Guide 2 Annex 2: Crucial points to consider during the 'golden hour'

The golden hour is crucial in the course of the treatment as a key moment to promote adherence to treatment, promote contact examination, and prevent mental health problems. Three points need to be considered during the 'golden hour':

1. Communicating information about the diagnosis, treatment and evolution

The ability to communicate a diagnosis with sensitivity and clarity can be practised using tools such as the WHO's Psychological First Aid guide, described in Annex 4. It is important to listen to the patient's distress and address his/her questions with empathy and warmth as appropriate to the cultural setting.

Some topics must be addressed immediately: transmissibility, progress of symptoms and the treatment regimen. Starting the treatment right away instead of a few days or months later is extremely important to alleviate the fears in the mind of the patient. It is very important to keep an open door of communication for the patient and family member to come back as needed, but you should make every effort to provide all the key information at the golden hour because there might not be a second chance to do it.

When you explain the diagnosis to the person, keep the following in mind:

- Take the time the person needs. Do not rush this stage.
- Find out what the person already knows and suspects.
- Assess the gap between the person's knowledge and reality.
- Provide just the necessary information.
- Allow the person to absorb the information.
- Encourage the person to express their feelings.
- Clarify doubts, misconceptions and fears.
- Briefly state the treatment plan in simple language, using use analogies from the patient's daily life that they can relate to.
- Assure the person that you are available for further clarification.

2. Disclosure

The person affected must be given freedom to decide if they want to disclose their condition to others. Their decision must be respected. To come to this decision, they should be encouraged to talk about their fears of disclosure. When the person is ready to disclose their condition, the health care provider should offer help and assurance to talk to family members. The health care provider should ask the person affected if they prefer to be alone or with a family member when the diagnosis is discussed. Sometimes in-laws may force themselves to be present in the room, it can help to tell them that it is policy to talk to the affected person alone.

Useful questions to ask include:

- Have you talked about your disease to anyone?
- Would you like any of your family or friends to know about your disease?
- If so, to whom do you want to disclose it?
- Would you want me to talk to them about it in your presence?
- What and how much would you want me to disclose?
- If you do not wish to disclose, do you want to discuss any issues related to keeping it secret?

An important part of disclosure is privacy. It is important to avoid unnecessary and involuntary disclosure. This can be done, for example, by ensuring that the service facilities to treat the patient are free of specific indication of the diagnosis (for example, more general labels such as 'tropical diseases' or 'dermatology' may be less stigmatising). Do not conduct home visits without the patient's prior informed consent. The connection to the disease name should be carefully thought out in order to avoid involuntary disclosure or linkage of the disease to the patient and the family.

In NTD programmes, house-to-house surveys are often conducted, in which health workers go to the neighbours of newly diagnosed patients and screen as many people as possible. This needs to be done in a manner that ensures confidentiality. Some health staff are known to the community as working with particular stigmatising diseases, so they must be careful before visiting any patient's house.

3. Communication with household members

Even if the individual allows you to disclose to those who are living in the same household, you should be cautious in what to tell family members. For example, in some situations if the individual fears that someone may react negatively it may be better to talk about the disease in more general terms and not mention its name, at least in the initial stages.

As caregivers to the patient, household members may also need psychological support once the disease is disclosed. It is essential to see household members and to help them to come to terms with the person's condition and hear their fears, doubts and reactions. Encourage household members to help the individual cope and to help with compliance and self-care issues.

Case study on the importance of nonverbal communication

'I was treated for leprosy 15 years ago but in the past six years I have noticed a loss of sensation on my left foot and pain on my right elbow similar to what I had before. I also have a minor loss of strength in my right hand. Despite having seen specialists twice during the period, none believed I had leprosy again until I saw the third specialist. She looked at my history and looked up the protocol for leprosy treatment. She concluded that I was not properly treated the first time (I was treated as a paucibacillary type of leprosy instead of multibacillary leprosy) and gave me her opinion right there, in front of the nurse.

‘I was shocked but totally convinced by her reasoning, which she explained thoroughly, patiently answering my questions. As I expressed my fears of transmitting the disease to my family, colleagues and friends because there was no medication available, the nurse reached out to the window handle to open it wide. I realised she wanted to get some air into the room because of me being there. Leaving the room after discussing how to go about getting the medication, the physician reached out her hand to greet me goodbye and kissed my cheek (a common greeting gesture among females in Brazil). I was surprised by her gesture, which contradicted the nurse’s previous one. Immediately I bonded to the physician and consequently to the service.’ (A woman affected by leprosy, Brazil).