Terminal Agitation

Terminal agitation often surprises many family members and caregivers alike. The loved one who is usually calm, suddenly and unexpectedly becomes agitated and restless. As patients near the end of a terminal illness they may experience profound mood changes. Therefore, terminal agitation is often accompanied by mood swings or personality changes which leave caregivers feeling helpless and bewildered. The sudden onset of behavior changes differentiates terminal agitation from the personality changes of dementia which are usually gradual.

**Related Behaviors**

<table>
<thead>
<tr>
<th>Agitation</th>
<th>Anxiety</th>
<th>Distress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extreme emotional disturbance; perturbation</td>
<td>State of uneasiness and apprehension</td>
<td>Anxiety or mental suffering</td>
</tr>
<tr>
<td>• Anger</td>
<td>• Nervousness</td>
<td>Behaviors listed under both agitation and anxiety included here</td>
</tr>
<tr>
<td>• Despair</td>
<td>• Tearfulness</td>
<td></td>
</tr>
<tr>
<td>• Combativeness</td>
<td>• Tension</td>
<td></td>
</tr>
<tr>
<td>• Irritability</td>
<td>• Fear</td>
<td></td>
</tr>
<tr>
<td>• Striking out</td>
<td>• Anguish</td>
<td></td>
</tr>
<tr>
<td>• Grimacing</td>
<td>• Furrowed brow</td>
<td></td>
</tr>
<tr>
<td>• Neck stiffness</td>
<td>• No eye contact</td>
<td></td>
</tr>
<tr>
<td>• Wild-eyed look</td>
<td>• Wild-eyed look</td>
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</tr>
</tbody>
</table>

**RESTLESSNESS**

Not able to rest, relax or be still

- Repetitive movement
- Constant moving or motion
- Inability to be still
- Movement
- Unable to rest
- Constantly changing positions
- Movement of limbs
- Increased movement
- Non-purposeful motor activity
- Hyperactivity
- Tossing and turning
- Busyness
- Thrashing/flailing

- Can not get comfortable
- Head rolling
- Trying to get out of bed
- Fidgeting/squirming
- Unsettled
- Shifting from side to side
- Jerking
- Pulling/picking at clothes and sheets
- Removing clothes and sheets
- Climbing out of bed
- Grabbing people
- Rocking

**SLEEP ISSUES**

- Inability to sleep
- Wakefulness/insomnia
- Impaired sleep
- Sleep disturbance

**VERBALIZATIONS**

- Singing/humming
- Confused speech
- Incoherent speech patterns
- Unintelligible babble
- Calling out
- Moaning/groaning
- Crying
- Rhymic vocalizations

**MENTAL STATE**

- Hallucinations
- Altered level of consciousness
- Confusion
- Incoherence
- Paranoia
- Disorientation
- Inability to concentrate
- Difficulty focusing

**Management**

Treat any underlying issues, such as:

- Pain
- Spiritual distress
- Full bladder
- Emotional distress

**Patient/Caregiver Support**

- Create a calm and safe environment
- Attempt to re-orient the patient as possible
- Educate the family on what is occurring as this can be a fearful time
- Encourage family assistance, as appropriate

**Medications**

- Ativan
- Thorazine
- Haldol
- Versed

**Statistics**

According to the National Hospice and Palliative Care Organization and Hospice Pharmacia, 42% of dying patients experience terminal restlessness in the final 48 hours of life.

The agitation is a terminal event, occurring only in the very last hours of life. It is NOT to be confused with the anguish and distress of many patients who are not yet dying and who need company and counseling and NOT sedatives.

**It is important to eliminate other causes**

- Does the patient have an infection?
- Is pain under control?
- Is the patient having any psychosocial or emotional issues?
- When was the last bowel movement?
- Does the patient have a fever?
- Does the patient have any breathing difficulty?
- Is the patient’s bladder full?
- Has the patient received any new medication?
- Is anything physically interfering with the patient’s comfort (ex: wrinkled sheets, room temperature)?