October 2022

Support group facilitator volunteer handbook

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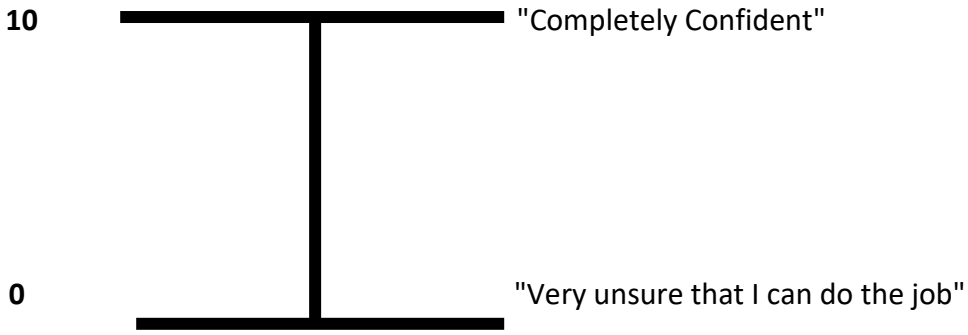
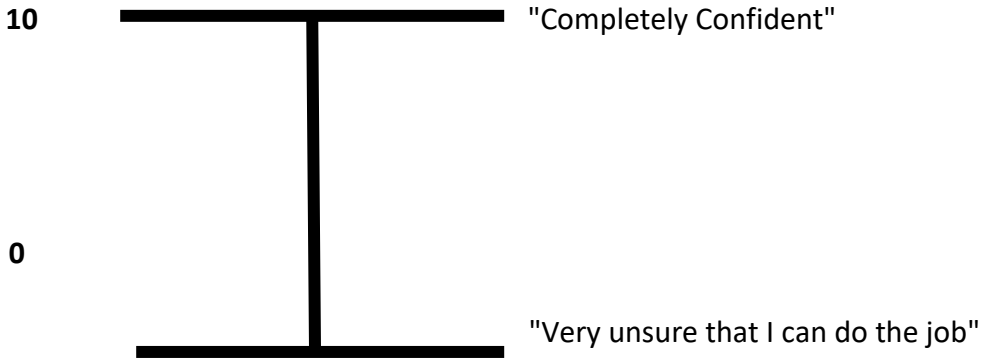
Exercise: "Scaling my Present Confidence as a Support Group Facilitator"

For My Eyes Only

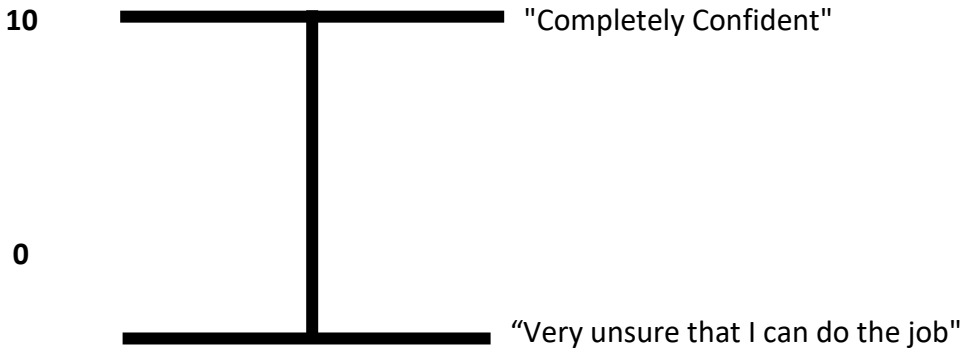
SAFE WITNESS / ACTIVE LISTENER ROLE



PROCESS FACILITATOR ROLE



INFORMING FACILITATOR ROLE



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PURPOSE OF THE FAMILY CAREGIVER SUPPORT GROUPS

The Focus of Family Caregiver Support Groups

Supporting a person with Alzheimer's disease or another dementia can be incredibly demanding, and family members experience a variety of feelings along the journey. The demands of the disease can make it difficult to stay in touch with friends and family. People with dementia and their caregivers may feel isolated as a result. Support groups offered by the Alzheimer Society of B.C., which are based on the *information and mutual aid model*, provide an opportunity for participants to meet others who are currently caring for someone with dementia, to share their feelings and experiences, and to realize that they are not alone.

Group members can be involved in providing a wide range of supports for the person with dementia. They may either be living at home with the person with dementia, supporting the person with dementia and their family from a distance, or the person with dementia may be living in a care facility. Members may be the primary caregiver or involved in a secondary caring role such as a supportive family member or friend.

All new members must speak with the local Alzheimer Society of B.C. staff or volunteer facilitator before attending the group to receive their welcome package and introduction to the group. In an effort to protect the safety and integrity of the group setting, we ask that members refrain from bringing friends, neighbours, or other family members along to the group without speaking with their local Alzheimer Society of B.C. staff member or volunteer facilitator in advance.

About the Information and Mutual Aid Model

Our support groups are based on the philosophy that people in similar situations are in a unique position to give support and receive support from others on the same journey. One of the ways that people can find help is through meeting with others who can relate to their feelings and experiences. Therefore, these groups rely on the sharing and mutual support of fellow group members more than on the knowledge of experts.

Mutual aid is about people helping each other. In a support group that operates according to mutual aid principles:

- All members of the support group are equally respected and valued.
- The group is based on people talking as equals; the facilitator's role is to help guide the discussion rather than offering expert knowledge.
- By following the *Ground Rules for Discussion,* members take an active role in ensuring that the group is safe and supportive for everyone who attends.

The Alzheimer Society of B.C. offers group members reliable information resources that can be used to supplement information shared amongst members. This takes the form of handouts, newsletters, and information sheets for facilitators. Trained support group facilitators will introduce information on topics relevant to the group, but they are not expected to be experts, nor to provide expert answers to

problems that are discussed in the group. Facilitators also ensure that the group starts and ends on time, and that group members adhere to the *Ground Rules for Discussion*.

Transitions

Our caregiver support groups are focused on the needs of family members and friends while they are currently caring for a person with Alzheimer's disease or another dementia. Alzheimer's disease and other dementias are terminal illnesses, and we recognize that after the death of the person with dementia, bereaved caregivers will require a different type of support. Bereaved caregivers will be provided with information to help them transition from Alzheimer Society of B.C. support groups to more appropriate community resources, such as grief support services, within a period of two to three months.

Benefits of Family Caregiver Support Groups

- A place to exchange information, support, and friendship with others whose lives are affected by dementia.
- A forum for exchanging practical tips and strategies for coping with the many changes connected with the disease.
- An opportunity to decrease feelings of isolation and loneliness.
- A place to express feelings and be reassured that these feelings are normal and expected.
- An opportunity to develop communication and problem-solving skills.
- A place to access the most current information provided by the Alzheimer Society of B.C.
- A chance to find a sense of hope and regain some control in the face of a disease that cannot be controlled.

Limitations of Family Caregiver Support Groups

It is important to recognize that support groups are not for everyone. Some people do not find group discussion helpful and prefer other forms of help. Similarly, a support group will probably not work well for a person who has little interest in the ideas and feelings of other group members. It is important to recognize that there are limits to what a group can do. For example, a support group is not**:**

- **A replacement for therapy or counselling**. Some people may seek professional help instead of, or in addition to, attending support group meetings.
- **A social gathering**, although some socializing does occur.
- **A formal educational group led by an expert**. The emphasis is on input from all group members based on personal experience rather than expert or professional knowledge.

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PURPOSE OF THE EARLY STAGE SUPPORT GROUPS

The Focus of Early Stage Support Groups

Having a diagnosis of Alzheimer's disease or a related dementia can be personally demanding and it can make it difficult to talk to others and stay in touch with friends and family.

The support groups offered by the Society are based on the philosophy that people with similar issues are in a unique position to offer support to others on the same journey.

Our early stage support groups are focused on the needs of the person with the early symptoms of Alzheimer's disease or another dementia. We recognize that a support group with this focus will not meet the needs of a person with dementia forever and there will come a time when they will move on. At that time and where possible, we assist members, and their family and friends to identify other community resources.

About Mutual Aid

Alzheimer Society of B.C. support groups are based on an *information and mutual aid* model. One of the ways that people experiencing difficult situations can find help and relief is through meeting with others in the same situation as themselves. These groups rely on the experience and mutual support of members more than on the knowledge of experts.

- Mutual aid is about people helping each other.
- All members of the support group are equally respected and valued.
    - The group is based on people talking as equals as opposed to being lectured to by an expert.
    - Members are encouraged to take an active role (e.g. welcoming group members, making coffee etc.).

About Information

The Alzheimer Society of B.C. provides groups with reliable information that can be used to supplement and check the information offered among members. This takes the form of handouts, newsletters, and information sheets for facilitators.

Support Group Facilitators will introduce information on topics relevant to the group, but they are not expected to be experts, nor to provide expert answers to problems that are discussed in the group.

