tidy the room.

Discussion of the situations

(1) Monique's Situation (Caregiver # 1)

Context: In this situation, a caseworker is adding sheets to the caregiver's bag; the caregiver is leaving the CLSC and trying with some difficulty (there is a hole right in front of her) to find the main path, running, exhausted and weighed down by a ton of information she has been given.

Examples of facilitating questions:

- What is happening in this situation?
- About whom does this situation make you think?
- What are your reactions to this situation?
- Where does the mistreatment seem to come from in this situation? (see examples below)
- Do you see an **imposition of the role** of caregiver or of over-accountability here? If yes, how does it manifest itself?
- Do you see Monique's **needs being denied** here? If yes, how might this manifest itself?
- Is it perhaps the opposite: the caregiver could be lacking some information?
- How could Monique be **well treated** here?

Here are some examples of responses to encourage discussion with the participants and help the facilitator.

Manifestations of mistreatment	Discussions
Imposition of the role	▪ The role has perhaps been imposed on Monique. She knows little about the role of caregiver and its consequences on her, and must go looking for information about this role, and also about the health of the person being cared for. ▪ Other:
Denial of needs	▪ She is fleeing because she is frightened or because this represents too much information for her, too early, at the wrong moment. She is not yet at that stage, she must first “digest” the information she has received. ▪ Her bag is full, she is in a hurry, she is tired, she is perspiring. ▪ There is a hole in the path that she does not seem to notice. Perhaps she needs someone to point out the obstacles in her way in this role. ▪ The information given to her only tells her about the illness/health situation and the way in which she should administer care. She receives no information about her role, about how to protect herself or about her rights that come with this role. ▪ Other:
Good treatment	▪ The caregiver could become aware of her own need for information, think about the imposition of her role: can she refuse it? Or refuse a portion of it? Set limits? Impose conditions? ▪ The caseworker has good intentions: She wants to provide the caregiver with more tools. Thus by having more tools, the caregiver could perform her role better. But caseworkers, the person being cared for and the entourage could respect the caregiver’s own pace, give her the proper information, at the right time, in sufficient quantity, to allow her to perform her role without drowning in the process. They could also be attentive to her feelings and emotions, for example if she is in a state of shock following a diagnosis. ▪ The information received is balanced between information about the illness/health situation of the person being cared for and the information aimed at supporting the caregiver, to help her understand and recognize the signs of exhaustion, to inform her of her rights, etc. ▪ Other:

(2) Pierre's Situation (Caregiver # 2)

Context: In this situation, the caregiver seems lost along the route; he is perplexed, alone in the centre of the pathway, not knowing what he should do, where he should go; he questions himself, not understanding what has happened to him since his spouse was moved to a care home.

Examples of facilitating questions:

- What has happened in this situation?
- About whom does this situation make you think?
- What are your reactions to this situation?
- Where does the mistreatment seem to come from in this situation? (see the examples below)
- Do you see an **imposition of the role** of caregiver or of over-accountability here? If yes, how does it manifest itself?
- Do you think that Pierre is being **judged** about the way in which he does things or about a decision he made? If yes, can you describe any instances?
- Is there an element that contributes to **normalizing his role**? If yes, how might it manifest itself?
- How could Pierre be **well treated** here?

Here are some examples of responses to encourage discussion with the participants and help the facilitator.

Manifestations of mistreatment	Discussions
Imposition of the role	▪ Pierre is suddenly being propelled along this pathway, with no preparation. He understands little about his role, his situation or the path to follow. He seems to be headed in the wrong direction. ▪ Perhaps he does not know what is involved in being a caregiver! ▪ Other:
Making judgments	▪ Perhaps he is questioning the route proposed. ▪ He feels incompetent in his role, he is dissatisfied and is judging his own ways of doing things. ▪ Men are perceived differently by caseworkers and the general population, and there can be prejudices against male caregivers *(he is not capable of taking care of someone, it's not in his genes, he needs more help, he may not understand, etc.)* ▪ Other:
Normalization of the role	▪ Signs along the route indicate the path to take, but they are not meaningful (e.g., CHSLD, CIUSSS/CISSS). The lettering is small, difficult to read. Moreover, he does not know what the acronyms mean, but it is assumed that he knows these institutions! ▪ He is left on his own to negotiate the healthcare system. It may be difficult for him to gain access to a caseworker. ▪ Perhaps we assume that he does not need help, information or recognition in order to carry out his role, and that it is normal for him to do it. ▪ Other:
Good treatment	▪ The caregiver could identify himself as such, acknowledge his needs, his limits and his strengths in order to assume the role and look for sources of support. ▪ Caseworkers could help him to navigate the system, accompany him as needed to allow him to continue performing his role in a care home setting without him feeling pushed to one side or that he should be more aware. ▪ Caseworkers could take into account that he feels he is to blame for his spouse being in a care home setting. ▪ Caseworkers could also tell him about the services that could help both his spouse and him; with his agreement, they could manage the initial steps for making contact. ▪ Other:

