

## The Caregiver's Handbook – Bizzarri

Communicating with older people and people with disabilities: how to understand the assisted person's needs and obstacles.

The following general techniques facilitate effective communication:

- Avoid using the so-called barriers to communication:
  - Evaluation → We must avoid judgement on the value or behaviour of the assisted person: "You are bad", "You are stupid". Also positive comments can be manipulative: e.g., "You are good" can cause the assisted person to behave in a complacent manner to receive appreciation. Also, describing behaviour as wrong without trying to understand the reasons behind it, generates conflict, devaluation and, in any case, the person will surely repeat the behaviour or even amplify it. If a behaviour has negative consequences, either practical or relational, it is good to express them and consider the relevant pros and cons in order to find a mediation: for example, with an older person we may say "I understand that you usually go down the stairs by yourself, but, please, call me so that I can help you and prevent you from falling"
  - Investigation → In a relationship with a disabled or older person, it is important to ask questions and acquire information. However, these requests must be placed in a non-investigative manner, without forgetting that we should respect the right to privacy of the assisted person and the boundaries of his/her private life. To get information, you may ask open questions: "How do you feel today?", "What would you like to do this morning?", "What would you like to eat?" Avoid the following types of questions: "Do you feel bad?", "Do you want to go for a walk?", "Do you want soup?" Similar questions draw attention to something specific rather than encouraging the expression of desires or moods. Therefore, we need to ask different kinds of questions. It is essential to build a relationship based on trust and give the assisted person the opportunity to express what he/she wants. We should allow him/her to take some time and think before expressing his/her thoughts. Elderly people and people with disabilities may have slower reaction and decision times.
  - Finding solutions → in a caregiving relationship, it may seem natural to propose your own solutions to problems. However, we should try to avoid this normal attitude and allow the person to find his/her own solution to a specific problem. Especially with young people with a disability, who are trying to achieve autonomy and independency in their lives, we should stimulate their ability to face and solve problems. And with the elderly, we should refrain from proposing our own solutions in order to avoid imposing a different behaviour than their own. In general, if we keep proposing our solutions insistently, the person may stop trusting us, because he/she feels overwhelmed by suggestions, advices and sometimes even reproaches, without having the opportunity to understand the problem and search for his/her own solutions.
  - Support → Elderly people and people with disabilities often experience moments of profound discouragement, anger or fear due to their condition since there is no possibility of radical improvement. We should always avoid minimizing the problem or filling silences with clichés, such as: "Everything

will be fine", "It is not a drama, come on!", "Be brave". Silence and empathic presence, characterized by attentive attitude and true availability, are the most suitable behaviours in similar situations. According to Rogers, empathy is the ability to understand the fear, anger or sadness of another person without adding your own fear, anger and sadness. In order to achieve this, you must be aware of your own emotions within the relationship and know how to manage them.

- Interpretation → when we communicate, we should always avoid attributing any extra meaning, other than the explicit one, to another person's behaviour or to what we are told. When we look for extra meaning, we often fall in the trap of attributing negative meaning and, consequently, we add mistrust and conflict to the relationship. For example, when a person with disability repeatedly drops something we may think that he/she is doing it in spite of us; this typical interpretation is ungrounded and misleading, and generates anger and conflict in the operator. If we think that a sentence or behaviour has an implicit meaning, we should ask and talk about it directly in order to verify it and speak openly. We should never take our interpretation of the other person's thoughts for granted.
- Use the reformulation and open questions techniques: for a better communication, we should repeat what the assisted person has said, especially in case of speech disorders. This will allow you to verify the correct comprehension of the message and the person will feel heard and understood. We can also use open questions, which encourage the person to freely express himself/herself, without getting lost in details that he/she does not want to discuss.
- Non-Verbal Communication: a good part of communication happens through facial expression, gesture, posture and tone of voice. These signals must always be taken into consideration, as they add meaning to words and allow us to tune with the mood of others. We should always keep in mind that non-verbal communication "reveals" our thoughts and moods, therefore it is important to avoid dissimulating, which is extremely difficult, and even if the other person does not realize it, he/she will somehow perceive that the caregiver is not authentic and this undermines trust, which is an essential element in caregiving relationships. Indeed, with neurological diseases, non-verbal communication can be a sign of inner states of mind, as well as due to motor control deficit, and we should be able to distinguish the two different cases (for example, trembling of a hand due to strong anxiety or Parkinson's onset).
- The "I" Message: since you cannot conceal negative emotions and at the same time you cannot express them in caregiving relationships (you cannot raise your voice if you are angry or cry while at work) it is useful to use the "I" Message. When another person's behaviour bothers us, we normally use expressions like "You are an untidy person", or "You are selfish", "You make me feel bad", "You are untrustworthy", they all start with "You are", attaching a label to the whole person. Often we add terms like "always" and "never", which contribute to the attachment of a generalized label to the person, generating the need for a reply. We can create the "I" Message, by using the following four steps:
  - When you ... (describe the disturbing behaviour in a concrete, specific and circumstantial way)
  - I feel ... (describe your emotions)
  - Because ... (describe the reason for your emotions)

