Terminal Agitation: A Major Distressful Symptom in the Dying

Many families may be surprised when a terminally ill (and usually calm) family member becomes restless or even agitated. The depth of such restlessness or agitation varies from patient to patient. When moods change or personalities seem to change, family members may be completely bewildered and feel helpless: not knowing what to do. It is common knowledge that individuals who are experiencing even minor illnesses may demonstrate mood changes such as irritability, anger, depression and avoid communication with others. When a terminal illness not only initially strikes, but is now nearing the end, patients may experience profound mood changes. Such mood changes are often difficult for family members to "handle." Causes and treatments for restlessness and agitation are well-known among the palliative care professionals who work with the dying on a regular basis.

What is Terminal Restlessness or Agitation?

Those who work with the dying know this type of restlessness or agitation almost immediately. However, the public and patient's family may have no idea what is going on and often become quite alarmed at their loved one's condition. What does it look like? Although it varies somewhat in each patient, there are common themes that are seen over and over again.

Patients may be too weak to walk or stand, but they insist on getting up from the bed to the chair, or from the chair back to the bed. Whatever position they are in, they complain they are not comfortable and demand to change positions, even if pain is well managed. They may yell out using uncharacteristic language, sometimes angrily accusing others around them. They appear extremely agitated and may not be objective about their own condition. They may be hallucinating, having psychotic episodes and be totally "out of control." At these times, the patient's safety is seriously threatened.

Some patients may demand to go to the hospital emergency room, even though there is nothing that can be done for them there. Some patients may insist that the police be called ... that someone unseen is trying to harm them. Some patients may not recognize those around them, confusing them with other people. They may act as if they were living in the past, confronting an old enemy.

Need to Eliminate Other Obvious Causes of Distress

Just as in all symptoms, other causes must first be ruled out or eliminated. Nurses must make sure that the physician's orders are being followed, that if any other symptoms are not well managed, the physician is contacted or adjustments are made in order to relieve those symptoms. Physicians and nurses must continually re-assess the patient's total overall condition, monitoring each body system's function. Checking vital signs including pain levels is a first step. Is the patient breathing effectively? Is oxygen being given if appropriate for the patient's disease condition? Carefully evaluating, recording and reporting all outward signs must be habitual with those caring for the dying. Any changes must be understood, evaluated and responded to if appropriate.

For example, patients experiencing intense pain may become agitated. The initial thought to use sedatives immediately might make sense if one is not thinking clearly: "... the patient is agitated, I'll use a sedative..." However, that may be a very short-sighted and uneducated approach. Why? Because sedating the patient is not the first action to

take. One must first determine what other causes might exist. When pain is severe, sedatives will not eliminate agitation! However, relieving the pain eliminates the agitation. On a more basic level, removing a hard object such as a syringe or catheter tubing that may have drifted underneath the patient may be all it takes to relieve the agitation. Common sense must first be applied!

Questions to be asked

The following are examples of questions that nurses and physicians ask themselves as they approach this problem:

- Is there anything physically interfering with the patient's comfort?
- Does the patient have pain that is not being well-managed? Observing outward facial expressions and body posture are important to evaluate.
- If the patient has a urinary catheter, is it "patent" (meaning open) and is urine flowing freely through it? If it is plugged, that could cause extreme pain from pressure in the bladder.
- Is the patient having regular bowel movements? When was the last bowel movement and what consistency did it have? Could the patient be impacted (blocked)?
- Is there some other sudden change in function that may be causing distress to the patient?
- Is there an infection causing the agitation?
- Is the infection an expected effect of the disease, such as brain cancer?
- Is the patient going through obvious psychological and emotional distress? Has a counselor or minister's services been offered to the patient and family? Is the restlessness purely psychological or is it metabolically based?
- Has a new medication been added? Has a medication dosage been recently increased or decreased? Is this a side-effect from a medication?
- Has the patient entered the pre-active phase of dying?

Universal Metabolic Changes May Cause Restlessness and Agitation

As the terminally ill near death, body organs and systems begin to fail to a greater and greater degree. Kidneys stop producing as much urine and function poorly, the liver and other organs also start to shut down. Waste products from the cells and tissues of the body begin to build up in the tissue spaces and blood stream. Biological and chemical balance is lost. The pH in the blood and other areas may change dramatically. In many patients, these changes alone may account for restlessness and agitation that may be quite severe.

Medications for Terminal Restlessness and Agitation

If, and only if, other obvious causes of restlessness and agitation have already been eliminated, then the physician may directly order medications to reduce the restlessness and agitation. In almost all cases, the physician will have written standing orders for certain medications to be given for these conditions. Such medications include anti-anxiety medications such as Lorazepam (Ativan) and Diazepam (Valium) and anti-psychotic medications such as Haloperidol (Haldol), Chlorpromazine HCl (Thorazine) and others.

The nurse and physician must be extremely careful not to give a medication that might be contraindicated for the patient's condition. It is not appropriate to give *all* patients

Ativan and Morphine, for example, if they become agitated. It they are in pain, then pain medication is appropriate. If their pain is well-managed and they are still agitated, then the other medications may be applied. Certain disease conditions respond well to these medications while others have an opposite or no effect.

Palliative care professionals need to be reading the latest journal articles and research in order to understand when and when not to use these medications. Any nurse or physician who *always* uses these medications with *all* patients who are agitated has more to learn about handling these situations.

Palliative care varies according to the patient, the disease, the stage of the disease and the exact situation being encountered. Some believe that palliative care is less demanding than say, acute care in the hospital or intensive care. However, that is not the case. Excellent palliative care requires the same degree of professionalism as in other specialties in health care. Constant patient assessment and re-assessment are necessary.