

Dementia and Communication: Problems faced, tips for family caregivers

*This document is the transcript of the video: **Dementia and Communication: Problems faced, tips for family caregivers**; the video can be viewed on youtube at: <http://www.youtube.com/watch?v=0g848fvG-Q4> The video and the transcript have been prepared by Swapna Kishore.*

Introduction

When someone we live with develops dementia, their lives and our lives change in many ways. As their abilities reduce, as their disorientation increases and their personalities change, we need to support them in more and more ways. But many of us start facing problems even in understanding the patients or in making them understand us. We therefore feel helpless and frustrated.

Effective communication with the patient is foundation for any support or caregiving that is required. We need to be able to communicate if we want to help the person with daily tasks. Communication is necessary to reduce the person's agitation or depression or challenging behaviors like wandering, yelling, and so on. And we need to communicate if we want to be able to relax with the person, and enjoy joint activities and outings.

This video focuses on this foundational caregiving skill: Communication.

Many of us have already faced the problems of poor communication. Before the person developed dementia, we may have enjoyed simple, pleasurable moments with them chatting about common topics, watching children play, and so on; we may even have depending on the person for advice and guidance. But after the person developed dementia, things changed. The person is no longer interested in the details of our lives, gives strange comments or advice, says lots of wrong things but gets angry if mistakes are pointed out. Often, even simple conversations are difficult. The person looks blank or confused, or gets angry for no apparent reason. They do not answer questions or appreciate it when we offer them choices. Sometimes after they have agreed to something they do the exact opposite and get angry when we point out their earlier agreement. They have difficulty telling us what they want. They use wrong words, look unhappy that they cannot explain, and get agitated or depressed.

In this video, we discuss the problems that dementia patients face while communicating. We offer tips for effective communication, ways to reduce the frustration for us and for the persons with dementia.

Communication problems occur because of the way dementia impacts patients and because we caregivers do not sufficiently take these into account while interacting with the person.

Understanding the problems persons with dementia face

The problems patients face depend on their type and stage of their dementia, and they vary from person to person. The following indicate the sort of challenges patients face when trying to understand us, or while trying to tell us what they want or think.

Difficulty in paying attention: Because of reduced capabilities, patients find it difficult to focus on a conversation, especially when there are many things happening around them. They cannot filter out what is important

Poor short term memory: Because of the poor short term memory, when we say something, the person may forget what we have just said by the time we reach the end of a long sentence

Difficulty in making choices: It is difficult for patients to keep multiple options in mind, compare them, and choose between them

Problems understanding or recalling words: The ability to understand and recall words is often affected in patients. This makes it tough for them to understand what is being said, or to explain what they want. So when we name something, like a toothbrush, or we talk of some activity, like having a bath, they may not immediately be able to imagine what we are talking about. When they try to understand what is being said, they may miss the next few sentences.

Disorientation about time and space: Often, patients are not very sure of where they are, or they are confused about the date and time. Because of this, they may not be able to remember who you are, or understand the topic you are talking about, because in their mind they are in a different city and era.

Difficulty in understanding complex things and new concepts: A complex explanation, a detailed description can be strenuous for the patient, because they cannot hold all the information in the mind and keep it neatly organized. Complex sentences, long sentences can be like a memory test to them. By the time we finish a lengthy explanation, they may not be remembering what the earlier part of the explanation was. New concepts are usually tough for them to understand. Humor may also be difficult to understand, and similes and metaphors may be a problem.

Confused by emotions they sense but do not understand the reason for: Persons with dementia often notice the emotional tone of the person speaking to them. So if we are excited or irritated when talking to them, they may notice that emotion. But as they may not understand the context of our emotion, they may assume we are angry with them or that we are hostile towards them, and they may respond with hurt or fear or hostility.

Frustration: Often, patients realize that they are not being able to do what is expected from them. Or they sense that they are less capable of doing things than they had been earlier. This could be frustrating or humiliating for them, and they may respond to the situation by withdrawing or by getting agitated, even yelling.