(3) Maude's Situation (Caregiver # 3)

Context: This situation illustrates the difficulty in conciliating several roles (work-family-caregiving) in the typical day of a caregiver. Maude is in the "sandwich" generation, which means that she must take care of an elderly parent while looking after a child. She is heading straight for a dead end in this difficult conciliation of her roles.

Examples of facilitating questions:

- What is happening in this situation?
- About whom does this situation make you think?
- What are your reactions to this situation?
- Where does the mistreatment seem to come from in this situation? (see the examples below)
- Do you see an **imposition of the role** of caregiver or of over-accountability here? If yes, how does it manifest itself??
- Do you think that Maude is being **judged** about the way in which she does things or about choices she made? If yes, can you describe any instances?
- Is there an element that contributes to **normalizing her role**? If yes, how does it manifest itself?
- Do you see **psychological abuse** being used in this situation? If yes, how does it manifest itself?
- Are we seeing a **denial of Maude's needs**? If yes, how does it manifest itself?
- Are we seeing a possible **contribution to her impoverishment**? If yes, in what way?
- How could Maude be **well treated** here?

Here are some examples of responses to encourage discussion with the participants and help the facilitator.

Manifestations of mistreatment	Discussions
Imposition of the role	▪ The role has perhaps been imposed on Maude. She is the caregiver for her mother, who sometimes phones her while she is at work. She feels strongly that she is indispensable to her because no one else is capable of providing the same level of care that she can. ▪ She also looks after her child, who refuses to cooperate (and who is perhaps disabled or challenged and also needs assistance), in addition to her work obligations. She finds herself caught in the middle, like in a sandwich, obliged to help both of them. Where is the opportunity for her to say no, to refuse these roles? ▪ Other:
Making judgments	▪ Perhaps Maude's entourage questions the way she does things, thinks that she should put her mother in a care home or institution. ▪ Her mother often criticises her and feels that her help is never sufficient or, in contrast, is patronizing. ▪ Her child reproaches her for not playing with him and always talking to his grandmother. ▪ Other:
Normalization of the role	▪ We consider it normal that children make sacrifices for their parents, and parents for their children. So we do not take it seriously when she says she is finding this difficult or needs help. It's "natural" to provide care, we take it for granted that she is going to care for her mother and her child. ▪ She has left the path, beyond the reach of services. We minimize the amount of help she might need. We may feel that she doesn't get enough support, information or recognition for performing her role. ▪ We minimize the mistreatment she is experiencing (judgments, imposition and normalization of the role). She feels guilty that she is not doing enough, and so she tolerates the mistreatment directed at her. ▪ Other:

Denial of her needs	▪ She wears shoes that are not suitable for walking on a gravel path. She is not equipped to provide help and take the caregiver route. Thus she is not considering her own needs in embarking on this journey. ▪ We see that she is overloaded with tasks (work-family-caregiving). Her own needs are not taken into account. ▪ Without realizing it, she is headed towards a dead end. If someone doesn't warn her, she will hit a brick wall. ▪ Perhaps too she wants to move beyond the caregiving situation, she wants to leave it behind as we see on the poster, but her child or her mother are preventing her from leaving this role and there is no one there to take up the slack. ▪ Other:
Use of psychological abuse	▪ Perhaps Maude is being harassed by her mother, or else her mother does not understand that she needs rest or refuses to allow Maude to find other help for her. ▪ The child (with or without issues) refuses to cooperate and move forward, and thus holds Maude back on her journey. The child may be jealous of the amount of time his mother spends with his grandmother. ▪ She is isolated, because she no longer has time for her husband, her other children or her friends. ▪ Other:
Contribution to impoverishment	▪ Maude is not able to use all the tax credits available because she lacks information at the opportune moment. ▪ She has lost income due to days of work she has missed in order to help her mother and her son. ▪ She pays expenses for her mother (transportation, parking, urinary protection), but either forgets to ask her mother to reimburse her or her mother is unwilling to pay her back. ▪ Other:
Good treatment	▪ Caseworkers could tell her about the existence of respite and support services to make her task easier, help her to have realistic expectations of her roles, encourage her to be kind to herself. ▪ Caseworkers could encourage her to speak to her employer, her family, her close friends, in order to share and delegate tasks. ▪ Other:

(4) Rachel's Situation (Caregiver # 4)

Context: This situation shows a caregiver who is being excluded, standing apart, from the discussion that the healthcare providers are having with the person being cared for.