- And I ask you to ... (describe the desired behaviour)

## How to approach the person with disability and/or the elderly with disabling diseases

In caregiving relationships it is even more important to relate to the person with:

- **EMPATHY:** empathy is the ability to understand the thoughts and emotions of a person at a given time and in a given situation. Empathy does not mean identification. Each person has his own unique way of reacting to events; therefore, we cannot expect the other person to act as we would in his/her situation. Empathic understanding is achieved through active listening, using reformulation techniques and open questions, as well as by paying attention to the non-verbal elements of the communication. We should also develop the ability to understand the signals sent through non-verbal communication.
- **AUTHENTICITY:** trust is an essential and fundamental factor in caregiving relationships. In order to build a relationship based on trust we should have an authentic attitude, which means, basically, be sincere and congruent. It does not mean that we should be spontaneous at all costs, for example by expressing our opinion when it is not required, but that, when asked, we must always tell the truth. **WE DO NOT NEED TO SAY EVERYTHING WE THINK, BUT TO THINK EVERYTHING WE SAY.** As mentioned above, our facial expressions, gestures and tone of voice reveal our thoughts and our emotions, therefore, lack of congruence, content and attitude are always perceived by others even if you do not realize it, and, on an unconscious level, they may feel like they should not trust you.
- **ASSERTIVE ATTITUDE:** constancy is the best quality of an operator. In other words, being able to give a good performance level throughout the day or the work shift. Furthermore, if the relationship lasts for many years, we can avoid the stress connected with change. In order to perform properly for many years in the same situation, the caregiver should duly protect his/her physical and mental health without overriding the needs and rights of the assisted person. In view of this, our attitude should neither be passive (e.g., please others at your own expense); nor aggressive (e.g., use your voice or hands to condition the behaviour of the assisted person); nor passive-aggressive (e.g., first, please the person, and then later vent your repressed anger with acts of spite). Assertiveness is the ability to express our own needs and rights, as well as positive and negative feelings, without violating the rights and limits of others. In order to be assertive you must be able to:
  - Identify and express your feelings;
  - Define and respect other people's limits;
  - Communicate and listen in an open, direct and congruent way;
  - Being aware of your right to have **needs and feelings**.

What rights does the operator have?

- The right to his/her own values, opinions and emotions;
- The right to change, modify and develop his/her life without causing harm to the assisted person;
- The right not to justify feelings or behaviours, however, it is important to be able to explain them and find a mediation;
- The right to have his/her needs and boundaries respected;

- The right to say "NO" when a request can impair his/her physical, mental and moral health, seeking a mediation and a creative solution together with the assisted person in order to meet the needs of both;
- The right to ask for help and information without negative feelings of shame and guilt;
- The right to take the time and get the help needed to formulate ideas and desires before expressing them;
- The right to make mistakes;
- The right to change his/her mind or, occasionally, even to behave illogically.

Why and how should we say "NO"?