We can see, if we pause to think about it, that the problems that dementia patients face are very real and frightening. The patients are coping with several difficulties. If we understand and remember their situation while interacting with them, we are more likely to use suitable

communication strategies. We will also have more realistic expectations. Our interactions will therefore be calmer and more effective.

Strategies for effective communication

For effective communication, we try to make communication simple and pleasant and respectful and keep it within the limits of what the patients are capable of.

- Help patients focus on what is being said
- Talk in a simple, respectful, easy to understand way
- Offer only relevant, simple choices
- Constantly adjust the approach depending on patient's response
- Listen attentively, and help the patients express themselves
- Do not correct the patient's mistakes. Do not argue.
- Keep the conversation stress-free, pleasant, and of suitable duration

Help patients focus on what is being said

The idea here is to make ourselves visible and clearly heard so that the person can pay attention to us fully. This increases the chance of the person understanding us.

One mistake many of us make is that we tend to call out to the person from another room, or from behind. This is not effective because

- the person may not know we are talking to them
- the person may get startled or disoriented, as they may be thinking of something else
- the person may not recognize who is talking to them

To talk to someone with dementia, we must talk to them face to face, keeping our bodies at the same level so as to have eye contact

It is difficult for a person with dementia to concentrate on what is being said if there is a lot of activity or noise around them. For example, if there are cross-conversations, or a TV or radio playing, or noises of the street, etc.

When talking to someone with dementia, we must remove sources of distraction like nearby sounds or other distractions.

It is possible that the person with dementia has poor eyesight or hearing. That means, the person cannot see or hear properly without appropriate spectacles or hearing aids.

We can make it easier for the person to focus on our conversation if the person is using the correct spectacles and hearing aids.

If the person is comfortable with, and likes being touched affectionately, you can also touch the person to connect to them and get their attention.

Talk in a simple, respectful, easy to understand way

The idea here is to speak in ways that take the person's current abilities into account, making it easy for the person to know what we are saying.

Introduce oneself: One problem is that the patient may not remember us, or know what we may be talking about. They may be disoriented and think of themselves as being in another place or time, or may simply not remember who we are or what we may be wanting.

We can start a conversation by briefly introducing ourselves at the beginning of every conversation, in a way that is friendly and not condescending. The type of introduction required depends on the patient's disorientation and memory problems. We can also address the person so that they know we are talking to them.

Use simple sentences and vocabulary: When talking to an elder, or to a spouse with dementia, we often forget that this person is facing problems understanding things. This is especially so when we have had many long and complicated discussions with this person in the past, because we tend to slip into our old pattern of talking. For example, we may give lengthy explanations about some problem, or start narrating a long sequence of events.

We forget that the person can no longer follow complicated reasoning or a long sequence of events. Also, the person may forget what they heard at the beginning by the time we reach the end of our long narrative.

We can be considerate to the patient by using small, simple sentences with common, simple words. Talk of only one topic in one sentence. Also, pause for enough time between sentences so that the person gets time to understand what has just been said.

We should use words that are easy to hear and understand, and speak in a language that the person knows well. Long, tongue-twisting words should be avoided. We should speak slowly and clearly.

Sticking to relevant material is good. If we add unnecessary detail we are adding to the patient's burden of understanding. Giving too many details is "overcommunicating". We are more considerate to patients if we focus on necessary things, and say the more important things at the end of the sentence.

Supplement words with gestures, smells and sounds: Given that the person with dementia may have problems understanding sounds and words, we can make our conversation simpler for them by adding gestures to explain.

Take, for example, if we are trying to make the person brush her teeth. Instead of just saying "brush your teeth", we can also point to the toothbrush or even make a gesture showing the act of brushing the teeth. Demonstrate what you are saying. Mimicking actions, and pointing to things are helpful ways to supplement what we say.

We can also use other cues to simplify understanding, such as smells and sounds around us.

For example, it may be simpler for someone to know we are suggesting it is time to eat if the person can also smell freshly cooked food.