Benefits of Early Stage Support Groups

- A place to exchange information, support and friendship with others whose lives are affected by dementia.
- A forum for exchanging practical tips and strategies for coping with the many changes connected with the disease.
- An opportunity to decrease feelings of isolation and loneliness.
- A place to express feelings and be reassured that these feelings are normal and expected.
- A place to laugh at the ridiculous side of tragedy without being misunderstood.
- The opportunity to develop communication and problem-solving skills.
- A place to access the most current information provided by the Alzheimer Society.
- The chance to regain some control in the face of a disease that cannot be controlled.
- A place to find a sense of hope.

Limitations of Early Stage Support Groups

It is important to recognize that support groups are not for everyone. Some people do not find group discussion helpful and prefer other forms of help, such as individual counseling or professional assistance. Similarly, a support group will probably not work well for a person who has little interest in the ideas and feelings of other group members.

It is important to recognize that there are limits to what a group can do. For example, a support group is not**:**

- **A replacement for therapy or counselling**. Some people may seek professional help instead of, or in addition to, attending support group meetings.
- **A social gathering**, although some socializing does occur.
- **A formal educational group led by an expert**. The emphasis is on input from all members based on personal experience rather than expert or professional knowledge.

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WHAT IS THE DIFFERENCE BETWEEN ALZHEIMER SOCIETY OF B.C. SUPPORT GROUPS AND OTHER TYPES OF SUPPORT?

ALZHEIMER SOCIETY OF B.C. Support Groups	Professional Therapy or Counselling
Reflect ideas and emotions (sounding board)	Explore ideas and emotions and may *challenge* ideas and emotions
Assist discussion and sharing	May aim to change perceptions, attitudes, and behaviours
Restricted to dementia related issues	Addresses whole personality and life of the person
May offer suggestions, options, and information	May give advice

ALZHEIMER SOCIETY OF B.C. Support Groups	1 to 1 Support
Time is shared among participants • Less individual attention • Group comes first, individuals second • Less time to explore individual issues • Less intense	Focus on one person and their individual situation and needs • More attention • More time to explore issues • More intense
Group process is essential • Safe environment • Sharing time	*Gift of Presence* is essential
Higher probability of experiencing challenging interactions	Lower probability of experiencing challenging interactions
Information is tailored to the needs of the group • May not be significant to all members • Sharing of information among members allows for insights, learning from others, and sense of belonging.	Information is tailored to the individual
Most often face to face • The Alzheimer Society of B.C. does offer a tele-support group for caregivers who cannot leave the house or access a support group in person.	Most often over the telephone
Relationships develop progressively	You may not speak to the person again

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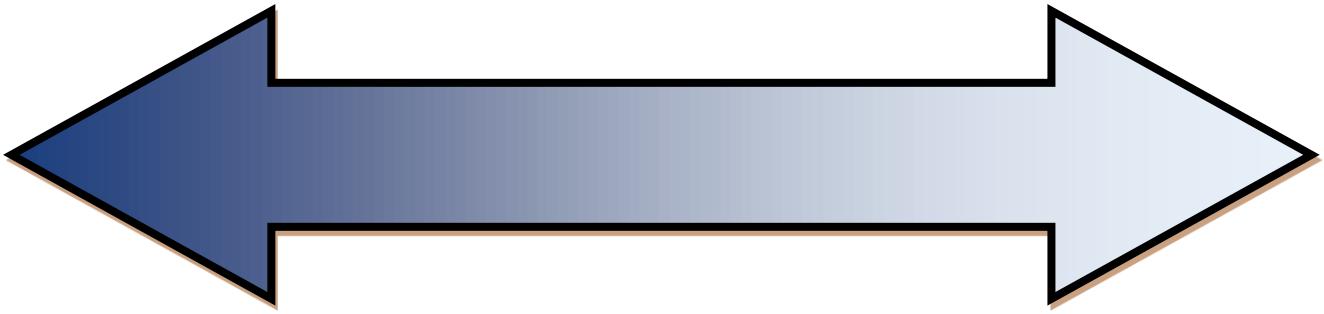
CONTINUUM OF FACILITATOR INVOLVEMENT IN SUPPORT GROUPS FOR CAREGIVERS

Self-help strategies are those processes and tasks directed *by* the members *for* the members.

Depending on the interest and ability of members, self-help strategies are directed more by the members or more by the facilitator:

- reviewing guidelines and meeting rules.
- conducting discussions, dialogues.
- sharing information and experiences in an inclusive and equitable manner.
- making decisions, solving problems and conflicts.
- including new members.
- monitoring and evaluation.
- closure and moving on.

The level of facilitator involvement needs to match the level of members' abilities and interests at any given time – note that the level of facilitator involvement will evolve as the group evolves. For example, group members will learn when the facilitator models helping behaviours.



Less experienced group = More facilitator involvement	More experienced group = Less facilitator involvement

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ESTABLISHING YOUR *GIFT OF PRESENCE*

Gift of Presence – Your 'Being'

In every human interaction, what we offer first is ourselves, our presence.

"Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around." Leo Buscaglia

Once a student of Carl Rogers, noted psychologist and founder of "the person-centered approach to life", approached this noted therapist with a question: "*How is it that every time I see you with a patient, any patient, they immediately open up to you with such candor*?" Dr. Rogers replied, "*Before I go into any room, I remind myself that I am not perfect. I am human. Therefore I am capable of any thought/emotion/act that has ever been had. Being perfect is not enough. I am called to be human and in that space I am one with all I meet*". (Rogers, C. A Way of Being, Boston: Houghton Mifflin, 1980, Page 121)

Recent information from brain studies have demonstrated that the part of our brain that is stirred up when we are challenged by life experiences (the limbic system - aka '*emotional brain'*) needs to settle in order for our thinking & problem-solving parts of the brain (the cerebral cortex – aka *'thinking brain'*) to be able to function well. One strategy for calming the limbic system is to make eye contact, talk about the emotions and the experience behind them, and experience a positive inter-personal relationship. These experiences allow energy from the 'emotional brain' to transfer to the 'thinking brain, which facilitates problem solving. Your **Gift of Presence** is what allows this process to occur.

Your Gift of Presence is:

- Your willingness and commitment to be there, fully present, and in the moment.
- Your unique experience, your journey, who you are.
- Your knowledge and integrity.
- Your genuineness and compassion.
- Your awareness of what is happening inside and around you.

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BEING A SAFE WITNESS

Is offering the person an opportunity to share with me in a different way. As the person hears themselves telling their story, they begin the process of separating from the story. As the person revisits areas of emotional pain from the past, or visits areas of anticipated emotional pain, the lifting of suffering occurs.

How I listen to the story affects how well the storyteller reflects on their story. When the person ends their story, they are starting a new story. That is, the emotional meaning the person gives those circumstances changes.

A safe witness for pain (fear, sadness, sorrow, frustration):

- listens to content and feelings.
- acknowledges content and feelings.
- remains objective.
- does not take over the story.
- does not try to fix problems.

I am <u>NOT</u> being a safe witness when I

- give advice right away: *"What you need to do is_____".*
- say: "*Everything will be alright*".
- say or indicate that the person shouldn't feel that way.
- use platitudes or clichés.
- say: "*I know how you feel*".
- change or avoid a subject because I'm uncomfortable with that subject.
- believe I need to protect the person from the subject (e.g. AD is a terminal illness) or feeling.
- tell <u>my</u> story.

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HOW CAN WE LISTEN WELL?

"Bearing witness...helps you see...that nothing is the right answer, that there are as many ways as there are people.... You have to be comfortable with the mystery, not having the right answers...."[1]

I have argued throughout that one listens to peoples stories not in order to fix them by doing something "therapeutic", but rather to honor them. People tell the stories they need to tell in order to work through the situation they are in. [2]

Validation is the act of honoring another's experience - of witnessing, receiving, embracing and welcoming it, just as it is presented to us and without making any attempt to change it. When we validate someone's experience, we accept or understand that this is how it is for them. We do not need to agree with or accept what we hear as 'the truth'.

The acronym "**VASE**" can help us to remember some essential points of attentive listening:

V We can **validate** the person's experience, whatever that may be. Validation is the opposite of annihilation, which is the dismissal or trivialization of someone's experience.

A We can **attend** to the person. By being truly present, we convey our respect, caring and concern. We can invite them to speak openly about any aspect of their experience.

S We can leave room for **silence**. Our own discomfort or anxiety can create a need in us to try to fill in silent moments; but if we can leave some silent spaces, we allow the bereaved person to reflect or tell us more about what is happening for them, in their own time.

E We can rely on our **empathy** to help us to understand what the bereaved person's experience is like for them. We try to take their point of view or consider what it might be like to 'walk in their shoes'.

[1] Tschanz, Coby Lynne (2006). *Bearing Witness for Nurses in Practice with Persons Living Their Dying*. Unpublished master's thesis, University of Victoria, Victoria, B.C. 90-91.

