

## III. Communication with a person with dementia

### What is communication?

The word communication comes from *communicare*, which is Latin and means ‘to share’. We can use a model to describe the communication process.

A simple communication model consists of a sender, a message, a receiver and a response. The sender conveys a message to the receiver. The receiver interprets the message. The response will tell the sender whether the receiver understood the message. The message contains something that the sender wants to express. The message can be conveyed in different ways, e.g:

- By spoken words, for instance in a conversation, in a lecture or in a TV program
- By written words, for instance in a report or journal, signposts at the workplace, e-mails or text messages sent via mobile phone.

### One-way communication

In one-way communication the sender is active and conveys a message. The receiver has little or no possibility to give feedback. An example is a written report or when a person gives a speech or lecture. A danger with one-way communication is that neither the sender nor receiver can check whether the message is understood as intended.

### Two-way communication

Two-way communication is when the communication goes back and forth between the sender and receiver. The persons alternate between the positions as sender and receiver. You exchange feedback during the conversation. You can ask each other questions and clear up misunderstandings immediately.

### Verbal communication.

Verbal communication requires the use of words, either orally or in writing. The words you choose when you speak and write, have great impact on how your message is perceived by the receiver. Words you think are neutral and harmless, may be offensive or hurtful to persons with a different background than yours. Other people may also be unaccustomed to your expressions and jargon, or they may have problems understanding your dialect. Keep in mind that people are different and come from diverse backgrounds when you are communicating with people that you do not know well.

### Nonverbal communication

In nonverbal communication we communicate without the use of words, but use for instance facial expressions, tone of voice, gestures and posture. How we situate ourselves in a room or in relation to the one we are talking to also convey a message. Another word for this is kind of

communication is “body language”. Body language can emphasize or contradict your words. Clothes convey a message. At most workplaces in health care, it is common to use uniforms.

### **Touching**

Touching is a part of body language. Words may not be enough some times, a touch can better convey what we wish to communicate, for instance, hugging someone to show them you are happy to see them, or placing your hand lightly on the back of someone you want to comfort. You can also use touch to get the attention of someone you want to talk to, for example by touching his or her arm.

### **Double communication**

For communication to be good, your body language must correspond with your words. However, this is not always the case. To say one thing with words and something else with your body language is called “double communication”. Double communication creates uncertainty, and most people will believe more in what your body language says than what you are saying with words. It is common to think that body language accounts for 80% of our communication.

Have you experienced double communication? What happened?

How can you avoid conveying a double message (double communication)?

### **Communication with persons with dementia**

Although the ability to engage in a conversation and perform routine activities is affected by dementia, they tend not to change emotional experiences. Emotions such as joy, sorrow, sadness, anger, powerlessness, affection, longing, success, feeling of calmness, restlessness and stress is present as before. It is therefore important to create situations that provide good experiences as a way of sustaining a meaningful social environment.

We all feel certain amount of discomfort when we are corrected and when high standards are expected of us. It is often very common to correct misconceptions when having a conversation with a person with dementia. It is often very easy to say: *‘No, it wasn’t so! No, you are wrong, remember that!’* Such statement gives a feeling of defeat, powerlessness and in some cases causes the person to react angrily.

Dementia can in some cases lead to a gradual change in a person’s ability to imagine how others feel about themselves. It can be difficult for family members to understand how a mother/father/spouse, who earlier on used to be thoughtful and engaged in others, does not display same interest any more.

There are evidences to the fact that openness during the sickness process is equally important for the person with dementia just as it is for family and friends. Both family members and persons with dementia ought to discuss the importance of talking together about the illness. This can reduce uncertainty, mitigate the pressure of expectations, and contribute to an increase in mutual understanding and a feeling of togetherness in the attempt to handle the challenges that arises with the illness. Taking all these points into consideration can be

challenging as we communicate to each other. With the busy daily schedule, it can be challenging to exercise patience. There may be a feeling of guilt as a result of inadequacies when caring a person with dementia. Many family members can therefore benefit from attending the school for next of kin and in discussion groups, or share their experiences with other family members, close friends or someone from the support service.

Each conversation and interaction has a start phase, an accomplishing phase and a closing phase and persons with dementia can experience challenges in all the three phases. It is the caregiver that must adapt his/herself and create a suitable environment for a positive and effective interaction.