Examples of facilitating questions:

- What is happening in this situation?
- About whom does this situation make you think?
- What are your reactions to this situation?
- Where does the mistreatment seem to come from in this situation? (see the examples below)
- Do you see an **imposition of the role** of caregiver or of over-accountability here? If yes, how does it manifest itself??
- Do you think that Rachel's **skills are being denigrated**? In what way?
- Do you see a **denial of Rachel's needs**? If yes, which needs in particular?
- Is there an element that contributes to **normalizing her role or the mistreatment** experienced? If yes, how does it manifest itself?
- Do you see **psychological abuse** being used in this situation? If yes, how does it manifest itself?
- How could Rachel be **well treated** here?

Here are some examples of responses to encourage discussion with the participants and help the facilitator.

Manifestations of mistreatment	Discussions
Denigration of her skills	▪ She feels that her skills are being minimized, she is visibly shut out of any decision-making. The healthcare providers are not interested in her opinion. ▪ They do not look at her, they do not consider her psychological or physical condition. ▪ Perhaps she is being excluded from decisions about changes to medication or services for the person being cared for. However, if the person being cared for has cognitive issues, she needs to be there to hear what is being said and then remind that person of the decisions made. ▪ She stands off the path, outside the network of services, even though she is depended on in the home. Once in the healthcare system, she no longer exists. ▪ Other:
Denial of her needs	▪ Her own needs are not taken into account. We see that she is not participating in the discussion with the healthcare providers, perhaps because her needs are considered less important than those of the person being cared for. ▪ Services are offered to the person being cared for even though Rachel is there to do it, without asking her whether she wants to, or is able to provide them. ▪ Other:
Normalization of the role and of the mistreatment experienced	▪ Perhaps we don't think she needs support, information or acknowledgement for performing her role. ▪ It is considered normal that she act as caregiver just because she is there, but it is not considered normal that she be consulted. ▪ The impacts on her of the decisions made for the person being cared for are not taken into consideration (e.g., changes in the services provided to the person being cared for without any input from her means that Rachel must provide them herself). Thus the mistreatment she is experiencing is being minimized. ▪ Other:
Use of psychological abuse	▪ The caseworkers lack empathy towards Rachel. The fact that they do not consider her opinion valuable and worth listening to can be seen as psychological abuse.

	▪ It may also be that the person being cared for is exercising control over her by refusing to involve her. ▪ Other:
Good treatment	▪ The caregiver could insist on being part of the care team. ▪ The caseworkers could include her in decisions concerning the person being cared for so that she understands the person's state of health, can follow its progress and can make sure that the services put in place are consistent, pertinent, useful to the situation of the caregiver/person being cared for dyad and meet the needs. ▪ The caseworkers could ask her how she is doing and which services she might need for herself. ▪ Other:

(5) Johanne's and Louis' Situation (Caregivers # 5 and # 6)

Context: This situation illustrates an elderly couple where it is not clear who the caregiver is (man, woman, both?). Sometimes it is one, sometimes the other. The man seems angry, the woman does not seem to take care of her appearance: scruffy clothing, uncombed hair. She takes small steps because of the weight of her bags.

Examples of facilitating questions:

- What is happening in this situation?
- About whom does this situation make you think?
- What are your reactions to this situation?
- Where does the mistreatment seem to come from in this situation? (see the examples below)
- In your opinion, who is the caregiver in this situation?
- Do you see an **imposition of the role** of caregiver or of **over-accountability** here? If yes, how does it manifest itself?
- Do you think that Johanne (or Louis) is being **judged** about the way in which they do things? If yes, can you describe any instances?
- Is there an element that contributes to **normalizing the caregiver role**? If yes, how does it manifest itself?
- Do you see a **denial of** Johanne's (or Louis') **needs**? If yes, which needs in particular?
- Do you see **psychological or physical abuse** being used in this situation? If yes, how does it manifest itself?
- Do you see a **contribution to impoverishment** of the caregiver or the couple here?
- How could Johanne (or Louis or the couple) be **well treated** here?