[2] Arthur Frank, " Just Listening: Narrative and Deep Illness," Families, Systems & Health Fall 1998: 11.

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ATTENDING SKILLS

Attitude of basic acceptance of the person's thoughts & feelings (doesn't mean agreement)

- Feelings always make sense when considered in the context of the individual's worldview.
- Everyone has a right to his/her feelings.
- Feelings are neither "bad" nor "good", they just ARE.
- Feelings are not dangerous; ACTIONS can be dangerous.
- Feelings DENIED do not go away.

"Open" posture & body position. Remove any obstacles (like a desk) between you and the other person. Adjust the space between you so it is a comfortable distance. Face the person fully. Lean forward, but not to the point where you intrude in the other person's space. Communicate with your whole being that you are immersed in what the other person has to say. Give your complete and undivided attention. You will be surprised how much this alone can be healing for others because it's so rare that any of us is accustomed to being really listened to.

Culturally appropriate body buffer zone. Respect the person's physical boundaries – in North American mainstream culture, this means getting no closer than about one arm's length distance from the person.

Animated facial expressions. The person is watching you carefully to see how you are responding to what is being said. Are you understanding what is going on? Because most people are not used to being listened to very well, you are being scrutinized, skeptically, to see if you really are paying attention, and if so, whether you hear what is really being expressed. You can use your facial expressions not only to show that you are listening intently, but also to resonate with what the person is feeling and expressing. You can use words to say that you understand, or you can use your face to communicate the same thing.

Nonverbal gestures. One other way to let the person know that you are tracking the conversation is use other attending behaviors, such as **occasionally** nodding your head and gesturing with your hands or using minimal verbal reinforcers, such as "*mm-mmm*". The key with all these attending behaviors is to use everything in your power to communicate your total and complete concentration on the interaction. Prove that you are listening by showing your interest with your behavior.

Gentle Eye Contact. Keep things natural, but use your eyes to make deep contact. If there is more than one person present, then use your eyes to draw each person in. Be sensitive to individual and cultural differences because some people feel invaded rather than soothed by intense scrutiny.

Milieu: Choose to meet in a space with privacy, confidentiality & minimal distractions.

Attending Checklist:

- ❑ Face the person fully.
- ❑ Communicate intense interest.
- ❑ Give undivided attention.
- ❑ Maintain natural eye contact.
- ❑ Be sensitive to cultural preferences.
- ❑ Use facial expressions.
- ❑ Nod your head.

- Present yourself authentically.

Attending in Groups:

- Challenges:
  - seating arrangements typically around a table.
  - more people to pay attention to.
  - more potential for distractions.
  - less privacy & confidentiality.
- Advantages:
  - others available to share in the attending – facilitator can use observations such as "*lots of heads nodding in agreement with your comment*" to draw connections amongst participants.

Possible barriers to 'attending':

- not being ready to listen attentively – "Gift of Presence"
- inappropriate body language
- a distracting environment
- not providing the appropriate amount of non-verbal cues to let that person know you are listening
- assuming everyone thinks the same way you do
- you think you know what the person is going to say
- being uncomfortable because the person is expressing intense emotions or a difficult subject

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WHAT TO LISTEN FOR

What is a Feeling?

- A feeling is a subjective response or reaction to a person or situation.
- Often the term *"emotion"* is used to mean the same thing.
- A feeling is neither a thought nor an action.
    - "I should have ...." is not a feeling, it is a thought.
    - "My friend forgot to invite me to the party because I'm not smart enough" is also a thought. It is different from feeling inferior, rejected, etc. because you were forgotten.
- Once a feeling comes into awareness, the chances of handling it appropriately improve. Such self-awareness is *being smart about what we feel*. Emotional intelligence is the ability to regulate emotion is a way that enhances living.

Dynamics of Feelings

- Feelings are neither good or bad, right or wrong; feelings just are, they exist. You need not, and should not, judge yourself negatively just because you have or don't have a particular feeling. Some feelings are more comfortable than others.
- Feelings don't last forever. No matter what you are feeling, eventually it will lift and another feeling will take its place.
- When a strong feeling comes, you do not have to act on it. All you have to do is recognize it and feel it. Feelings are not dangerous; actions can be dangerous.
- Everyone has a right to his/her feelings. Everyone is responsible for his/her own feelings.
- Feelings always make sense when considered in context of the individual's worldview.
- Denying a feeling won't make it go away. Not talking about a feeling won't make it go away.

What is "Active Listening"?

"Active" Listening is a special way of **responding** to people in which the listener communicates his/her understanding both of the feelings and thoughts (contents of the "story") expressed by the other person. Helping theory holds that an individual has a built-in ability to adapt and the vehicle for assisting adaptation is one person who understands.

1. Observe both verbal & non-verbal messages to discern both the surface and the deep feeling(s) being expressed.

- *"I feel that ____" = a thought vs "I feel _____"*

- Decode the feelings(s) – is the person mad, sad, glad or afraid?

2. Identify content:

- What is the content of the person's story, and how does it relate to the feelings being expressed?

3. Generate a response:

- Communicate understanding and validation
- Encourage the person to continue with their story

Three main benefits to this kind of active listening:

1. Lets the speaker know that you have been listening to him/her. This encourages trust and further disclosure.
2. Allows the speaker the opportunity to correct any misunderstandings you might have.
3. Provides the speaker with the opportunity to further explore his/her thoughts and feelings.

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MODES OF RESPONDING

There is no one correct response to the other person's statement. Your goal as a helper is to better understand the person's experience, and to **communicate your understanding back to that person**. Being a Safe Witness includes responding in a way that shows you understand. Listed below are several modes of helper responses. Please note that it is rarely helpful to say: *"I understand"*. Instead, demonstrate your understanding by using one of the following modes.

1. **Paraphrase**: The listener repeats (in his/her own words) the content expressed by the other person.

2. **Basic Reflection** (aka empathic response): The listener acknowledges both the content as well as the spoken and unspoken feelings which the other person is expressing.

3. **Summary Statement**: The listener draws together all the different threads that have been expressed into one concise, organized, description that captures the essence of the various messages.

4. **Probe (Open Question)**: The listener asks for further information for the purpose of enriching the understanding of the other person's experience. To be used selectively – not merely to fill in space because the listener does not know what to say – and not for the sake of curiosity. Take care to avoid sounding like a detective. Avoid "why" questions, which are not helpful. Open questions are more effective.

5. **Provision of Information**: The listener shares his/her knowledge about the other person's experience, as appropriate. Must be accurate information!

6. **Silence**: The listener may choose to remain "gently" silent, thereby creating space for the other person's expression of feelings and/or time to reflect and answer.

7. **Self-disclosure**: On rare occasions, the listener may share with the person his/her own experiences and feelings *for the purpose of communicating empathy and support of the other person*. To be used very briefly – always returning the focus to the other person (e.g.: *"Is that what it's like for you?"*).

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CONTROLLING MY REACTIVITY: TIPS FOR SELF-SOOTHING

1. Avoid taking the other's behavior personally.
2. Foster an attitude of: "*what's happening is what is supposed to happen*".
3. Recognize the physiological signs that you are becoming triggered (e.g. shaking, sweating, breathing changes, the "fight or flight" response)
4. To self-soothe:
    - Breathe! (Goal is to get your heart rate down and your primitive brain under control).
    - Stop any negative "tapes". Imagine a big red stop sign. Breathe!
    - Replace the negative thoughts with more positive ones. Breathe!
        - repeat your mantra{s}
    - If you can't control your emotion(s), control your behaviour (s).
    - Self-soothing may require breaking contact with the other – a 'time-out'.
        - Use this 'time-out' productively to calm & support self. Support yourself from within, rather than seeking validation and positive self-esteem from others. Know that you are doing the best you can in the situation you are in, that you are a good listener, a good facilitator, and that you can handle the situation at hand.
    - Debrief with your co-facilitator and your staff supervisor. Talking about it will make you feel better, and help you learn from the experience in a way that will make you a stronger facilitator in the future.

Someone must respond to the group member's remarks – in order to let the person know he/she has been understood (and complete the 'helping' circuit). That someone might be a group member. However, other members of the support group will struggle at times with their own ability to be a safe witness – when we as support group facilitators model being a safe witness, others may learn it.

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PROCESS FACILITATION SKILLS

What is a Process Facilitator role?

- The Process Facilitator role refers to the **how** of the meeting.
- It requires ongoing monitoring throughout the meeting time.
- The Process Facilitator will use his/her active listening skills to 'hear' what to do and when to do it. When you model these skills, other group members will learn them too!