### **Eye contact and close attention**

It is easier to understand each other when you are together in a close proximity, facing each other and that you call the person by their name and have direct eye contact before a conversation. It is often difficult for a person with dementia to understand what is said if the speaker is backing them or talking from another room.

### **Short, simple sentences and one issue at a time**

It can be very easy for family members to forget how difficult it is for persons with dementia to understand long sentences and messages. It is less difficult to understand when you use short sentences, say one thing at a time and waiting for a response before proceeding to the next point. It is also ideal to avoid asking complicated or challenging questions as the illness gets to a more serious stage. Ask a yes or no type of question instead. Avoid asking such questions as: *'do you remember .....'*?

Try to positively put words into feelings, for example: *'I see that you feel sad .... I see that you feel happy .... I now feel happy too,'* or: *'You have found the newspaper, which is good; we can now read a little'*

### **Some concrete tips**

#### **Speak slowly and use a softly accentuated voice**

Talking fast and too much at a time can create confusion for a person with dementia. Talk slowly and use your voice in a way that strengthens the message as illustrated in the following example: *David and Mojca sits in the common room watching TV together. The doorbell rings. David looks up scaringly. Mojca says: 'David'. David looks at her, Mojca looks back at her with a smile and tells him with a soft and tender voice: 'it is just the doorbell'. David looks at her and says: yes, 'it certainly is'. Mojca says: 'You may want to see who it is'. David stands up and walks towards the door.*

#### **Repeat the message, allow for some time before expecting a feedback**

It is important to expect a response or reaction from the person. Sometimes, it can be quite challenging to wait too long for a response, but this can be perceived as overriding for those who struggle to communicate, if they are not given enough time to speak out what they have in their mind in a situation. Repeating what you have said makes it easier for understanding and to convey what you intend to say.

### **Avoid interruption and reprimands**

We all have experienced some discomfort if interrupted while talking and when we are corrected by others. Persons with dementia also feel the same way if they are interrupted when trying to say something. It will also lead to a negative experience if a person is corrected or reprimanded by a family member, when they are trying to express something from their own worldview. You may easily start discussing: *'No dad! That was not what happened. You are wrong!'* *What happened was that ....'* Such situation can easily make the person feel dumbfounded, irritated or angry. It is better not to contradict but rather let go. Where an explanation is important, it would be ideal to say: *'Oh, is that how you feel about it? I have a slightly different opinion about it'*.

Some family members are good with the use of humor. Laughing together can create an alliance and improve the bonds. It can be uncomfortable for everybody, when there is little or no connection. Sharing one's experience can create a feeling of commonness and a sense of belonging.

### **Get rid of distractions**

Too many visual and hearing impressions can lead to disorientation. Keep things simple in every situation. It can be ideal to reduce or turn down the volume of the radio or TV when you are having a conversation. If you are in a social environment with many other people, it is ideal to pause and go to another room for a while, take a walk out or simply cut the visit short.

### **Short introduction to methods of communications**

Communication is vital for an effective interaction. This means that we *must talk to* and *listen to* the person. How do we talk to a person with dementia? How can the person make his/herself understood, if he/she has a poor ability to express him/herself?

It is speculated that 20 percent of all communication between people are verbal, whereas 80 percent is non-verbal. This means that we perceive much more than words, when we talk to each other. Persons with dementia, who has some challenges with language, may perceive other things than what the words are meant to convey; the facial expression, looks and attitudes, can show a sign of acceptance or rejection.

It is important to map out what method of communication is best useful, as we interact with a person with dementia. It helps to talk slowly and clearly if the person has some challenges with hearing; while talking loudly may not necessarily be helpful to persons with low language ability. It may be rather helpful to accompany your intended message with facts, facial expressions and display of objects that may be useful for the interaction.

It is important that we as caregivers are aware of the manner at which we express ourselves. We ought to use short sentences with few words and request or ask for one thing at a time.

### **Anxiety, delusion and agitation**

Some persons with dementia experience challenges with emotional imbalance that is

connected to disorientation and memory loss. Anxiety and insecurity can contribute to more delusions. Caregivers or family members must be able to understand such and meet them at that level of communication and make them feel safe in such situation.

### **Validation therapy**

Validation literally means *to make valid or confirm*

During our communication with persons having dementia, validation shows that we understand the person's feeling of unrest and anxiety. We can support the person to feel safer and therefore reduce the complications, by recognizing the person's feeling, rather than overlooking it. We show that we recognize the person's anxiety, without necessarily confirming or denying the person's delusion. Their ability to communicate will gradually improve once anxiety is reduced.