Here are some examples of responses to encourage discussion with the participants and help the facilitator.

Manifestations of mistreatment	Discussions
Imposition of the role	▪ Johanne is experiencing social pressure: it is her duty to look after her spouse or partner. It's "natural" to provide care, it's taken for granted that she will help her spouse. ▪ Louis also acts as caregiver when Johanne needs help (e.g., she doesn't hear well and Louis speaks for her). ▪ The couple acts as caregiver for their adult child who is ill or handicapped. Despite their advanced age, they have no choice but to assume this role, otherwise their child will be placed in a CHSLD. ▪ Other:
Making judgments	▪ Louis is dissatisfied and criticizes his caregiver. ▪ Johanne is not able to provide Louis with the desired level of care, she feels incompetent in her role, because he reacts badly, he is aggressive towards others. She feels guilty and devalued. ▪ Other:
Normalization of the role	▪ The mistreatment experienced by Johanne is minimized. ▪ The mistreatment experienced by Johanne is excused and explained away by Louis' neurocognitive disorders. ▪ It is considered normal for parents to care for a child who is ill or handicapped, and they know how to do it because they have always done it without any help: it's their child after all! ▪ Other siblings are absent because they work or assume that their parents will perform this role, putting off until later their turn to be caregiver of their handicapped sister/brother. ▪ Other:
Denial of needs	▪ Johanne's needs are not taken into consideration. She is tired, exhausted. There may be consequences for her physical health. She neglects herself (hair uncombed, old clothes). She wears slippers, which are unsuitable for the route taken.

	▪ She does not want to displease the family, so she doesn't ask for help. She is also frightened about living in a care home (which will involve separating the couple). ▪ Louis refuses to go to a care home and does not want to acknowledge that his caregiver is no longer able to carry out her role. ▪ The couple has numerous unmet needs, because their age means that caring for their ill child is becoming more and more difficult. In addition, they are worried that they do not know who will take over if they have to go to a care home or worse, they die. ▪ Other:
Use of psychological or physical abuse	▪ Johanne is perhaps controlled or intimidated by Louis. He walks ahead of her (he controls the direction they take). He, as the person being cared for, is demanding. He refuses to acknowledge or minimizes Johanne's need for rest and does not allow anyone else to look after him. ▪ He threatens suicide or physical abuse whenever Johanne tries to ask for help or mentions putting him in a care home. ▪ The person being cared for looks angry and also has a "speech balloon", indicating offensive rhetoric. He sometimes bangs his cane. Is he violent or is he responding to an attack on himself? ▪ Johanne feels guilty for having brought a handicapped child into the world, while Louis blames the child. ▪ Other:
Contribution to impoverishment	▪ Johanne does not have access to her spouse's money because he is in denial about his illness. He refuses to give her the information necessary to better manage their assets. So she is having to pay all the costs by herself even though she had to take early retirement in order to care for him. ▪ Their financial problems prevent them accessing the necessary services (e.g., home adaptation). ▪ The couple is perhaps finding them in a precarious financial situation because their child, who is ill or handicapped, is in a care home or because Johanne had to stop working in order to look after him at home. ▪ Other:
Good treatment	▪ The caseworkers could tell her that respite and support services exist to alleviate her tasks, could encourage her to talk to her spouse, her family, her close friends, in order to share and delegate these tasks. ▪ A family intervention could be arranged. ▪ Other:

(6) Rachid's Situation (Caregiver # 7)

Context: In this situation, Rachid, a young caregiver, is making good progress, the person he is caring for seems cooperative, she is supportive and appreciative. She also accepts help. However they come across an obstacle along the way (fallen tree trunk and branches), which will slow them down (notion of risk, even if the outcome is good). In front of the table is a caseworker who is encouraging and offering water. Behind the table, a caseworker stands further back. She is waiting for the caregiver to ask her for help.

