Confusion and Terminal Restlessness

What is confusion?
Confusion is the clouding of consciousness or limited awareness. A person’s capacity to think clearly and respond appropriately may be reduced. Speech may be rambling or incoherent. The person may be unaware of where they are or what is happening. They may misinterpret sights, sounds or experiences. They may be very anxious, restless or agitated, or express other emotions that are difficult to understand or that seem to be excessive in the circumstances.

Sometimes carers and relatives think that the person is mentally ill or becoming demented. This is rarely the case. Confusion is far more likely to be due to physical causes.

Confusion can be caused by:
- raised temperature (e.g. fever from infection)
- medications (new or higher dose)
- anything that affects the amount of oxygen reaching the brain (e.g. diseases of heart or lungs)
- disease processes that affect the brain directly (e.g. brain tumour, stroke)
- pain or other physical discomfort
- chemical imbalances within the body due to disease processes or the failure of vital organs.

Issues such as conflict with loved ones or ‘unfinished business’ don’t cause confusion, but may feature in the confused person’s thinking.

What makes confusion worse?
Confusion may be worse in the evening, at night, or when the ill person is subjected to changes in routine, the site of care, or care staff. Irritants such as excess or uncomfortable bedding or clothing or unfamiliar sounds can add to confusion. Nightmares or night terrors may accompany confusion or may be the only or first symptoms of confusion.

What should the carer do?
Tell the nurse and doctor about the ill person’s changed behaviour immediately. They will check for, and treat, any conditions that may be contributing to the patient’s confused state. Confusion can clear up rapidly if it’s cause can be treated. It could be as straightforward as a full bladder or rectum, which can be readily fixed. The doctor will review the person’s medication, and look for any other medical causes or contributions. Sometimes confusion due to medication clears as the person’s body adapts. Sometimes a change of medication is needed.

General care measures are helpful. Even if these do not eliminate the problem, they will lessen its severity and make it less distressing.

For example:
- It is pointless to argue with the person about a delusion.
- Gently remind the person where they are and who you are. Sit with the person, taking their hand and talking to them, even if they seem unaware of you. Relatives, friends and volunteer support workers assist with this.
- Avoid sudden demands, or any feelings of haste. Try to create a feeling of peace and safety. Talk reassuringly about what you are about to do while you are tending them, even if you think they do not hear or understand you.
• Avoid changing the person’s surroundings, the position of the bed in the room etc.
• Check that the person is not too hot. An ill person does not require an electric blanket.
• Check the bed and clothes for anything that may be causing irritation.
• At night try using a night-light (low watt lamp) or leave the hall light on and the door open.
• Keep the environment free of distracting or distressing noise. Music helps some, but not all people to settle. If a windy night or intermittent noise increases the confusion, try masking the noise with familiar sounds such as the radio or TV.

What is terminal restlessness?

Terminal restlessness is a variant of confusion that occurs in the last days or hours of life. It is less common than confusion, but the signs and symptoms can be particularly distressing for carers and relatives.

In addition to the usual symptoms of confusion, there may be increased physical restlessness or agitation, muscle twitches, or unusual patterns of muscular contraction. The person may pick at or continuously handle the bedclothes.

The person may moan or call out. Sometimes they vocalise each time they breathe out. These vocal symptoms can be particularly worrying for carers, but do not mean that the patient is distressed. Supporting the person in a more upright position, turned slightly to one side, can reduce or eliminate this. Sometimes the ill person, even if apparently unconscious, may react with distress to sudden stimulation.

Let the doctor and nurse know straight away if the patient shows signs of terminal restlessness.

They will assess the problem and decide which medical and nursing measures to take. The same factors that lead to confusion can cause terminal restlessness or make it worse. Toxins in the body due to the slowing of function of vital organs such as the liver and kidneys are usually the cause. Specific drug treatment can stop twitches or muscle contractions. Sedation is needed when terminal restlessness is severe. Explanation to carers and family, and medication for agitation or other physical symptoms are the basis of treatment.

As well as seeking treatment for the ill person, carers need to share their feelings of distress or concern with team members, family and friends.