

FEELING FORGETFUL? LET'S TALK



Conversation starters for people living with dementia who want to talk about their thoughts, feelings and dreams for the future.



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Feeling Forgetful?

Let's Talk

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© August 2016; Updated March, 2023

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ISBN: 978-1-926511-27-6

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Notes for the Facilitator

The purpose of this book is to open up the lines of communication between those living with dementia and those who provide support and care. To do that, we wanted to know what people living with dementia, who resided in long-term care, would like to talk about. We decided we needed to know more, so we asked individuals living with dementia, who resided in LTC, to guide our journey. We developed a set of standardized questions, tested them out to determine if we had missed any important details, modified our questions, and then interviewed people who were living in a long-term care home in Ontario, Canada. Each person had previously been diagnosed with dementia and everyone who was interviewed struggled with memory loss. They all gave us permission to use the answers to the questions we asked, and so did their loved ones. It was interesting to find that some of the participants acknowledged that they have memory problems, while others were not aware of any such problems. However, some did say they do find there are times they are forgetful. Even though some did not admit to having challenges with their own memory, they all said they would like to talk to others who do. Some said, “It would actually be quite helpful to talk to others about these things”.

One message was perfectly clear in the interviews: no one wanted the word dementia or the word Alzheimer’s used. Although this is a small sample size (with only 16 participants), we have omitted these words and recommend that they be used if the facilitator feels comfortable adding the words dementia and/or Alzheimer’s to their discussions. Perhaps you could ask if anyone has dementia or Alzheimer’s after the group has become closely connected, and is ready to confide in each other. If the discussion goes well, ask what it is like to have dementia or Alzheimer’s Disease. We suspect there will be people that will embrace the discussion, while others shy away from it. Feel free to ask additional questions about what it is like to live with dementia or Alzheimer’s, and what advice they would give to others. The goal is to respond to the needs of each individual in the group.

Note: You might want to know more about each person before you begin. Even if a person has been diagnosed with dementia, it is not the role of the facilitator to share the diagnosis of dementia! If they ask, however, and you decide it is important to share the truth, be prepared to acknowledge the person’s feelings and lend your support. The DementiAbility Communication course offers techniques to address this situation.

The topics presented in this book are the ones identified in our findings as being the most important areas for discussion. While we asked each participant the same set of questions, the answers were often quite similar, but also, at times, quite different. This aligns with the DementiAbility WOW Model, and the statement “If you know one person with dementia, you know one person with dementia.” It

is interesting to note that one person actually said, “You people don’t want to talk about what we want to talk about”. That tells us so much about the need to open up the lines of communication in dementia care. We thank everyone for their participation in this project.

When we asked this group of people what they would call a book about memory loss, and the topics people would like to discuss, they were happy to provide some suggestions. Some of their answers included:

- Memory Lapse
- What Memory Should Be for Me
- Do You Remember?
- I Don’t Know
- My Broken Brain
- The Loss of the Person’s Mind

While all of these were good ideas, we decided to call the book “Feeling Forgetful – Let’s Talk”. Why? Because many of the comments we documented had statements about being forgetful and how important it is to talk about what they want to talk about. This title seems to capture the essence of the discussions that were held with those who often forget!

10 Factors for Facilitating “Feeling Forgetful – Let’s Talk”

The topics, and the respective questions presented in this book, are based on conversations with individuals who have been diagnosed with dementia (prior to their move into long-term care). These discussions raised a number of interesting findings. For example, no one wanted to hear the words, or be associated with the words, "dementia" or "Alzheimer's". The words dementia and Alzheimer's are therefore not used in this book. Each person had an opinion about dementia, memory loss and Alzheimer's disease. While all said that they did encounter situations where they might not remember something, some said they did not have memory problems, and definitely did not have Alzheimer's or dementia. While you may encounter people who do not object to using these words, it is recommended that you avoid using them during the initial group discussions. Instead, use the words "memory problems" or "forgetful".

Please note that participants/group members do not necessarily need to have insight into their own memory loss to benefit from this book. The people who were interviewed did not admit to having problems with memory, but later said there might be times they do indeed forget things.

The goal is to provide you, the facilitator, with a tool that will encourage open discussion about some of the struggles that are experienced by those who are increasingly challenged by memory loss.

The following factors provide a set of guidelines for facilitating **“Feeling Forgetful – Let’s Talk”** discussions in a group setting.