Examples of facilitating questions:

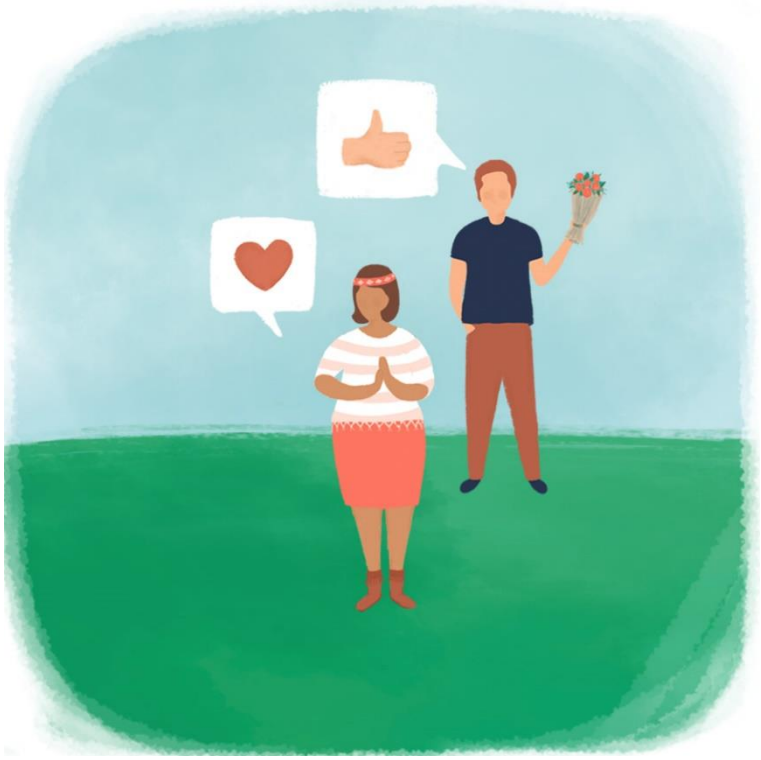
- What is happening in this situation?
- About whom does this situation make you think?
- What are your reactions to this situation?
- Where does the mistreatment seem to come from in this situation? (see the examples below)
- Do you see an **imposition of the role** of caregiver or of **over-accountability** here? If yes, how does it manifest itself?
- Do you think that Rachid is being **judged** about the way in which he does things? If yes, can you describe any instances?
- Is there an element that contributes to **normalizing his role** here? If yes, how does it manifest itself?
- Do you think Rachid is facing **denigration of his familial and social contribution**? If yes, how does it manifest itself?
- Do you see a **denial of** Rashid's **needs** here?
- Is the rest area easy to access?
- How could Rashid carry out his role in a context of good treatment?

Here are some examples of responses to encourage discussion with the participants and help the facilitator.

Manifestations of mistreatment	Discussions
Imposition of the role	▪ Perhaps Rachid is unaware that he is his grandmother's caregiver. ▪ Rachid's grandmother and parents expect him to be available all the time, carry out his tasks properly, and make no mistakes. ▪ No one acknowledges Rachid's responsibilities in regard to his grandmother because the parents take her to her medical appointments, although as they are often absent, it's Rachid who carries out the main tasks. ▪ Other:
Making judgments	▪ Men, especially young men, are perceived differently by caseworkers and the general population: there can be prejudices against male caregivers (he's not capable of providing care, it's not in his genes, he will need more help, etc.) ▪ There are also prejudices against young caregivers: they never do enough because they belong to a generation that is spoiled, even though they should be respectful of their elders. ▪ Other:
Normalization of the role	▪ Perhaps it is felt that he does not need support, information or acknowledgement in order to carry out his role and that it's normal that he does it because his tasks are relatively simple and occasional. ▪ Other:
Denigration of the familial and social contribution	▪ No one has explained his grandmother's condition to Rachid: he is not the main, official caregiver. ▪ He is not listened to when he tries to talk about the symptoms that he sees or when he asks questions about his grandmother's state of health. ▪ Other:
Denial of needs	▪ By helping his grandmother, he has less and less free time for leisure activities or to see his friends. His school performance may be affected by his caregiver role. ▪ The rest area is not always easy to access and the eligibility criteria may exclude him (being the main caregiver, living with the person being cared for, etc.)

	▪ Other:
Good treatment	▪ The caregiver could impose their own limits and go at their own pace, take advantage of the rest areas placed along the route, know that help is available. ▪ The caseworkers are able to provide concrete help (water), show empathy, anticipate the needs, provide support without blame. ▪ The caseworkers could acknowledge Rachid's role and his specific needs as a young caregiver and as a secondary helper. ▪ The person being cared for seems to be well treated here: she encourages the caregiver, acknowledges what he is doing, and accepts the help of the caseworker (water). ▪ Other:

(7) Entourage present along the route



Context: Members of the entourage can be seen (family, friends, neighbours); they encourage caregivers on their journey: they offer flowers and tokens of love.