- If we are unable to say "NO", we say "Yes" even when we want to say "NO"; and saying "Yes" when we would like to say "NO" mortifies our ability to control our lives; we take more responsibility than what we want; it puts us in the condition of having to carry out too many tasks without respecting our physical, psychological and intellectual limits; it generates stress, which has a strong impact on our physical and mental health;
- Saying "NO" can be very difficult; people with low self-esteem usually lack of assertiveness and think that they have to adapt to all the expectations of others. They may feel shameful or guilty when they say NO. And doing things against their own will and possibility makes them feel even more taken advantage of and angry.
- These are some ways to say "NO": "I cannot do this now"; "NO, I'm sorry"; "I hope you will understand that I cannot come"; "I would rather not"; "I cannot do this in this way because it creates this problem, can we find an alternative solution together?"

Make correct and congruent decisions to be consistent. If someone makes a request, you have the right to take some time and think about it. The decision should be up to you, but it can be difficult to say NO immediately in specific circumstances. You can try to use an empathic NO and explain the reasons for the refusal without giving the impression of justifying yourself.

Manage conflict. In the long run, living in an environment with unsolved conflicts is detrimental to everyone because all our energies are absorbed by such conflicts and there is no possibility of progressing or creating a state of well-being; it is a condition of oppression and division. On the other hand, someone in the relational system may take advantage from permanent conflict: it is the standard "divide and rule" strategy. One of the first things to do to manage conflict is to identify if there is someone in the relational system (e.g., family members) who seeks, either consciously or not, to take advantage of the situation of conflict and unveil such an intention. When this game is unveiled, it will be easier to avoid sterile discussions. In other circumstances, conflict has more genuine reasons: different objectives, values, interests, misunderstandings and unsatisfied needs are some examples.

Why do we accept conflicts?

- We think that things cannot change;
- Fear of getting in trouble, if we try to mediate between two conflicting parties or react to an aggressive behaviour;

- Lack of self-esteem;
- We may think to be the only person who believes that there is something wrong and feels bad;
- The tendency to delegate responsibilities;

Conflict acceptance and empathy. There is a “one-to-one” relationship between empathy, and conflict acknowledgement and management: if we do not admit that there is a conflict, we will probably tend to ignore the other person’s needs (usually the weakest one) and, at the same time, if we are not able to understand the other’s needs and feelings, we will hardly be able to find a mediation between the conflicting parties.

Conflict resolution strategies:

- Identify and define the problem: in the first place, we must express what we feel and think. See Communication barriers and The “I” Message;
- Propose different solutions: ask the other person to propose a solution, in the meantime think about your own solutions and make a list of options;
- Take a decision together: do not try to persuade the other person to accept "your" solution, you should rather define a common strategy, in a clear and unequivocal way;
- Implement the decision: after deciding what to do, you must agree on how to do it (WHO must do WHAT, and WHEN); responsibilities and tasks should be divided equally;
- Monitor your strategy: when the agreed practice has been followed for a while, you should discuss its effects TOGETHER and negotiate the necessary changes, if any.

Self-destructive thoughts. We are often the concurrent cause of our conflicts, victims and actors at the same time. This happens when negative thoughts prevail in our minds, when we think that we are surrounded by people who want to deliberately harm us. When we realize these thoughts, we should proceed with the so-called reality test, i.e. ask others to express their "real" intention.

- **KEEP CONFIDENTIALITY:** when assisting an elderly or disabled person, he/she will share very intimate parts of his/her life with you: medical appointments, private relationships with friends, acquaintances and family members, business meetings or even situations related to sexuality. YOU SHOULD NEVER TELL OTHER PEOPLE WHAT YOU LEARN IN SIMILAR SITUATIONS. THE CAREGIVER SHOULD KEEP UTMOST CONFIDENTIALITY OF ANY PERSONAL INFORMATION OF THE ASSISTED PERSON THAT HE/SHE LEARNS INCIDENTALLY. Furthermore, we should avoid any comment or humour on intimate matters without the permission of the concerned person.
- **BE RESPECTFUL:** respect is fundamental in any relationship. It means avoiding offensive or abusive behaviour towards the assisted person, and especially in the presence of other people. People often tend to relate to the caregiver even when the person is perfectly able to understand and wants to relate and communicate. THE CAREGIVER SHOULD NEVER SUPPORT THIS ATTITUDE AND HE/SHE SHOULD GIVE THE ASSISTED PERSON ENOUGH TIME TO RESPOND.