### **Disorientation**

There are times when a person with dementia becomes disoriented. A disoriented person has difficulty remembering even simple things like year, date, time and where they are. Many among family and friends may think that the person 'goes back to childhood'. He/she does not recognize family members, neighbors or friends any more. Many with dementia may mix up the future with the present, which makes life even more confusing for them.

### **Reality orientation**

*Reality orientation is a form of communication that aims to provide information on reality awareness. It is therefore a way to meet the need of elderly people with memory loss. The method supports their everyday attempt to keep themselves oriented with the 'here and now' situation. Through the use of the method, persons can receive the help they need, to remember what their everyday things and actions center around. They also get help to orient themselves on time and place. It therefore provides them a kind of 'compass' to navigate in a world that can be very confusing for them.*

*Reality orientation is about meeting the patient where he/she is in time and place and then leading them forward to the present with respect. The difference between Validation and Reality Orientation is that the latter aims to direct the patient back to the present. This is not the main objective with Validation, although it is also a tool used in guiding the patient toward the present.*

### **The person's knowledge and skills**

In the case of dementia, there is damage to the brain's functioning and the person is not able to function as they earlier did. This can cause changes in communication patterns; the person does not remember what is being discussed and the conversation gets to a halt or cessation. To stimulate the person's memory center, it can be of help to bring up things that are very much known from the person's early life or work life. The type of projects or work responsibility the person had engaged in, or had accomplished with much pride, can be a 'silent' knowledge and a reference point that can be used to steer the person back into the initially intended

action. To be successful, one ought to know what the person was good at, so as to often refer to them and perform activities with familiar actions.

### **Reminiscence**

Reminiscence is a form of memory activity such as: recalling, recognition, dissemination and sharing of memories or remembrance. Through reminiscence, we share with others our experiences and accomplishments in life. Such activities enable us to reflect over the choices we had made in the past, and the consequences that followed. As a result, one would have easily participated in a meaningful and valuable conversation. The central team may often relate to the person's experiences from childhood, school age, work life, family life etc. It is important to know the person's good and difficult experiences to be able to rightly influence the topic of choice during communication.

## **III. Social relations, activities and interactions**

### **Daily life activities**

Daily activities are things we do or are engaged in, during our everyday life. Things like waking up, going to work, school or a care center; going to the groceries, making dinner, eating, engaging in leisure activities, eating an evening meal and going to bed. Start by finding out who the person is, then find out the kind of activities that may be of interest for him/her. It is normal to ask the person directly, even as family members can provide useful information.

Humans are social beings and everyone feels some sense of satisfaction being with others some times during the day. We are not just together for nothing. We get together for one activity or another, for example: a meal. Meal time is a common activity that comes with many known routines. The activity itself can be a reason to be together, for example:

- Dressing up/undressing
- Walking on the stairs
- Eating
- Making the table
- Dish washing
- Making waffles
- Peeling of vegetables or fruits
- Folding of clothing or towels
  
- Reading out a newspaper, poem or a book
- Taking a walk
- Baking
- Playing bocce
- Memory activity or conversation (reminiscence)
- Polishing of brass or silver

- Sowing or dressing a flower or any kind of plants
- Making body movement to a music or dancing
- Playing bingo
- Swimming
- Group singing

Such activities can be used in motivating people to participate, while it is also important for persons with dementia to get the balance between activities and rest. They can be exhausted and start acting restless. This happens often in the afternoons or evenings when they start to get tired. There can be several reasons for their restlessness and it is important to find out the cause of restlessness.

### **Everyday practical issues associated with communication**

It is often challenging to carry out daily activities, when a person suffers a type of disease condition. Rehabilitation can improve such person's situation in many case, but not in the case of dementia. The person's practical abilities will often gradually reduce. The surroundings of persons with dementia must be reorganized to suit their condition in order to enable them maintain their daily activities as long as possible. This entails making adjustments to the physical environment, use of aids, guidance and help from the caregiver.

Evidences show that family members may find it easier to accept the changes occurring in the person's life, if they can stop expecting that he/she will perform as before. Accepting the changes can create opportunities for exploring new ways of staying together. Practicing on being present together here and now may contribute to new and positive experiences.