Engaging Facilitation Skills:

- Creating an open environment – welcoming new people to be part of the group; reminding members of 'ground rules' at the beginning of each meeting, or when existing group members seem to need a gentle reminder!
- Encouraging connections – helping people make connections with one another.
- Building group rapport – facilitating a sense of comfort and safety for sharing. Discouraging advice giving and thwarting judgments.
- demonstrating leadership when necessary (to maintain safety for the group as a whole):
    - starting and ending as scheduled.
    - managing the flow and the pace of the meeting.
    - managing the sharing of 'air time'.
    - managing challenges.
    - holding silences.
    - providing timely reminders about advice-giving.
    - balancing inclusiveness with safety of the group as a whole.
    - defining group identity – reviewing the group's purpose.
    - intervening to protect "space to be" as required.
    - managing some of the other dynamics of groups.

Involving Facilitation Skills:

- inviting participation and interaction – promoting contact and dialogue.
- bouncing back to the group – shifting the focus away from the facilitator.

- recognizing commonalities.
- summarizing themes.
- handling 'loaded moments' (expanding the comfort zone of the group, as needed).
- calling attention to something that is happening in the group on an emotional level.
- finding a way to balance the individual's needs in the moment with needs of the group as a whole.
- brainstorming – identifying multiple possibilities.
- asking probe questions to further exploration.
- strategizing – considering approaches to an issue.
- redirecting as needed.

WHEN TO INTERVENE IN GROUPS

"I think of this little bell ringing in my head every time certain situations come up in a group. I may not know what I should do, such as when silence occurs for a long time, but I know I have to do something. It is time for some action on my part. I would suggest that you wire some little bells in your brain, as well, so that when you are leading a group, if any of the following situations arise (summarized in the table below), you will know that it's time to intervene" (Betty Anderson).

Stop abusive behaviour or hostility:

You must have rules in your groups that are enforced consistently to maximize the safety of all the participants. Some of these might include forbidding disrespectful language. Regardless of the specific norms that are established, you must intervene decisively whenever someone is treating others in ways that are less than considerate.

Cut of distractions or digressions:

People ramble a lot in groups. They may take too long to say what they want. They may be upset by something that is being discussed and so seek a distraction. Sometimes, they are just singularly ineffective in their interpersonal skills. If you do not intervene at these times, you will lose others in the group who will become bored and disengaged.

Spice up boredom or passivity:

When you sense the energy is low or things have become predictable, you must do something to increase the level of engagement in the group. You may have to change directions or structure abruptly, abandoning the present course of action. In some cases, you will have to use your body language *and* your tone of voice to get things going.

Stop complaining:

Don't let people whine and complain too much. They will talk about how miserable they are and how helpless they feel. There is a point at which such complaints, especially when chronic and continuous, lead more to increased helplessness rather than relief.

Support Someone Feeling Anxious

If you sense that someone is having a particularly hard time, you must take steps to offer comfort. You can either do this yourself, or even better, encourage others to do so.

When to Intervene in Groups		
Build trust and cohesiveness	Enforce appropriate rules and norms	Reflect feelings or content
Redirect focus	Cue member input	Draw connections among members
Correct irrational thinking	Model appropriate behaviour	Offer support as needed
Reinforce helpful contributions	Encourage consideration of possibilities	Stop complaining
Stop disrespect or hostility	Draw closure on a topic or session	

GROUND RULES FOR DISCUSSION

1. Everyone has a chance to talk; no one dominates the discussion.
2. One person talks at a time, uninterrupted, while others listen. No side conversations.
3. At times of sharing, everyone has the right to pass. Share only what you feel comfortable with.
4. Feeling upset or sad is allowed, tears are ok.
5. Silences are sometimes necessary.
6. Respect the perspectives of others, even if you do not share them.
7. Do not ask direct questions to individual members; rather ask the group as a whole for their input.
8. Share thoughts, feelings, and ideas, but do not give advice.
9. Speak up as there may be some members of the group who have difficulty hearing.
10. Keep cell phones turned off, if possible. If you must have them on in case your family member with dementia needs to get in touch with you, please turn the volume to vibrate and quietly leave the room to take the call.
11. Keep other members' identities and issues confidential; what is said in the group stays in the group.
12. The facilitator may need to discuss what happens during the group with his/her professional supervisor or with an external agency when imminent danger, abuse or neglect are suspected.
13. By sharing the time and respecting these ground rules, everyone shares responsibility for making sure that the group works.

INFORMING FACILITATION SKILLS

The Informing Facilitator role refers to **what is discussed** in the meeting.

- Be prepared with (and be aware of) different kinds of information and/or know where to get information (model this information-seeking behaviour for the group). **Keep in mind that all information given to clients MUST be vetted by ALZHEIMER SOCIETY OF B.C. staff.** Please refrain from doing your own research or presenting information you have gained online or in the media without first getting the information approved by your staff supervisor.

- Recognize when a participant and/or the whole group wants or needs some information.

- Correct misinformation as required. If you notice that someone has given the wrong information, take a deep breath and decide if it is important to correct

    - NO → Ignore

    - YES → now or later (?) → decide your next step

- Admit "*I don't know / we don't know*" and offer to bring the information back to the group OR offer to have someone from the Society staff team get back to the group with the information they need.

- Solicit Information by asking probing questions, in particular to solicit members' knowledge from their own experience. This will foster mutual learning from within the group itself, promoting the recognition of all group members as valuable sources of experience.

- Provide Information:

    - Conceptualizing can help to further group members' understanding and adaptation. For example, many caregivers have never heard of the term "anticipatory grief", yet most can relate to how it feels. Providing 'labels' to name experiences can help normalize their experiences.

- Present facts, resources, knowledge, ideas in an engaging way as possible, when appropriate (see our discussion segments, In Touch Bulletin, and our First Link Bulletin).

- Pace the provision of information to the group's interest & readiness and needs *that month or meeting.* Be aware that the information you prepared to present based on last month's group might not be appropriate for the attendance and dynamics of the current group (e.g. new members, members absent, members experiencing significant changes unrelated to your topic, etc.).

- Always be aware and up to date on the workshops and events being held by the Society in your community or by tele-workshop. Promote education workshops as often as possible when questions come up in the group. Have copies of the First Link Bulletin and posters on hand to give out at the end of the group.

Presentation Tips:

- Look at your audience, not as a sea of intimidating faces, but as friendly individuals who want to hear your information.

- Maintain maximum eye contact with your group; glance only briefly at your notes.

- Speak loudly, clearly, and slowly as some in the group might have hearing impairment or may speak English as a second language.

- Remember, you DON'T have to be perfect.

- A key presentation skill is handling nervousness.

- Keep your presentation as brief as possible so as not to interfere with the members' sharing time. Remember the *Information and Mutual Aid Model* emphasizes the unique benefits of caregivers learning from each other.

- Conclude by reiterating your key points.

WHAT YOU CAN SAY WHEN…

…people mention news articles or present information in your group that you are not aware of, or are not comfortable with:

"This medication sounds like it could be promising, but let's remember that a lot more testing must be done before it will be available to the general public."

> *"I am not aware of this. Let me find out more about it and I will get back to you at the next meeting."*

"This is interesting information, but let's keep in mind that that there have been similar studies in the past that came up with different results than what we are looking at today. So, at this point, the results are not conclusive."

> *"This is a point of interest for a lot of people, thank you for bringing this up. But we now know that (or science has demonstrated), it is not ____ (correct the misinformation), but this____ (present the right information)."*

"We know that good eating habits, mental and physical activity, and maintaining overall good health, helps reduce the risk of dementia. Taking one particular vitamin or ingredient, or doing one specific exercise should be put into that general context. "

> *"If you think that this could be helpful for you, be sure that you talk to your doctor first. What works for one person may not work for someone else. It may even be unsafe."*

"What you are saying sounds very controversial to me. When something sounds too good to be true, it sometimes is."

> *"This early research shows a lot of potential, but it's important to note that the results are still preliminary. We're excited to see what further research shows."*

"I am very surprised by this information. Let's put this aside for today, and I will contact the Alzheimer Society of B.C. on this topic. I will share the results with you at the next meeting."

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WORKING WITH A CO-FACILITATOR

Working with a co-facilitator offers some distinct advantages to the group participants. When two facilitators are working in a synchronized, effective way, the group can become an even more supportive atmosphere for change/adjustment to occur.

When working with a co-facilitator, make sure you spend time together preparing how you will function as a team – demonstrating respect and collaboration in the ways you work together. Consider using the co-facilitator worksheet below to increase your knowledge of each other's style.

To help ensure that both facilitators work in concert with one another, it is a good idea to sit on opposite sides of the circle/table. This makes it possible for you to observe and scan different members, while it also allows you both to watch one another closely for signals and cues. It is also a good idea to develop a signal system between you so that you can communicate during the meeting. At the very least, you would want a signal to indicate: "*Time is almost up*", "*Let's move on*", "*I'm confused*", and "*Let's take a time-out*".