1. **Select group members:** Invite 2 – 4 people with dementia – people who are forgetful – to participate in a **“Feeling Forgetful – Let’s Talk”** discussion group. Develop a routine of meeting at the same time on a regular basis (e.g. – once or twice a week). Some of our participants said they would enjoy meeting weekly to discuss some of the things we asked about during our interviews. These topics are included in this book.
2. **Focus on good listening skills:** The role of the facilitator is to ask the questions and then listen to the responses of each person. Encourage each participant to take turns sharing their thoughts and listening to everyone in the group. **Consider copying the questions, so everyone is holding the**

question that is the focus of the discussion. (You have permission to photocopy.)

3. **Make sure no one person dominates the conversation.** Encourage participants to give everyone equal time for talking and sharing.
4. **Do not judge:** There are no right or wrong responses to the questions that are included in the book. The role of the facilitator is to create a safe environment that welcomes all thoughts and opinions. While it is important for the facilitators not to judge, it is equally important for the facilitator to remind participants to support the group members, rather than judging or ridiculing.
5. **Develop an environment that fosters trust:** Tell the group members that you will keep their conversations confidential. This is a safe environment for sharing their thoughts and feelings.
6. **Acknowledge and validate feelings:** The facilitator must always make an effort to acknowledge and validate the way each member of the group feels as he/she expresses thoughts, concerns and opinions. Use sentences such as, "That must be hard." Or "That would be upsetting." Another strategy to pursue is that of asking other members of the group to comment on how difficult this might be.
7. **Assist when word finding difficulties arise:** If a person struggles to find the words or the thoughts he/she wants to share, the facilitator should be ready to step in and/or ask questions that would help the person find his/her words and complete his/her thoughts.
8. **Don't attempt to complete the whole book during one session.** Each page could be the focus of discussion for one session. You may want to set a start and end time for the meeting, covering only a few questions at a time.
9. **Take breaks when needed.** If possible, provide refreshments part way through the session so people can socialize.
10. **Enjoy!** Create bonds between program participants and help them to look forward to their regular meetings.

What do you do if someone becomes extremely upset?

When someone becomes upset during the group, consider the following:

- 1) Decide whether this person simply needs to feel supported, with an opportunity to express feelings. Does this person simply need to let his/her emotions spill? Will the opportunity to cry – and feel supported address the situation? There is a difference between needing to cry and an upset that will need to be de-escalated. Let your observations guide your plan of action.
- 2) If the person becomes extremely upset, take a break.
- 3) Acknowledge and validate feelings using the techniques you learned in DementiAbility's communication course.
- 4) Lead the group in some deep breathing exercises or gentle stretches. Consider ending the group for today, and start again another day.
- 5) Offer a different activity to divert the attention to something positive.

Using the questions to guide discussion

The questions provided in this book are presented in no particular order. It is up to you to decide which questions you would like to discuss during a session with those in your care. You can engage in conversation with individuals, or run a group with 3 – 6 people. The goal is to provide people living with dementia the opportunity to connect, discuss, feel supported and, generally, talk about the things that matter to them.

Many people have problems with their memory, especially when they get older. Everyone forgets things sometimes.

Do you ever have troubles with your memory? Do ever think feel forgetful?

How does that make you feel?

Most people say that just because you have trouble with your memory, it doesn't mean you are crazy. People who struggle with their memory want others to know they don't belong in a "looney bin". Many people have used these words. Do you think this is silly?

What does it mean to be "looney"?

Why do you think some people connect memory loss with the word "looney"?

Living with memory problems isn't easy. It can be difficult to remember details like dates, names and where things have been put. Some people have problems remembering things such as recent events, what they had for lunch today or who came to visit yesterday.

Have you ever had problems remembering details such as these?

How does that make you feel?

Some people find it helpful to write down details when they want to remember important things, such as when a family member will call or when they have an appointment with their doctor.

Have you ever used an agenda or note pads to help you remember what you will be doing?

Do you think an agenda and/or notes are helpful for those who have problems remembering details about what is in their calendar?

Losing important things is a big concern for many people who have memory problems. It is very frustrating when they can't find an item they are looking for, especially something with sentimental value or something that helps them to remember a loved one. Some people find it helpful to label drawers and cupboards. Others put things away in the same place every time.

How do you feel when you can't find things?

Do you get frustrated when you can't find things?

Have you ever put labels on drawers and cupboards? Do you think this is helpful? If you haven't done this, would you be willing to give it a try?

Memory isn't the only concern older adults experience. Some people have problems with their vision or hearing or both. Others may have painful arthritis and/or experience problems with walking. Life in a wheelchair is not easy.