Examples of facilitating questions:

- What is happening in this situation?
- About whom does this situation make you think?
- What are your reactions to this situation?
- Where does the mistreatment seem to come from in this situation? (see the examples below)
- In what ways could the entourage be mistreating the caregivers?

Here are some examples of responses to encourage discussion with the participants and help the facilitator.

Manifestations of good treatment	Discussions
▪ Acknowledgement of needs ▪ Acknowledgement of skills ▪ Acknowledgement of the familial and social contribution ▪ Positive judgments	▪ The entourage draws attention to the role and skills of caregivers. ▪ Members of the entourage send caregivers positive messages, without judgments, without blame by their actions, their attitudes and their presence. ▪ The entourage recognizes that caregivers need support. ▪ Members of the entourage offer caregivers their help.

(8) Entourage at a distance

Context: Members of the entourage (family, friends, neighbours), are seated on a bench some distance away. They make comments, observe from afar, without intervening directly to support the caregiver. It is possible to interpret their conversation in different ways. They are hidden by trees but they can be heard nonetheless.

Examples of facilitating questions:

- What is happening in this situation?
- About whom does this situation make you think?
- What are your reactions to this situation?
- Where does the mistreatment seem to come from in this situation? (see the examples below)
- Do you think the entourage is being judgmental?
- Is there an element that contributes to **normalizing the role** of caregiver?
- Do you think the entourage is **denigrating the familial and social contribution** made by the caregiver?
- Do you see a **denial of the caregiver's needs**?
- In what ways could the entourage treat the caregiver well?

Here are some examples of responses to encourage discussion with the participants and help the facilitator.

Manifestations of mistreatment	Discussions
Making judgments	▪ The entourage sometimes offers opinions, makes value judgments or simply comments on the ways caregivers do things or react, or about their intentions (claiming an inheritance, looking for attention, etc.).
Normalization of the role	▪ The entourage may find it normal for the caregiver to look after the person being cared for and not offer any support for this role. ▪ The entourage may make a comment such as “it’s their choice”.
Denigration of the familial and social contribution	▪ The fact that a caregiver is not supported by their entourage (by staying away, by observing) is in itself a denigration of the familial and social contribution in this role.
Denial of needs	▪ With a comment such as “it’s not our business”, the entourage frees itself from its responsibilities and in this sense, denies the caregiver’s needs for support. ▪ It is easier for the entourage not to imagine that the caregiver may have unmet needs.
Good treatment	▪ With a comment such as “they look as if they need help”, the members of the entourage are making a first step towards treating the caregiver well. The members just need to get up off the bench and offer their help!

(9) Symbols

Context: In addition to the characters depicted on the poster, the route for the caregivers is dotted with symbols that could also give rise to discussions.

Examples of facilitating questions:

- What symbols do you see on this poster, apart from the characters, that tell us about caregiver situations?

Here are some examples of responses to encourage discussion with the participants and help the facilitator.

Symbols	Discussions
 **Stop sign**	▪ The stop sign might represent a forced halt on the caregiver's journey: illness, exhaustion, death of the person being cared for. ▪ The stop sign might also represent the need to stop, take a break, deservedly to avoid being obliged to continue: respite, other aid services, stepping back to reflect.
 **Tree branches, hole and dead end**	▪ The tree branches and the hole along the route might symbolize obstacles, pitfalls or setbacks encountered along the way: those than can be foreseen, those that happen anyway because they are inevitable, those we don't see coming, those we create ourselves, those that others place in our way. ▪ The obstacles might represent a rapid degradation of the situation of the person being cared for, a reduction in services, a member of the entourage who is no longer able to support the caregiver, etc.

	**Dead end sign**	▪ The dead end may represent the “tunnel vision” that caregivers may experience when they feel confined in this role. They can see no possible way out of their situation. ▪ This might also be a symbol of their destination if caregivers do not have the opportunity to meet their own needs or take care of themselves.
	**Signs pointing to help resources**	▪ Signs to the resources available are pointing in opposite directions, display acronyms that may not be recognized, demonstrating the complexity of the health and social services network and the fact that it is difficult to know exactly to which services we have a right in terms of the criteria for eligibility. There is no doubt that caregivers need to be guided and accompanied when they seek help. ▪ The rest area seems to be far away, therefore difficult to access or invisible despite the sign. Often, caregivers reach it only as a last resort. ▪ The phone numbers at the bottom of the poster are those of the resources where caregivers, the entourage, caseworkers and healthcare providers can get information about the mistreatment of caregivers as well as support in their search for behaviours representing good treatment.
	**Sun**	▪ The sun represents hope, good moments along the route, the positive aspects of the caregiver’s role, and a warm welcome from kind caseworkers, healthcare providers and members of the entourage encountered along the route.