When you work with a co-facilitator, follow these basic guidelines:

1. Sit opposite one another so you can see each other and also different members.
2. Take responsibility for making sure that both of you share equal chores and participation.
3. Take turns scanning while the other is doing the work so that you can cue nonverbal behaviour and monitor participants (better coverage and safety for members)
4. Play off each other's energy to keep things dynamic and exciting.
5. Avoid falling into predictable roles (good cop, bad cop) but alternate the functions you serve.
6. Make a plan for what you might do in the meeting, then be prepared to throw it away and to with what is happening, if appropriate.
7. Debrief one another after the group by not only talking about the members but also giving one another feedback that contains both supportive and constructive elements.

For Co-Facilitators:

Think about how you would answer the following questions. Be prepared to share your answers with your co-facilitator to enhance your experience of working together as a team.

1. I feel my strengths in this role are_____
2. One important thing to me about co-facilitating is_____
3. I feel uneasy when_____
4. You will know that I am getting triggered when_____
5. My signal to ask for help is _____
6. If you have a great idea while I'm talking, please_____
7. I'd like some feedback from my co-facilitator on_____
8. When I plan I like to _____
9. I feel well prepared when _____
10. I am most comfortable discussing the topic of_____
11. I am least comfortable discussing the topic of_____
12. I'd like to learn more about _____

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COPING WITH CHALLENGING INTERACTIONS

Challenging interactions can occur before, during and after support groups. It is important to acknowledge that these difficult situations are a part of the reality of our work. There are ways that we can prepare ourselves for challenging interactions by understanding what commonly underlies these situations, and how to cope when they do occur. As facilitators, we will all be different in what we determine to be a "challenging" interaction.

Challenging interactions might occur when group members:

- Communicate or behave in ways that are different from what we expect.
- Challenge (directly or indirectly) one's sense of competence.
- Ignore appropriate boundaries.
- Bring up topics outside the mandate of the support group.
- Refuse responsibility.
- Actively resistant, "Yeah, but" everything people say.
- Seem angry or argumentative most of the time.
- Make offensive comments.
- Mismatch with your personality or style.
- Push your buttons.
- Lack patience.
- Need more than the support group can provide, or a different mode of support.
- 'Stuck' in negativity, seemingly determined to be uncooperative.
- Hidden agendas.
- Makes choices that fly in the face of reason and safety.
- Has layers & layers of challenges.
- Go on and on during their sharing.
- Have incompatible personality styles with other group members or facilitators.
- When facilitators hold invalid assumptions.
- When the facilitator has lost compassion.

Why might group members conduct themselves in challenging ways?

- Deeply engrained personality styles or coping patterns (e.g. learned helplessness)
- Being 'challenging' allows the person to procrastinate, put off action, or avoid taking risks.
    - *"I distract you from my issues" Or "I prevent you from getting close"*
    - Coded message: "*I'm afraid; I need to go at my own pace*"

- Being 'challenging' maintains the status quo.
    - "*I may be miserable, but at least there are no surprises*"
    - Coded message: "*I'm afraid of the unknown*"
- Being challenging aids the person in avoiding responsibility.
    - *It's not my fault, I can't help it"*
    - Coded message: "*I'm afraid I can't do it"*
- Being 'challenging' is powerful.
    - "I get lots of sympathy" or "I'm doing things on my own terms"
    - Coded message: "*I must feel in control" (*therefore, the other feels powerless).

Emotional Disguises

Rather than making a direct statement about being in emotional pain, group members may disguise their distress by:

- Being critical
- Being judgmental
- Being defensive
- Fighting/fleeing
- Blaming
- Projecting on to others
- Losing self in the needs of others
- Being overly positive and/or optimistic
- Using drugs, alcohol, or excessive activity
- Generating "unproductive conflict" which serves as a distraction

As a part of improving your own level of comfort in dealing with people who behave in these ways (i.e. a person who wears one or more of these disguises), it can be useful to try to decode his/her behavioural message. Attempt to identify the emotional pain behind the disguise. This will help you to understand your own reactions, and be better able to choose an appropriate response. Do your best to maintain your Safe Witness skills in the face of these challenging interactions.

How to respond:
There is no 'one right way' to handle these situations. Each person and each situation is unique. The road map for generating possible strategies to better work with the challenging interactions has one proactive, and three reactive strategies:

Proactive Strategy: Whenever possible, pre-screen potential support group members to identify certain individuals who may not do well in a group setting at this time (or ever) because of crisis situations, mental health concerns, personality styles, or other complicating factors (e.g. drug or alcohol abuse).

Reactive Strategies

Make your assessment of the challenge(s):

1. **Whose problem is it? Who is affected? Whose responsibility is it?** Give yourself 'permission' to intervene when it's a situation that negatively impacts the group. Refer to the section on *When to Intervene in Groups*. Remind yourself that it's part of your Facilitator role to intervene when one member's behaviour is negatively impacting the group, even when it moves you out of your comfort zone.

2. **What does the person want? What is best for the group?** What are the person's goals? Consider (without being judgmental) some of the secondary gains of the behaviour or situation. Remember, hypothesizing about the person's secondary gains' generates only assumptions that may not be true. Proceed with caution, prioritizing the needs of the group over the individual.

3. **What strategies have been most helpful? What strategies have been least helpful?** Speaking with the member before or after the group to remind them of the group guidelines? Sitting next to the group member so that you can gently touch them on the arm to signal they are going off track? Having that member speak first or last in the order of sharing?

4. **Ask yourself: What am I doing to create or exacerbate his/her being challenging?** What personal issues of mine are being triggered? What is it that gets stirred up in me? What needs of mine are not being met? How am I acting out my impatience with this person? What can I learn from this encounter? Remember to self-soothe (breath, repeat mantra(s), moderate your own reactivity).

5. **Decide on a possible strategy - Experiment with that strategy**

6. **Pay attention to the feedback from the experiment in Part Two, and return to Part One as required.**

7. **Get support – from your co-facilitator and your ALZHEIMER SOCIETY OF B.C. staff supervisor.** If you have a co-facilitator, you equally share responsibility for handling the challenging situations. Work together to come to a mutual solution. If one gets triggered more than the other, be sure the co-facilitator who is least triggered is the one who communicates with the challenging group member. If necessary, one co-facilitator may need to take the challenging group member outside of the room do diffuse the situation while the other stays with the group.

   Always debrief with your ALZHEIMER SOCIETY OF B.C. staff supervisor after a challenging situation has occurred in your group. She will speak with the member directly, clarify the ground

rules and why his/her behaviour was disruptive to the group, and will determine whether or not the support group is a good fit for this member. The member may be asked to leave the group permanently, to take a temporary leave from the group (e.g. in crisis situations until things are resolved) and in some cases, there may be a need for a Manager to get involved and an incident report to be completed and put on record. Incident reports are meant to protect you as a volunteer, as well as the organization, in the event a client files a formal complaint.

MODERATING MY OWN REACTIVITY

Embrace the principle of working on "*how to bring SELF differently to these situations*". When I find a situation that unsettles me, it's important to work on SELF – that is, I can teach myself something.

Question: "*What is it that gets stirred up in me*?"

Refuse to be terrorized by the person's reactivity. Remain curious because reactivity is taking the person back to something in his/her emotional history. When someone seems "out of control", it represents a sacred moment with his/her pain. During these times of emotional reactivity, become a "*safe witness*":

Step 1	Stop everything
Step 2	Pay attention to the sacred moment
Step 3	Clear your mind
Step 4	Breathe. Then breathe again. Taking a deep breath stimulates the vagus nerve, which signals the prefrontal cortex (the brake) to signal the brain to turn off/ down our anxiety response.
Step 5	Stay non-judgmental
Step 6	Calm yourself down using intellect (thinking brain) to manage anxious feelings (emotional brain)
Step 7	Be open to the pain. Be curious. *"What is it that gets stirred up?* (meta-mood)
Step 8	Ask self: *"Are there any positive actions I can take to meet my needs so that I can be a safe-witness for this person"*

A "safe witness" for pain (fear, sadness & sorrow, frustration) is:

- Someone who has the ability to listen without judgment to the other's story
- Someone who does NOT personalize, project, take over, nor try to fix
- Someone who listens and comprehends the fullest meaning while conveying verbally & non-verbally this understanding
- Someone who listens to the intention of the story (the metaphorical meaning of the story) rather than the content
- Someone who manages their own feelings by: containing (waiting to react), monitoring (observing), and understanding (reflective curiosity).

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CREATING AND MAINTAINING HEALTHY BOUNDARIES

Creating and maintaining healthy boundaries is critical for a successful group. Some ways that you can set the boundaries in your group and work to maintain them include:

- **Be consistent.**
    - As a facilitator, you are always modelling and setting the standards of what's acceptable and what's not.
    - When you waiver from that consistency, you increase the risk of being tested on where the boundary lies.
    - For example, allowing a group member to bring a friend who hasn't been screened by an SEC first may undermine the screening procedures done by Support and Education Coordinators. The risks include allowing someone into the group who may not fit with the dynamics of the group, thus compromising the safety of the group.