Good sensuous experiences through seeing, hearing, tasting, smelling and touching can provide strong positive moments, despite the fact that the condition affects the ability to understand what is seen and heard. Sensory activities often contribute to the recollection of memories. Good memories can create good feelings, even if the incident that triggered the recollection of such memories may not be remembered. It remains in the body. Research shows that a pleasant experience of 10 -15 seconds have a positive effect that may last much longer.

### **How does it feel to be reminded about daily routines?**

People often answer 'yes' when they are asked such questions as: have you brushed your teeth, showered, eaten or been out for a walk, even if the person no longer remembers what he/she had done. A dementia patient understands what daily routines are but does not remember what has been done through the day. Imagine how embarrassing it would feel if you are ask a question such as: have you had a bath today? The first thought for many would be: *am I smelly?* It can be very uncomfortable if we are directly asked such questions concerning our daily routine.

### **Challenges with complex tasks and technical installations**

In several cases, the first sign of dementia is that the person faces challenges with tasks such as: driving a car, handling of bills, use of kitchen equipment, computer or similar equipment

that require technical understanding. The aforementioned tasks and almost all unnecessary activities consist of several parts and stages that must be completed sequentially and in an orderly manner, if you are to get the expected result. An example is when you put on a coffee machine: this requires filling the can with water to the right level. You may not get a good coffee otherwise.

Something as easy as brushing of teeth requires that you can:

- Find the sink
- Find the toothbrush
- Find the toothpaste
- Unscrew the cap
- Squeeze out the paste
- Take out just enough paste
- Put back the cap again
- Turn on the tap

Persons with dementia may easily forget some of the steps in such sequential activity. For example: brushing their teeth without toothpaste and/or water. They can easily get stuck in the middle of an activity and that is when they need guidance from others.

### **How can one provide guidance for the daily activities?**

As a result of dementia, many become more passive as compared to how they were before the onset of the disease. It may seem as if the person has lost his/her inner drive. It is also easy for others to interpret this as laziness, but it is important to be aware that the ability to take initiative is no longer present in the same way as before. The person needs others to get them started, for example, assisting them to the bathroom and showing them where the toothbrush and toothpaste lies over the sink. This could be enough for some. Others may need someone to stand by them and guide them through the whole process. The example on guiding a person through the process of tooth brushing, illustrates how activities can be organized:

- Explain what is going to be done – brushing of teeth
- Provide illustrations – give an illustration of tooth brushing
- Put tool in the hand – give the person the toothbrush
- Hand-lead into action – Support the person's hand with yours and gently direct it to the mouth.
- Gently take over the process – do the brushing for the person.

When a verbal instruction and the act of getting the toothbrush in the person's hand is not enough, it helps to guide the person's hand into the mouth with the toothbrush. This action signals the brain and conveys the messages about what is to be done. The person will then continue and complete the tooth brushing on his/her own.

Another example is when a family member takes the hair comb from the person's hand and completes the combing, because the patient did not get it done properly. It could have strengthened the person's self-esteem, if the family member did the combing from start since

it is known that the patient would not be able to do it properly, and then give the patient the opportunity to finish the process. This gives the feeling that the person has been able to complete a task without help from others, which could strengthen the person's self-esteem on their competences. It is easy to take over the task when we see that the person is struggling. This can be seen as offensive for some persons.

Some persons with dementia are unable to conclude a task and they may repeat the same task several times. It is better that the caregiver redirect their attention to something different, which signals them to conclude the task and move on to something else. It could for example be a great idea to say: *'Ah, here comes a sweet smell'*, while you are showing them the deodorant, if the person repeatedly brushes his/her teeth without being able to stop. By providing the support that person needs at the moment, one may strengthen the person's ability of performing daily task such that the acquired ability holds longer. At a given point in the developmental stage of dementia, patients may no longer manage to actively participate in their daily routines. It becomes necessary that others take over the daily tasks and the approaches described above would longer be appropriate. It creates an unnecessary sense of defeat for the patient, when he/she is no longer able to complete a daily task that everyone else would otherwise expect them to do.

The daily fitness of persons with dementia may vary and this can be confusing to family members. Today, they may struggle to complete the same task that was not a challenge the other day. It can be very demanding and tiresome for caregivers to adjust their approach through the day or from day to day.

### **Keeping the physical environment simple**

Keeping the surrounding simple has some great benefit. This means to keep what is important and remove unnecessary things that may contribute to undesirable stimuli. Here are some examples that may be appropriate, but this may not necessarily work for everybody. For many, it helps to have fewer options to choose from when completing a task. Example: Toothbrush, toothpaste and deodorant are the only things that should be available around the wash-hand basin in the bathroom. It can be a great advantage that different creams are kept in different kind of tubes and jars, such that foot cream is not mistaken for toothpaste, for example. It is however not ideal to change a type of cream that a person had always used.