Stay clear of baby language or other condescending behavior

Some persons assume that because persons with dementia cannot understand things as easily as other adults, dementia is a sort of second childhood. Because of this, they sometimes assume a sort of condescending baby language way of speaking to adults, just because these persons have dementia. This talk is typically ineffective and condescending and not liked by the persons with dementia who feel belittled or angry because of it. Persons with dementia are still adults, except that they are facing challenges because of the disease. They are not children. They should not be spoken to as if they are children. They are adults who need some consideration and understanding.

Keep body language and tone friendly and relaxed: Words are only a fraction of what forms a communication; a lot of communication is the non-verbal part, things like body language and facial expressions and tone of voice. We need to remember this when talking to the patients.

Keep your facial expression relaxed. This is only possible if you genuinely feel relaxed and remain genuinely connected and involved with the patient. Remembering that the patient is facing actual problems may help us stay calm and helpful, and avoid impatience and frustration.

Avoid any irritation or hurry in your tone. Even excitement or urgency in your voice can alarm the patient, because the patient may not understand the reason for this changed tone. The patient may start feeling anxious because of this tone and not even pay attention to the words. Keep your tone warm, friendly, and gentle.

Offer only relevant, simple choices that are easy to select from

Keep our questions simple: We sometimes give too many choices to the person with dementia, who may start getting confused and not be able to select. The patient cannot remember all the choices or understand them. Sometimes, we may make this even more confusing by adding detailed explanations between the choices.

For example, we may say something like, *"If you want, you can go with Aditi to Karol Bagh. She has to go there to pick up the sarees for Garima's wedding gifts anyway. Aditi can even take you to Nandini's house for lunch; I'm sure Nandini would love to have you over, and she makes such lovely pulao, just the way you like it. Or you can stay at home here, I will ask Ramu to cook you peas pulao with raita. Will that be okay? What would you like to do?"*

Then, when the patient looks blank, we often start adding even more explanations, such as, *"Maybe Karol Bagh will be tiring. I think they have started digging it up for the Metro or gas pipeline or something, it is a real mess. Maybe it will be better if you stay at home. Hey, should I ask Munki to come over to give you company? You can play Ludo with her. Or watch TV, I think there is a rerun of one of the old serials you used to like."*

All this explanation burdens the patient who has to process this complicated sentences, explanations and choices and then give us an answer. No wonder the person looks puzzled or irritated, or even snaps back!

Choices should be clean and easy to understand, like, "Do you want to go to Karol Bagh with Aditi? Or do you want to stay at home?"

As patients find it easier to remember what is said at the end of the sentence, they are likely to select the last option offered. Keep this in mind when offering a choice.

Avoid questions where a patient needs to use memory to answer the question. Expecting a patient to use a memory of a past event, to compare that event with the present, and then to give an answer is expecting too much work from someone facing memory problems.

In fact, avoid anything that could seem like a memory test to the person. For example, avoid asking them whether they are feeling better today than they were feeling yesterday. Instead, see if you can keep the question simple, by just asking them whether, right now, they are feeling well or not. Questions with just Yes and No answers are easiest for patients.

Also, avoid unnecessary questions: Sometimes we ask questions we don't really want answers for. For example, "Would you like to come for your bath?" The person with dementia may think this is a real question and wonder what to answer, or may even say "No."

It is best to avoid such unnecessary questions. In such cases, we can simply say, "Let us go for your bath now."

Constantly adjust your approach so that the conversation remains effective

Communication is not just saying what you want to say. It involves connecting to the other person. Stay alert on the person's expression and body language, and use that understanding to change the way you are talking to the person. Some examples:

Is the patient looking confused? Perhaps you need to slow down, say things in a simpler way, maybe repeat things after a pause. Or maybe you need to give the person more time to understand what you have said. Or maybe you need to use more gestures.

Is the patient looking agitated or scared? Check your body language and tone, and adjust them to make them friendlier and more relaxed. Make your message simpler.

Is the patient fidgeting or looking around? See if you can get their attention back. Or maybe they need something, and it is better to stop the conversation now and find out what they want.

Is the patient looking tired? If the patient is tired, maybe you should see whether you need to really continue the conversation. Is the topic you are talking about really important? Maybe it will be better to stop talking and resume the conversation later when the person is more willing to listen.