- **If necessary, buy time for a response.**
    - If you're unsure if a group member's request is acceptable or not, it's okay to tell a group member that you need to check with your staff supervisor first or that you will think about their request and get back to them.

- **Say "no" directly instead of using soft language.**
    - "No" has more power and is clearer than soft language, such as, "Well, I don't think so..."
    - Soft language gives the person the impression that you are unsure in your response and can be convinced to change your mind.

- **Match your non-verbal communication to your verbal.**
    - Your body language, tone of voice, etc. should match the message you're delivering verbally. Be clear in your body language and your words.

- **Don't over-explain your reasons.**
    - If you over-explain and try to give too many reasons for why you're saying "no", the person may try to argue with your points or reasons about why they aren't good. Avoid arguing. Just say, "no" again.
    - You may have to say "no" several times before the person fully "hears" you. If the person refuses to accept your answer, even after repeating it several times, you can tell the person you will not discuss it anymore and move on.

It may take practice to become comfortable enforcing boundaries in your group. It is natural that as a facilitator, we don't want to upset the group members or dissuade someone from attending the group who needs support. It is important to remember that our role as a facilitator is to protect the safety of the group. Maintaining healthy boundaries in a support group protects your needs as a facilitator, the needs of the person challenging the boundary, and the needs and safety of the greater group.

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SELF-CARE FOR FACILTIATORS

Facilitating a support group can be very rewarding, but at the same time, very demanding. Listening when someone is going through a difficult time can cause added stress that can be difficult to leave at the group. As facilitators, it's important to recognize that you need to take care of yourself.

Some strategies for your own self-care as facilitators include:

- **Maintaining healthy boundaries.**
    - This protects you as a facilitator and helps to keep the hardship heard at the group.
- **Take care of your body.**
    - Those who eat well and exercise tend to handle stress the best.
    - Try to get restful sleep, particularly before a meeting to help you maintain your emotional energy throughout the group and after.
- **Take a break.**
    - If you find yourself being triggered by something said during the group, signal to your co-facilitator that you need to take a break. It's okay to step outside of the room for a few minutes to take a deep breath and regroup while your co-facilitator continues.
    - Outside of facilitating the group, try to take your mind away from the topic of dementia and away from caring for others. Give your brain a break and do some activities that will help you recharge your batteries, e.g. walking in nature, yoga, reading a book, etc.
- **Practice self-compassion.**
    - This is particularly important for those in caring roles. When we're in the presence of suffering, we feel it in our bodies. In order to remain in the presence of suffering without being overwhelmed, we need to generate extra compassion for ourselves and the people we're supporting. Giving yourselves compassion first will allow you the capacity to be compassionate towards others while protecting your mental health.
    - Treat yourself as you would a good friend and be kind and understanding. Leave the criticism and negative self-talk out of it.
    - Try to catch negative thoughts that may be adding to your stress. For example:
        - "This member's behaviour is a reflection of where he is in his dementia journey and not a reflection of who I am as a facilitator."
        - "I am being triggered right now. I need to breath and relax."
        - "I am feeling overwhelmed in this moment but will be fine in a few minutes."
        - "I am a good facilitator and am doing a good job."
- **Put group members' behaviour into perspective.**

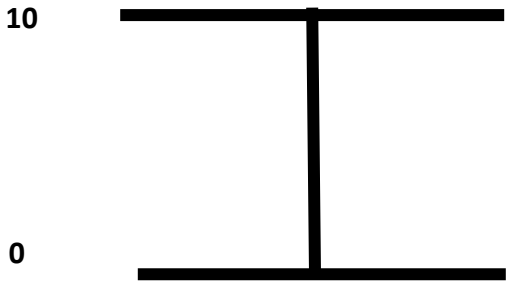
- A group member may be upset with the situation they're in or at a person in their network that may not be as helpful as they're needing them to be. Or they may simply be at the end of their rope, exhausted and having trouble managing their emotions.
- People have a tendency to direct their anger towards anyone in a position of authority. In a support group, this is most likely you, as the facilitator.
- Try not to take it personally. With practice, this gets easier.
- Remember that support groups provide group members the opportunity to share intense feelings. They are sharing these feelings, however challenging, because they feel comfortable to do so. Sometimes these feelings are more of an eruption. This is part of the process of the support group and not a reflection on your skills as a facilitator.

- **Debrief.**
  - After the group, debrief with your co-facilitator and talk with your staff supervisor if you need additional support or are particularly concerned about a group member.
  - Remember that you are not in this alone.

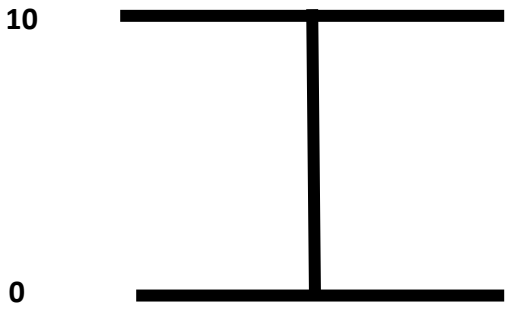
EXERCISE: "SCALING MY PRESENT CONFIDENCE AS A SUPPORT GROUP FACILITATOR"

For My Eyes Only

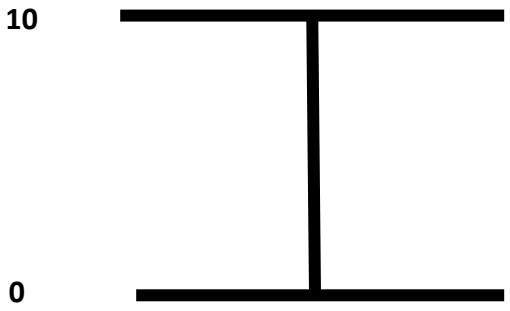
SAFE WITNESS / ACTIVE LISTENER ROLE



PROCESS FACILITATOR ROLE



INFORMING FACILITATOR ROLE



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FOR MY EYES ONLY - ME AS A FACILITATOR

Strengths:

_____

_____

_____

_____

_____

Areas of improvement:

_____

_____

_____

_____

_____

What stands out for me today?:

_____

_____

_____

_____

_____

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FOR MY EYES ONLY - HIGHLIGHTS

Some highlights from the training that I want to remember:

1.

2.

3.

4.

5.

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TRAINING ETIQUETTE

Etiquette for observing a support group

When observing a support group, please be early and introduce yourself to the co-facilitator(s) when arriving. Facilitators will likely have been made aware that you are coming by their supervisor but may confuse you with a new group member prior to your introduction.

Ask the facilitator where they would like you to sit. The facilitators will introduce you to the group and welcome you. If there are no group members present when you arrive, take some time to ask the facilitator about the group dynamics and any rituals the group may have. Help the facilitator prepare for the group by assisting with setup if this has not yet been completed.

Your role is to observe how the co-facilitators manage the session, how they respond to difficult questions or unexpected situations (highly emotional, angry, sad, etc.), the techniques to encourage conversation among the participants, and the resources used/referred to.

We ask that you not participate in the conversation, ask questions or provide advice when observing a support group. If you need to discuss anything with the facilitators, you can do that at the end of the meeting. But please respect their time.

After the group, make a note of any observations or questions to discuss with the co-facilitator(s). At your next meeting with your supervisor, discuss what you observed and any questions that you have from the meeting.

Etiquette for attending a workshop

You will likely observe one or several workshops as a part of your volunteer training. When attending these workshops, you have two main responsibilities. One is to be attending to the material being presented as part of your learning. The other is to be observing the facilitation skills of the presenter. See how they prepare prior to the workshop, create a welcoming environment, engage the audience in participation and handle questions.

Please arrive early for the workshop. Introduce yourself to the presenter as an observer and volunteer-in-training and offer to help with setup. Please do not ask questions during the session. Instead, make a note of any questions you might have and bring them to discuss with your supervisor. Remember that the presenter's first responsibility is to the wellbeing of the group and its members, and (s)he needs to focus on *them*, which might mean being available during the break or after the presentation to answer their questions. You will have ample opportunity to learn and have questions answered by your supervisor during training.

Please resist the temptation to contribute or share your thoughts or observations to the audience, either individually in the breaks or to the group.

Thank you for respecting the needs of our families. Your time and effort in participating in these learning opportunities is much appreciated.

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FREQUENTLY ASKED QUESTIONS

Here are some frequently asked questions that may come up during your support groups. This is not an exhaustive list of FAQ's, nor are you expected to know everything off by heart. The information is here as a reference point for you as you move forward with your volunteering. Also, the information contained in this section is subject to change, so please check the Volunteer Portal and Society website for updates. Please ask your staff supervisor for a copy of the handouts referred to below that are not available in the Support Volunteer Resource Binder.

When clients contact the Society for the first time, we offer to send them a General Information Package in the mail, along with a letter introducing them to our services. The Keeping in Touch (KIT) form can be used to gather the client's contact information, and to sign them up for any regular publications, such as In Touch, Insight, or the First Link Bulletin in their area.