Keeping to an earlier routine is often easier than learning something new. The same principle on reducing stimuli and putting more emphasis on necessary things, applies also to things such as cupboards in the sleeping room, kitchen or refrigerator. It may be challenging for some persons to find what to put on in the wardrobe. It is therefore ideal to put aside clothes that would be use the next day. These should be kept properly on a chair or at a position that would be easier for the person to reach. Another strategy is to remove from the wardrobe all other cloths that are not in use. Some patients can scatter all the clothes in the wardrobe because they are not able find the very one they intend to put. This becomes chaotic and even more stressful for them. It is also ideal to lockup some of the cupboard/wardrobes and leave the ones in use unlocked, that is if the person accepts the idea.

The aforementioned principle also applies here. Put food that would be eaten earliest to the outer most part of the refrigerator, so that the person can easily reach it upon opening the refrigerator door. They also need help with getting rid of old food stuff.

Some persons may find it problematic to identify dirty cloths. They may then need help with putting the clean clothes in sight, so that it is easier for them to choose. Some may struggle with putting on their clothes in the right order; a woman may put on her bra on her shirt or sweater; underwear on long pants. They may need help with putting on their clothes in the right order.

Keeping track with the night and day circle can be challenging at a later stage of the disease. Many enjoy reading newspapers to keep themselves updated. They therefore get themselves oriented with current news if they are helped with removing the older newspapers.

In summary, we can conclude that a person with dementia needs a considerable amount of help from a care-giver who has basic knowledge of the disease and understands how best to provide help.

### **Person centered care**

Person-centered care is about seeing the person with dementia as an individual with feelings, rights, wishes and a life's history that characterizes her as the person she was before she had dementia. The questions we ought to ask ourselves during person centered care are: Who is she? What are her life's experiences? What does she appreciate the most today?

The main values that are presented as person centered care for people with dementia, was developed by the British neuropsychologist Tom Kitwood. The philosophy about person centered care lays much emphasis on growth promoting communication that is based on the premise of accepting the person as he/she actually is or appear; to show dedication(empathy) and to be honest (genuine).

Persons with dementia may feel that the people around them just see them in the light of what they no longer are capable of doing; that they are not treated with the same respect as before. Being a person means having feelings, such that someone reacts and tries to understand when one cries, is worried, or laughs. Being a person also means having the sense of choice. As care givers, we must treat them as human beings, take them seriously, are open to stimulating their opinion.

### **A short introduction to the V.I.P.S. practice model**

We 'place' people by judging them from their personality, behavior, life's history, resources and need. According Kitwood's description, being a person means one is considered in relation to another. Kitwood was influenced by the American psychologist Carl Rogers. He is one of the founders of the humanistic line in psychology and have had a strong influence in the development of the person centered approach. Carl Rogers emphasized on growth promoting communication on the premise of accepting the person as they actually are or appear; to dedicate (empathy) and to be honest (genuine).

Personhood as a concept means that we are dependent on each other's recognition, respect and trust. We have the urge to be a dignified part of community. We will constantly seek feedback and confirmation of ourselves in relation to other people and thus learn to know ourselves and know who we really are. The desire does not disappear even when we develop dementia. We may only express the desire in a different way.

The term environmental therapy is often mentioned in connection with person centered care. What is the difference? It can be generally said that a person centered care uses environmental therapy, but it also entails more. Another terminology for environmental therapy is 'non-drug treatment'. It includes different types of activities, both individual-based or in groups. Examples are: music therapy, memory groups or other suitable activities that may help the patient function in the best possible way.

Environmental therapy can be used in one or several ways so as to give the patient the opportunity to use his/her skills and gain a successful experience.

The VIPS-framework helps us focus on all the four areas that are included in the person centered care. Each letter of the **V-I-P-S** represents an area that must be considered, in order that the care can be person centered.

V- Values

I – Individual adaptation

P – Perspective of the person with dementia

S – Social need and community

In order to provide care for a person with dementia via using the V.I.P.S model, it is required that one has the knowledge of environmental therapy, both theoretical and practical knowledge. A course plan has been developed in Norway from which a health personnel working with dementia patients is expected obtain some education.