Do you think people find it hard to adapt to these changes?

Would it be hard to lose the ability to see or hear or walk? Which one would be the worst?

Do you have any advice for people who need to adapt to changes that affect their brain and body?

Oddly enough, it is sometimes easier for people to remember details from the distant past, like what their mother made for Sunday dinner or who their best friend was in school. It all depends on what people are trying to remember.

Do you like to recall some of the things that you did when you were younger?

What are your favourite memories?
Was it school? Playing with friends? Or something else?

Would it help if photos were labeled with names, dates and locations?

Some people are afraid they will forget some of their treasured memories from the past. It feels good to reminisce about happier times and to recall the proud accomplishments they enjoyed in the past. It is fun to talk about these things with others.

Have you ever written down some of the stories from your past?

Do you enjoy looking at old photos and reading about the things you used to do?

Is there anything you would like to share about yourself?

A lot of people with memory problems say they feel stupid and/or embarrassed when they can't remember something. Other people feel angry, and wonder, "Why me? Why must I be so forgetful?" Some people say it would be nice to share their frustrations with others.

If you had trouble with your memory, would you want to share your experiences with others who are having the same problems?

Would you like to support others who have memory problems, even if you don't have memory problems?

Some people who have problems with their memory are worried about finances. They worry that they haven't paid their bills or they are concerned that there are things they need to pay or do. Others are concerned they will run out of money or they may have to move again. It is important for loved ones to remind people who have memory problems that their financial affairs are in order.

Are you ever concerned about forgetting to pay bills?

Are you ever concerned about running out of money?

How do you manage these concerns?

Some people who are forgetful feel lost and confused at times, especially if they are in a new place or with people they've never met before.

Do you ever feel lost?

How does getting lost make people feel?

Should there be signs for people to find rooms and to find things?

Memory loss can be a very lonely experience for some people. It can be difficult to talk to other people when the words won't come or people can't express what they want to say! Some people worry about saying the wrong thing or repeating themselves. One person who has problems with her memory says, "I start every conversation by saying, stop me if you've heard this one before." She says, "That way the person I'm talking to can tell me if I'm repeating myself." Some people like to be corrected when they forget something. They often worry that they are annoying people by asking too many questions.

Would it bother you if you realized you were repeating yourself?

What would you do if you found out you asked too many questions? How would you feel?

A lot of people are uncomfortable talking about memory loss. There are many reasons for this. Sometimes people feel embarrassed because they have problems with their own memory. They may also worry about offending or embarrassing someone else who may be forgetful. Some people get very sad when they think about someone they care about who is struggling with their memory.

Do you think people should be embarrassed if they are forgetful and can't remember things?

Would you be sad if you couldn't remember things? Would it depend on the type of information you can't remember?

People may also worry that memory problems might happen to them one day!

Do you worry about your memory?

A lot of people who have problems with their memory don't mind talking about it! It can be a relief to know that other people around them are struggling too.

People with memory loss shouldn't be so hard on themselves. After all, they can't help it. Their brain is different than it used to be. People who have problems with their memory are often very capable of taking care of themselves. Nobody wants to be a burden.

What words of comfort do you have for people who are worried about their memory or worried about being a burden?

Many people find joy in helping others. People often say, "I like to help. If there is a job that needs doing, they only need to ask!"

Do you like to help others?

What types of things do you like to do?

Would you like to help make meals?

Would you like to set tables or clear tables?

Did you have volunteer jobs when you were younger? Would you like a volunteer job now?

People who have problems with their memory have shared their tips for coping when they feel stressed and upset. Religious and spiritual beliefs are a source of comfort for many people. Some people like to spend time with family, pets and loved ones, others prefer to rest and spend time alone. Getting involved in an activity can also be helpful. Most people would say, “No one wants to be bored”.

What would you want to do if you were upset about your memory? Would you want to be with others or would you want to be alone?

Do you have any religious beliefs that provide you comfort?

People who have problems with their memory are just like anyone else! They have hopes and many still have dreams of meeting that special someone. Some hope that a handsome man or woman will sweep them off their feet! No matter our age, everyone wants to feel loved.

Do you hope to meet someone and fall in love again?

Would you want to get married at your age?

How would you describe a perfect partner?

What makes you feel better when you are feeling upset?

How important is it to keep a smile on your face at all times?

What makes you happy?

What messages would you give to people who are forgetful?

What advice would you give young people about growing old?

What advice would you give people if they want to know how to live a happy life?

Are there any questions you would like to ask others?