Listen attentively, and help the patients express themselves

When the patient talks or tries to express a need or feeling, make sure you pay full attention.

If you are unable to understand what the patient is saying, admit your problem, and then try to make it easier for the patients to express themselves. For this, you can point to objects, or make gestures to clarify your understanding.

For example, if you think the patient is saying she wants to brush her teeth, you can make a gesture of teeth being brushed and ask for confirmation. Or you can point to a toothbrush.

Or if you think the patient is in pain, you can point to body parts, or grimace as if in pain, and ask if that is the patient's problem.

But do not be in a hurry to complete the patient's sentences, because that is rude. Be calm and give the person time to find the words or gestures needed to convey what they want to convey and offer hints and assistance gently.

Do not correct the patient's mistakes. Do not argue.

Often patients will use wrong words, remember things wrongly, and do things wrongly. As family members, our normal tendency is to "correct" them, or argue with them to "set them right". Somehow, many of us feel that we cannot let the wrong memory or action remain. We feel that it is our duty to correct the patient.

This is just not suitable when communicating with a dementia patient.

Dementia patients will make mistakes. We must understand that. We must accept it. We do not have to correct the patients, we only have to try and understand them, and help them communicate.

Things are difficult enough for dementia patients. They are often aware that they are not being able to do things well enough. To rub in their mistakes by trying to correct them only increases their frustration. They may get agitated or even aggressive, or even withdraw.

Memory loss is a known problem of dementia. So are confusion, problems with words, problems in deciding and so on. Mistakes are natural and realistic to expect.

Sometimes family members feel that if they do not correct the patient, they are "allowing" the person to get worse. This is not a correct view of the dementia problem. Arguing with the patient or pointing out and correcting mistakes will only make the conversation unpleasant and upset everyone. It will stress the patient, and stress always makes things worse.

Instead of pointing out mistakes, just focus on understanding what the patient wants or is feeling, and on helping the patient understand what you are saying.

For family members, used to seeing the person with dementia in the pattern of older times (when the person did not have dementia), seeing such mistakes is often very difficult. It is difficult for them to leave mistakes uncorrected. But many family caregivers who finally stop their habit of arguing and correcting the patients often notice a marked improvement in patients once this tendency to argue is stopped.

No one likes to be told they are wrong. No one likes mistakes pointed out. Dementia patients do not like it either. What they are saying is based on what their memory tells them, and if their

memory is faulty, that is because of their dementia. It is a mistake to assume that such corrections will "improve" the patient's memory.

Keep the conversation stress-free, pleasant, and of suitable duration

Conversations may be tiring for patients, because they have to work so hard to understand and respond.

When talking to, or listening to a person with dementia, stay especially careful that the conversation does not stress or tire the patient.

**

As we have seen, there are many strategies we can consider to improve our ability to communicate with persons with dementia. These include things like helping the patients focus on what is being said, using simple, respectful, and easy to understand ways while talking, offering only relevant and simple choices, and constantly remaining alert to the patient's responses and adjusting our approach accordingly. We can help patients express themselves using various ways, and listen attentively to what they are saying. We can avoid correcting mistakes and avoid arguing with the persons. We can keep our conversations stress-free, pleasant, and of suitable duration so that they are pleasant experiences for us and for the person with dementia.

We can select what is effective depending on the situation and the stage of the person with dementia. Over time, by trying out various things and by observing what works and what doesn't, we can improve our communication with the persons with dementia.

In conclusion

The key for effective communication is always remembering the difficulty the patient is facing and adjusting the way we speak to them, adjusting the way we ask them things, and adjusting the way we help them express themselves.

Once we find ways to talk to patients, we will find it easier to help and support them in other things, too. For example, it will be easier to help them with their daily tasks, it will be easier to reduce challenging behaviors like agitation, repetition, wandering, etc. We will also be able to relax with them and enjoy activities together. Being able to effectively communicate helps improve the overall care environment around the dementia patient and makes life easier and more pleasant for the patient and all of us around the patient. Understanding the patient's problems and implementing various tips accordingly is well worth the effort.

Thank you for watching this video. You may also find other related videos on this channel helpful for dementia caregiving.