Closing words and workshop evaluation

The closing words bring the workshop to an end. Depending on the agenda, they will repeat the essential points to be remembered: sources of mistreatment, ways to recognize its manifestations and above all, the importance of treating caregivers well. Once these points have been discussed, we no longer see the poster in the same way. Participants should be able to use these points to bring awareness to other people.

The workshop concludes with an evaluation of the experience. Appendix 3 offers an evaluation form, but others can be developed as needed. The evaluation, either verbal or written, provides the opportunity to find out how participants perceived the content and the way the workshop was presented, and thus to adapt and improve the facilitation for a future workshop.

APPENDIX 1:
Facilitating an awareness workshop

Prepare yourself to facilitate

The person given the responsibility to facilitate must give themselves adequate time to consult and understand the contents of this facilitation guide. This preparation is important in order to feel comfortable when facilitating the workshop.

Functions of the workshop facilitator

The workshop is facilitated by someone who is concerned with caregivers and who has experience in intervention with them. This person does not need to pose as an expert in mistreatment. Instead, they act as a facilitator to support the participants in their discussions on the subject. They must be capable of running a workshop and ensuring cohesion in meeting the objective. In addition, they will need to adapt the workshop to its target audience (e.g., caseworker or caregiver, young or elderly caregiver, etc.).

Another important function of the workshop facilitator is the role of time-keeper, which involves both flexibility and strictness: flexibility so that the participants have time to express themselves and strictness so that they complete the workshop agenda without feeling the pressure of time. This role also involves maintaining a balance between participants who have a lot to say and those who say little.

It is up to the workshop facilitator to stimulate discussions among the participants. To do this, they can encourage the participants to describe and present their points of view and then make connections among their various experiences. They can also invite the participants to add to their stories by means of open questions, thereby widening and enriching the experiences of others. Examples of questions are offered in the guide (Section 2).

Characteristics of the facilitator's approach:

- Adopt an approach that's fun
- Encourage active participation
- Stimulate critical thinking
- Use experimentation and role-playing
- Sharpen the imagination and creativity
- Encourage decision-making and initiatives
- Awaken curiosity
- Invite collaboration, discussion and sharing of information
- Promote empathy
- Elicit knowledge and experience
- Reinforce autonomy
- Create links between theory and practice (Beaulieu, Pelletier and Dubuc, 2018)

Co-facilitation

The workshop also works well with two facilitators. However, co-facilitation requires advance reflection on the roles of each person. There must be synergy between them, and their roles must complement each other. Mixed co-facilitation (male/female or caregiver/caseworker, for example) can enhance the presentation through differing visions. Complementary types of facilitation may also be considered, if warranted.

Facilitation skills for a group

According to Turcotte and Lindsay (2019), these are the essential skills for intervention in a group setting that can be used in facilitating an awareness workshop.

Favour the formation of a cohesive group	▪ Establish visual contact with all members ▪ Pay particular attention to each member ▪ Determine the members' perceptions about their needs ▪ Involve the group as a single entity
Set the parameters for how the group operates	▪ Establish rules and standards with the group members ▪ Clarify the roles
Energize the performance of the tasks	▪ Organize the work ▪ Together, set goals and remind the group what they are ▪ Put the group to work and keep them focused on the tasks to be completed ▪ Take stock of the progress made
Enrich the communication	▪ Provide information ▪ Manage the communications ▪ Take non-verbal messages into consideration ▪ Encourage the appropriate expression of feelings ▪ Facilitate group participation
Smooth the passage through difficult moments	▪ Launch discussion on delicate subjects ▪ Clarify any barriers to the work ▪ Invite divergent opinions ▪ Establish links among the different interventions ▪ Find out if there is a consensus

Encourage a positive climate	▪ Support the members and acknowledge their efforts ▪ Allow the group some down time ▪ Encourage them to express reactions to the group experience

For a description of these skills, see Turcotte, D. and Lindsay, J. (2019). *L'intervention sociale auprès des groupes* (4th edition). Chenelière éducation.