FAQs:

- Progression of the disease: symptoms, diagnosis, how long it lasts.
- UBC Clinic: who goes to it, how to access it and are there other clinics providing a similar service?
- Medications.
- How does the Home and Community Care system work?
- Personal Planning (e.g. Power of Attorney, Representation Agreement).
- Are there any tax breaks available?
- Communicating with a person who has dementia.
- Wandering.
- Communicating with others about the disease and about the person with dementia.
- Long-distance caregiving.
- Motivating people with dementia and helping them to feel useful.
- How can I get my loved one to take a bath?
- Do all persons with dementia become aggressive? What is the best way to handle this?
- How do you know when your family member is ready to go into a care facility?
- When to register with private care facilities.
- How to handle caregiver anger and guilt.
- End-of-life/palliative care issues.

The answers to each question generally have two parts:

Resources: Refers to resource material (brochures, fact sheets, books, etc.) that goes into more detail about the issue. Unless otherwise noted, the publications are Alzheimer Society of B.C. or Alzheimer Society of Canada brochures or fact sheets. The Discussion Segments from your Tool Kit, as well as the Alzheimer Society of B.C. website (www.alzheimerbc.org), are also good resources.

Facts: Outlines important points that can be used to answer the question.

The term "dementia" will be used in most cases, instead of Alzheimer's disease, since it is more general and encompasses other types of cognitive decline, like Lewy Body dementia and vascular dementia.

This document is for internal use only and is not to be copied to support group members or other clients of the Alzheimer Society. It is simply a guide for support group facilitators in answering some difficult questions.

Questions about the disease: Symptoms, Diagnosis, Progression

Resources: "What is Alzheimer's disease?" (or another ASC fact sheet on Vascular Dementia, Fronto-Temporal Dementia, Lewy Body Dementia, MCI, or another rarer form of dementia); "10 Warning Signs"; "Getting a Diagnosis", "Dispelling the Myths", "The Progression of Alzheimer's Disease: Overview."

Facts: The term *Dementia* is an umbrella medical term that is used to describe a collection of symptoms that indicate something is changing in the brain. Alzheimer's disease and other forms of dementia are neurological conditions that do not fall under the umbrella of mental illness. Many other conditions (e.g. medication interactions, urinary tract infections, thyroid disease, depression, other severe infections, brain tumors, alcoholism) can cause temporary symptoms that look like Alzheimer's disease or another form of dementia. Therefore, a complete medical assessment by a family doctor or specialist is necessary to rule out these other, reversible medical conditions that could be causing the symptoms. Diagnosing Alzheimer's disease and other forms of dementia is a process of elimination that can only be conducted by a doctor.

Everyone who is diagnosed with Alzheimer's disease or another form of dementia will experience the disease differently. The length of time that the person has been living with the disease before the official diagnosis will also vary from person to person. Therefore, there is no way to 'accurately' predict the length of time a person will live with the disease after their diagnosis. Generally speaking, the earlier a person is diagnosed, the better the chances that they may be able to take medications that will help them maintain a good quality of life

Alzheimer's disease and other dementias are often described in stages. The three-stage model: Early Stage, Middle Stage, Late Stage; or the Riesberg's Global Deterioration Scale: 1 = No Impairment – 7= Severe Impairment. It is important to note that a person can be early in the disease and exhibit symptoms from later stages, and that symptoms may fluctuate from day to day.

Centre for Alzheimer's Disease and Related Disorders: U.B.C. Clinic:

Resources: http://www.centreforbrainhealth.ca/clinics/clinic-information/CARD

Facts: The Clinic for Alzheimer's Disease & Related Disorders (CARD) is part of the UBC Centre for Brain Health. Patients may be referred by their family doctor or another specialist to the clinic for diagnosis and treatment. The doctors at the UBC Clinic also specialize in diagnosing some of the rarer forms of dementia that may be more challenging to diagnose by a family doctor. People interested in participating in clinical trials, research studies, or who would like information on genetic counselling can also contact the clinic. Their contact information is:

UB.C. Clinic for Alzheimer Disease and Related Dementias
Djavad Mowafaghian Centre for Brain Health
2215 Wesbrook Mall
Vancouver, B.C. V6T 1Z3

Phone: 604-822-7031

The UBC Clinic is not the only option for accessing a specialist for diagnosis or treatment. Many communities have *Seniors Specialized Clinics* where Geriatricians and other medical professionals can diagnose and treat Alzheimer's disease and other forms of dementia. *Seniors Specialized Clinics* are often a key source of formal referrals to our First Link® Program, so be sure to talk to your Staff Supervisor about the nearest Seniors Specialized Clinic in your community.

Medications

Resources: Please refer to the Treatment Options page on our website for information. Also refer to ASC drug information sheet called, "*Medications for Alzheimer's disease: are they right for you?"*

Facts: The four medications listed in the handout above are used to treat early symptoms of dementia, however they do not provide a cure for the disease itself. These medications are designed to help the person with dementia function better for longer.

These medications do not work for everyone, nor can they be safely prescribed to everyone with a diagnosis of dementia. Decisions about using these drugs or discontinuing their use should only be made in consultation with a physician.

Research into different forms of dementia medications is ongoing, and often discussed in the media. Often these drugs are being experimented on in very preliminary stages using mice and rats, yet media reports present the information in such a way that it may be misinterpreted by the general public, potentially instilling false hope.

Volunteers are not expected to know about all the different clinical trials and research studies being conducted on medications and other forms of treatment, but it is helpful to have a way to respond to clients' questions or comments in a way that is respectful, yet realistic. While there is a great deal of research happening around the world, and researchers are learning new things about the disease and potential treatments every day, we are still many years away from finding a cause or a cure.

Many people living with dementia are prescribed other forms of medication, such as anti-depressants, anti-anxiety medications, and in some cases anti-psychotics, to help with symptom management. When clients have questions or concerns about any types of medication, please suggest that they consult their physician and/or pharmacist. Other than distributing the above information sheets, do not answer questions about medications.

How does the Home and Community Care system work?

Resources: Refer to your local *Community Resource List* for information about the *Home and Community Care* system in your local Health Authority.

Refer to the province's *Home and Community Care* website:

http://www2.gov.B.C..ca/gov/content/health/accessing-health-care/home-community-care

Facts: Home and community care services are provided by the regional Health Authorities. Anyone can call their local *Home and Community Care* office to request an assessment by a Case Manager. Persons with dementia and their caregivers are supported at home through access to home support, adult day programs, respite care, and eventually transition to long-term care. There is a cost associated with these services, typically based on a percentage of the client's (or couple's) previous year's net income.

The above listed services may also be accessed privately. When clients access these services privately, requests do not go through a Case Manager, nor does the Health Authority subsidize the cost; the client pays 100% of the cost of privately accessed services. The Alzheimer Society of B.C. cannot endorse any particular private home support agencies, adult day programs, or respite facilities, however we may provide a comprehensive list of options for clients to choose from.

Legal and Financial Questions

Resources: Please refer to the Personal Planning page on our website for information and resources. The Alzheimer Society of B.C.'s "*Personal planning: along the dementia journey!*" document is also helpful.

Another important source if information is The Nidus Personal Planning Resource Centre, a non-profit, charitable organization that provides information to British Columbians about personal planning. They also operate a centralized Registry for personal planning documents. Alzheimer Society of B.C. Resource Centres also have Nidus print resources on hand to provide to clients wishing to get more information.

Facts: Remember, the Alzheimer Society of B.C. cannot dispense legal or financial advice. Instead, we provide information and refer people to other resources such as the Nidus Centre. Similarly, we do not provide names of Lawyers, Accountants, or Financial Planners.

Early personal planning is important because it honours the person with dementia by allowing them to participate in planning for their own future. It also helps give families peace of mind and avoid crises in the future. Personal planning involves legal documents such as Enduring Power of Attorney, Representation Agreements, and Advanced Directives. These topics are discussed during the Planning for the Future segment of our Family Caregiver Series or through www.nidus.ca.

Tax Credits

Resources: The Canada Revenue Agency (CRA) toll-free number is 1-800-959-8281, or clients can visit their website at www.cra.gc.ca/forms to download forms and publications.

The Alzheimer Society of B.C. publishes a yearly Guide to Income Tax and Benefits handout that can be found on our website.

Facts: Remember, the Alzheimer Society of B.C. cannot dispense advice related to taxes or tax benefits. Instead, we provide basic information and refer people to the CRA for more information. However, we

can inform clients that a person living with dementia qualifies for the Disability Tax Credit retroactive to the date they are diagnosed. Again, please refer clients to the CRA for more information about the Disability Tax Credit and other tax benefits.

Communication

Resources: Please visit the Ways to Communicate page on our website, as well as the ASC Day to Day Series summary sheet on *Communication*. The Alzheimer Society of B.C. also has a handout on Communication, available in the respective discussion segment in your volunteer kit.

