Care Home Collaborative

Terminal Agitation

Heather Tonner
Advanced Nurse Specialist in Palliative Care
Care Home Collaborative

Aim

To increase understanding of palliative terminal agitation

Learning Outcomes

- Know what is meant by the term “terminal agitation”
- Know the signs of terminal agitation
- Know how to assess a resident with terminal agitation
- Know how to support a resident with terminal agitation
- Understand the rationale behind use of medication to sedate

What is Terminal Agitation?

Terminal agitation means agitation that occurs in the last few days of life.

You might also hear terminal agitation being described as terminal restlessness, terminal anguish, confusion at the end of life, or terminal delirium. These terms all have different meanings but they **do** overlap.

Agitation can be a sign that the person is in the last days of life but it can also occur in earlier stages of their advanced illness.

Causes

Agitation can be caused by medications the patient is on, their condition, or psychological factors.

Signs of agitation

Agitation can come on suddenly or gradually, and often it comes and goes.

Signs and symptoms of terminal agitation can include:

- Distressed behaviour
- Not being able to get settled
- Confusion
- Calling out, moaning, shouting or screaming
- Hallucinations
- Trying to get out of bed when its unsafe or wandering
- Being sleepy during the day but active at night
- Becoming harder to rouse from sleep

Signs of agitation cont…

- Being unable to concentrate or relax, or getting easily distracted
- Rambling conversation or switching topics often
- Sometimes angry and aggressive behaviour
- Facial cues, like frowning, grimacing, and looking less peaceful
- Fidgeting, including repeatedly picking at clothes or bed sheets.

These changes can be very distressing for the patient and their carers, family or friends.

Assessing a resident with agitation

When trying to diagnose the cause of a resident's agitation, it's important to gather information about the patient, including if anything new has happened which might have caused their agitation, like starting a new medication.

You can speak to the patient, their family (if the patient gives consent), and professionals involved in the patient's care.

There are a number of things you can consider:

- How long have they been agitated?
- Did it come on gradually or suddenly?
- Is the patient's behaviour different to normal, and in what ways?
- Has anything changed in their treatment or medication?
- Has anything changed in their environment?
- Could the patient have a full bladder or faecal impaction?
- Do you they have uncontrolled pain or other symptoms, like nausea?
- Are there signs of alcohol or other substance withdrawal?

Supporting someone with agitation

Care Home Collaborative

Agitation is not an inevitable part of the dying process. If a patient is agitated at the end of life, it's important to try to manage it.

- Patients who are agitated may struggle to communicate how they are feeling. They may be extremely fatigued or confused. It's important to check their symptoms, check if there are any reversible causes of their agitation, and try to communicate with them where possible. Use moments when they're calmer and less agitated to speak to them.
- Don't dismiss what someone is experiencing when they have terminal agitation. You can support them by saying something like: "I can see that you are feeling unsettled". Ask open questions, and encourage them to express what they're thinking and feeling. Speak clearly and calmly.
- Simple methods can help to reduce agitation and distress. Find out what the patient finds comforting and reassuring.
- Sometimes agitation can be caused by emotional distress. Providing a calm and safe environment that suits the patient's needs can help.

Supporting those around the patient

Care Home Collaborative

Agitation can be distressing for those around the patient, including family, friends, and other health professionals.

Here are some things you can do to support them:

- Explain what agitation is and talk to them about what could be causing the patient's agitation.
- Avoid using jargon.
- Share information with the resident, family and friends about end of life symptoms and what to expect in the last weeks and days.
- Explain what is being done to manage the patient's agitation.
- Make sure they know they can ask you questions and speak to you about any worries or concerns.
- Encourage them to use the techniques above to help reduce the patient's agitation and distress.

Getting support for yourself

Caring for someone with agitation can be very distressing. It's important to be aware of how you are feeling and seek support if you need it.

Talk to your manager or other colleagues about how you're feeling.

If you feel you need extra support, you could consider seeing a counsellor or psychologist.

Sedation and agitation

Care Home Collaborative

Sometimes when a person's agitation can't be relieved by other measures, medication is needed to sedate them. Sedation means using medicines to lower a person's consciousness so that they are calm, or even asleep.

- The patient will commonly be started on a small dose of sedative (such as a benzodiazepine like midazolam or lorazepam). They may also be given an anti-psychotic (such as haloperidol).
- Medicines are usually given as subcutaneous injections or through a continuous Subcutaneous Infusion Pump (CSCI) also known as a syringe pump.

There are many ethical issues to consider when making a decision about sedation.

- The person may no longer be able to eat, drink or communicate if they are sedated. The patient's medical team, the patient themselves, and their close family or friends should be involved in the discussion.
- A common worry about sedation is that it makes death come more quickly. Sedation does not make death come more quickly, but it can bring relief from distressing symptoms and allow a more peaceful death.
- It is important to discuss this with the patient, and their carer, family or friends, and address their concerns and worries.

Medication

Sedation/Anxiety

- Usually **Midazolam** (benzodiazepine) at a dose of e.g. 5 to 10mg over 24 hrs by SC infusion and 2mg SC as required
- May have to use higher doses e.g. up to 80mg/24 hrs (tolerance)
- Preferred preparation is 10mg/2ml amps
- Cause drowsiness and relax the patient thereby reducing anxiety and muscle tension
- Also useful as an anti-epileptic
- Diazepam ***NOT*** suitable for SC use

Medications for Sedation/Anxiety (Under the supervision of Specialist Palliative Care Team or Pharmacist)

- Use haloperidol if delirium present e.g. 500 micrograms to 3mg SC once daily (long half-life) and titrate up
- Can use higher doses of levomepromazine e.g. 10mg to 25mg once/twice daily SC (or much higher)
- Very occasionally use phenobarbital 200mg to 1200mg/day SC

Care Home Collaborative

Questions?