APPENDIX 2:
Planning an awareness workshop

Determining the needs of the community for such a workshop

Before organizing a workshop, the needs of the community or the organization where the workshop will be held should be defined in advance. Here are a few guidelines for reflection to help implement this step:

- What is the level of knowledge of the participants (caregivers, caseworkers, entourage or people being cared for) about the phenomenon of caregiver mistreatment?
- What are the barriers and resources (organizational, financial, partnership issues) to be considered in holding a workshop?
- What benefits could the participants, organizers and community take away with them?

Recruiting workshop participants

Prior to recruiting participants, workshop recipients need to be properly identified. This information will help orientate recruitment of people who will participate in the planned activities.

- What are the characteristics of the target audience? (age bracket, level of functional autonomy, level of literacy, motivations, other characteristics)
- What are the best time windows and times available for the workshop for the participants targeted?

Recruitment of participants can be done by caseworkers working with the target population by means of the poster, the leaflets and word-of-mouth.

Number of participants

- What are the minimum and maximum numbers for a group?
- Will the group be closed (registrations in advance) or open (no registration)?

The ideal number of participants suggested for a workshop depends on the formula adopted. If the workshop forms part of a training program, a support group or a coffee meeting, a number between 6 and 9 people offers conditions for good discussion.

An awareness workshop can also organized after a conference on the mistreatment of caregivers. However a conference may involve a large number of people (from 40 to 50). Conference participants should then be divided into sub-groups of 6 to 9 people for workshops, depending on the space and number of small rooms available. More than 10 participants is not recommended as a larger number will hinder discussion. Following the workshop, a return to the conference setting can be helpful in pooling the essential points derived from the workshops. In this case, this will be a meeting that extends to half a day (3-4 hours).

APPENDIX 3:
Evaluating an awareness workshop

Satisfaction form for the awareness workshop on the mistreatment of caregivers

Please rate each of the following statements.

A = Strongly agree *B = Agree* *C = Disagree* *D = Strongly disagree*

	A	B	C	D
I enjoyed the presentation of the definition and sources of mistreatment of caregivers.	☐	☐	☐	☐
I enjoyed the presentation of the poster.	☐	☐	☐	☐
I enjoyed the discussions about the different situations shown on the poster.	☐	☐	☐	☐
I enjoyed the sharing and conversations within the group.	☐	☐	☐	☐

Do you feel better equipped to recognize situations of caregiver mistreatment ? ☐ Yes ☐ No

What will you remember most from this workshop (what new knowledge will you take away)?

APPENDIX 4:
Collective agreement

Goal of the awareness workshop

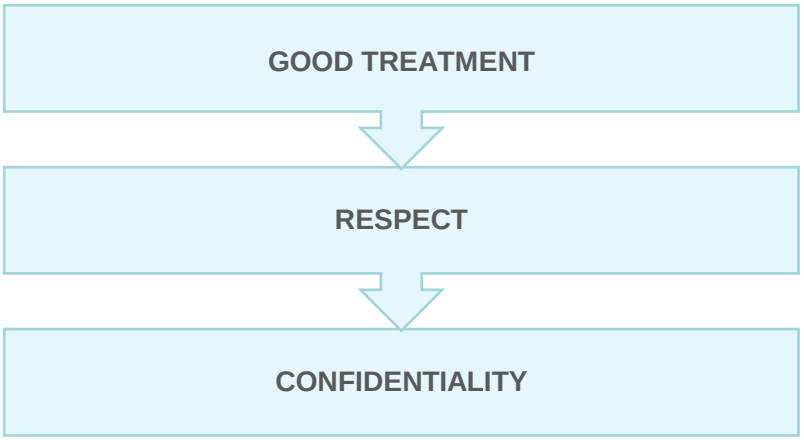
To make people aware of the mistreatment of caregivers through the presentation of a poster

Specific Observations

At the conclusion of the workshop, participants

- will be aware that mistreatment of caregivers exists
- will be able to identify the different people involved in a situation of mistreatment of caregivers
- will be equipped to recognize situations of mistreatment
- will have had the opportunity to discuss the mistreatment they are experiencing or may have experienced, or may have perpetrated

Behaviours and attitudes expected by participants



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THANK YOU FOR CONTRIBUTING
TO THE GOOD TREATMENT OF CAREGIVERS