Facts: All people with dementia experience changes in their ability to communicate as the disease progresses. Communication is one of the most challenging aspects of caregiving and can be a significant source of stress for caregivers. The "Communication Tips for Caregivers" on the last page of the ASC Day to Day series on Communication is an excellent source of information on how caregivers can adapt their ways of communicating.

Although we suggest caregivers learn to adapt or adjust the way they communicate with the person they are caring for, it is important to deliver this information in a manner that does not contribute to the sense of guilt they may already be feeling. Many caregivers carry a great deal of guilt for not always saying the "right" thing or reacting the "right" way. Others may not realize that, because of the disease, they need to change the way they communicate by not asking open-ended questions or reminding the person that they have already answered their question several times. It is always best to encourage caregivers while reminding them that no one is perfect, and there will still be times when they do or say the wrong thing. Unreasonable expectations will only contribute to their feelings of stress and guilt.

Wandering

Resources: Refer to the Wandering page on our website. Every Alzheimer Society of B.C. Resource Centre has Wandering Guides that contain information about wandering and dementia, identification kits, tips for police, and locating devices. This information can also be found on our website.

Facts: The Alzheimer Society of B.C. does not endorse any personal locating devices at this time. The most effective strategy is to try to avoid the wandering before it happens by planning ahead and learning as much as possible about wandering through our Wandering Information Package. When a person with dementia is missing, the family should call 911 immediately. Time is sensitive as people with dementia, when lost or disoriented, tend to walk in straight lines until they can't go any further.

It is also important to note that wandering behaviour may have a purpose for the person with dementia. They may have a clear idea of where they want to go, or something they are trying to do, although it may not possible or realistic to others (e.g. they want to go home when they are already at home). Caregivers are encouraged to inform neighbours, friends, and other family members so that if the person with dementia is found and appears to be lost or disoriented, they will understand why.

When possible, caregivers should encourage movement and exercise in a safe space, therefore reducing the person with dementia's urge to walk outdoors. Strategies to secure the home depend on how far the dementia has advanced, and can range from installing locks on doors and windows and using alarm

systems, to visual adjustments (black mat in front of doors, camouflaging doors), to not ever leaving the person alone.

Communicating with others about the disease and about the person with dementia

Resources: Refer to brochures "What is Alzheimer's Disease?" and "Dispelling the myths."

Facts: While respecting the privacy of the person with dementia is important, sensitively informing people in his/her life about what is happening and how to deal with some of the changes they see ultimately is more respectful than having people deal with the person with dementia in a way that frustrates them and causes them to pull away from social contact. Some people report experiencing stigma around the communication of the diagnosis, others report receiving nothing but support and understanding from friends and family members.

Long-distance caregiving

Resources: Refer to the "Personal planning: along the dementia journey" (July 2018) document and visit our website (www.alzheimerbc.org - type "long distance caregiving" in the search box). There is also a discussion segment on "long distance caregiving" available on the Support Volunteer Resource page (facilitator guide and corresponding handout) that your support group members may find beneficial.

Facts: Don't assume that the long-distance caregiver is experiencing less stress than the "hands-on" caregiver. They don't really know what is happening on a day-to-day basis, often have little or no say in the person with dementia's care, feel helpless that they can't do more, and may experience a strong sense of isolation (and incredible guilt) about the whole situation. Open and honest communication with all involved family members is essential. If no one lives near the person with dementia it is important to have a local contact to monitor the person with dementia and to communicate any concerns to the long-distance caregiver. Make sure that legal documents are in order (see "Personal planning: along the dementia journey"). If there is a local caregiver, the long-distance caregiver can help a lot by taking over for a few weeks and by providing regular emotional support.

Motivating people with dementia and helping them to feel useful.

Resources: Refer to (1) booklet, "Shared Experiences," (2) "Quality of Life" (Tough Issues summary sheet), and (3) "A Handbook for Care."

Facts: Sometimes a lack of motivation is a result of depression, particularly in the early stages of dementia. If this is suspected, the person should see his/her doctor. The person with dementia has progressive brain damage, and this can result in the lack of motivation/initiative. Routine is important, and as much as possible a continuation of the routines that the person with dementia has been used to for most of his/her life. This helps the person know what to expect and be less fearful and confused. Confusion can undermine motivation, since the person becomes paralyzed not knowing what to do. Schedule activities that the person enjoys, even if they have to be modified to accommodate their declining abilities. Bring stimulation to the person; e.g. putting the coffee pot on so they can smell the coffee, asking friends over to watch the football game on TV. Keep tasks simple, to minimize confusion, maximize success, and to reinforce the person's ability to participate in life in a meaningful way.

How can I get the person with dementia to take a bath?

Resources: Refer to Day to Day summary sheet, "Personal Care."

Facts: Be aware that many factors may contribute to the difficulty in getting the person with dementia to bathe: fear of falling (depth perception changes), fear of water (brain damage changing the sensation of water), embarrassment, temperature problems (room and/or water too hot or too cold), inability to understand the purpose of bathing anymore, etc. Strategies can then address these factors. The person needs to feel safe, respected, and not rushed. Sometimes it helps if the caregiver showers with the person with dementia, or if the person leaves his/her underwear on. Sponge baths can be given under a large, soft towel, on the bed. Music may calm the person. Try to schedule the bath for the same time of day the person has always bathed in the past. If the person gets too stressed, distract and do something else for a while. If necessary, put it off until the next day. Some "battles" are not worth fighting. Be realistic. If a bath every day is too much for the caregiver to handle, try every second day.

Do all persons with dementia become angry or violent? What is the best way to handle this?

Resources: Refer to discussion segment on reactive behaviours.

Facts: The answer to this is absolutely not. However, it is important to see the angry or violent behaviour as a cue that something is not right. The person may be tired, afraid, confused, or overwhelmed. They may also be experiencing some kind of physical discomfort that they cannot verbalize or responding to drug side effects or hallucinations. All behaviour is an attempt to communicate. Don't take it personally. Instead, try to calm the person and distract them as quickly as possible. The best solution is to avoid the problem in the first place, by being watchful of the person's moods and attempting to redirect them as soon as you are concerned that something might be amiss. Also, do your best to deal with environmental and physical stressors. In the early stages of the illness the person may be feeling that they are losing control of their life. These feelings need to be validated.

How do you know when your family member is ready to go into a care facility?

Resources: Refer to Day to Day summary sheet: "Caregiving Options: Considering Long-Term Care."

Facts: There is no hard and fast rule here. Several factors need to be considered, including the needs of the person with dementia, the primary caregiver's health and ability to continue caregiving, the family's ability to provide the care that is required, and the availability of supports through Home and Community Care. Unless the family is paying privately, this decision will not be made by them, but will be made with their input. B.C.'s subsidized long-term care facilities are accessed on an "at risk" basis, which means that the person who is most at risk gets the next bed. Waiting lists are not used. The person must take the bed, but the family can apply to have the person with dementia moved to another facility after 30 days if the original placement is not to their liking. It is important to reassure caregivers that they have not failed if they have placed the person with dementia in a care facility. They are still caregivers, but they are now doing this job with the assistance of many staff. Instead of providing day-to-day care, however, the caregiver is now their family member's primary advocate. This is one of the reasons why it is so important that they visit the facility regularly.

How to handle caregiver anger and guilt

Resources: Refer to brochure, "Reducing caregiver stress" and discussion segment on Guilt

Facts: Anger and guilt are natural reactions to the caregiving experience. Joining a support group and attending the Family Caregiver Series helps a lot. The resilient caregiver learns about the disease, accepts it, and is realistic about the disease, the person who has it, and their own limitations. Planning for the future is important, especially if this is done when the person with dementia is still able to participate in decisions about his/her life. Build a support network and use it. Take care of yourself. A burnt-out caregiver is tired, impatient, and inflexible – then comes guilt. Share with others – share the load, share your feelings, share your experience. If your anger has escalated to the point that you fear for the person with dementia's safety, get help NOW, even if it means placing him/her in a respite program for weeks while you take time to heal yourself.

End-of-life/palliative care issues

Resources: Refer to Day to Day summary sheets: "The Progression of Alzheimer's disease: Late Stage and End of Life". Refer to our website: End-of-life care

Facts: Providing comfort and dignity to the person with dementia continues to be important as the disease nears the end of its course. Planning ahead really helps, since it is much easier to make decisions on another person's behalf when you have actually discussed this very thing with the person when they were able to articulate their wishes. It is important to follow the person's wishes if they are known. If not, an awareness of the person's values and beliefs can guide the decision-making process. Any decisions should take into account several factors, including the progression of the dementia, the individual's overall health, and the risks and benefits of proposed treatments. Strictly speaking, the goal of palliative care is to provide comfort when there is no treatment for the illness and death is near. Caregivers should be encouraged to get support for their grief.