Handout 3: Notes to accompany Terminal restlessness PowerPoint Presentation

Terminal restlessness (Slide 1-2)

Learning Outcomes
By the end of this unit you will be able to:

- Describe the term ‘terminal restlessness’
- Understand the possible causes of terminal restlessness
- Describe appropriate assessment, care and treatment approaches used to support a person experiencing terminal restlessness
- Consider the support needs of family and friends.

It is also essential that you follow the Health Protection Scotland Guidance on COVID-19 relevant to your area of practice [https://www.hps.scot.nhs.uk/](https://www.hps.scot.nhs.uk/)

The term ‘terminal restlessness’ (Slide 3)

Terminal restlessness is a distressing experience that may occur in the last days of life. There are several terms used to describe it. You might also hear it being described as terminal agitation, terminal anguish, pre-death restlessness or terminal delirium. These terms all have different meanings, but they do overlap.

Is it delirium? (Slide 4 and 5)

Delirium is a serious medical condition that results in a person becoming more confused than usual with disruptions in thinking and behaviour, including changes in perception, attention, mood and activity level. It develops rapidly over hours and days and can vary throughout the day and night.

Terminal restlessness is a subtype of delirium that affects between 25 and 85% of people who are in the last days of their life. Sometimes it can be reversible if the cause is identified and easy to treat such as an underlying urinary tract infection. However, sometimes delirium is part of the final stages of dying—so is called terminal delirium/restlessness. This becomes an irreversible process.

Indicators of terminal restlessness (Slide 6)

In the last days and hours, the person may be unable to stay in one position and may be trying to move frequently. This could include:

- Plucking at clothing, fidgeting or tossing and turning.
- Myoclonus which is twitches or jerking movement caused by sudden muscle contraction. Hiccupping is one example of a myoclonic twitch and can be caused by opioids such as Morphine. Morphine is used quite frequently for pain management in terminal illness.
- Myoclonus can also be caused by any medicines that lowers the bodies seizure threshold.
- Other symptoms may include
  - irritability,
  - anxiety,
  - unease,
  - distress,
  - inattention
  - hallucinations
  - nightmares.

Terminal restlessness has the potential to be confused with changes being experienced when a person has a diagnosis of dementia which is often referred to as ‘diagnostic overshadowing’ and can lead to the person not receiving appropriate treatment. It can also be confused with the
person experiencing 'heightened consciousness' which is described in Handout 1: Recognising dying notes. It's important to carry out an holistic assessment of the persons needs and provide appropriate care, treatment and support.

**Causes of terminal restlessness (Slide 7)**

- **Medication** such as opioids or corticosteroids are the biggest cause of delirium and terminal restlessness. Older people with complex physical healthcare needs, frailty and/or dementia absorb medication slower and these are slower to leave the body. So, medicines cannot be tolerated in the same way as in younger adults. This is further complicated at the end of life when vital organs particularly the liver and kidneys have diminished functioning, causing a build-up of toxins in the system. It is also important to remember that the person may be experiencing withdrawal of tobacco, caffeine or alcohol.

- **Pain** - If the person is unable to tell you they are in pain it can be difficult to establish - the person may be grimacing and have continuous facial tension, particularly across the forehead and between the eyebrows. However, this may also be a sign of dreams or hallucinations. It is essential that you use an evidenced based observational assessment tool such as the Abbey Pain Scale or 'Doloplus 2' while recognising that both have limitations and need to be used in conjunction with a knowledge of the person and their pain history.

**Assessing fundamental care needs and wider health and wellbeing (Slide 8 and 9)**

As well as carrying out an holistic assessment of the person it is important to take a systematic approach. If an urgent medical cause is not identified start with an assessment of fundamental care needs. Start with the person and what changes may be causing distress, then moving to immediate care needs, environment and care delivery.

When speaking to someone with terminal agitation, it is important not to dismiss them. Validate their experience by saying something like, 'I can see that you are having distressing thoughts.' Encourage them to express what they are thinking and feeling if they are able to do so.

Sometimes, simple methods may help to reduce agitation and distress but these must be based on holistic assessment. This can include;

- re-positioning the person
- playing music that they enjoy
- talking in a gentle and reassuring manner, and touching them gently, for example holding the person's hand
- providing a calm and safe environment that suits the person's needs
- supporting and reassuring the person by orientating them to their surroundings for example
  - ensure that lighting is adequate
  - make sure a clock is visible
  - have familiar objects nearby, such as photos and ornament.

**Support family and friends and include them in care delivery (Slide 10)**

If it is established that the person is experiencing terminal restlessness and is actively dying the emphasis needs to be not on treatment of the underlying cause, but rather on decreasing the
agitation, hallucinations, and behavioural changes being experienced and helping the person to stay comfortable in this stage of their dying process.

It is essential to understand that terminal restlessness is very distressing for family and friends and they may be frightened and feel helplessness. It can also have a profound and lasting impact on their experience of grief after the person has died.

You should provide reassurance to family and friends by explaining what’s happening and outline the treatment care and support the is being delivered. It may be necessary for them to be with the person (in line with Health Protection Scotland Guidance https://www.hps.scot.nhs.uk/guidance/) as this maybe the most appropriate support to reduce the dying persons agitation and distress.

Managing medication and terminal restlessness (Slides 11-14)
Managing pain, breathlessness, anxiety and distress is key to a peaceful death. Effective recognition and treatment of such restlessness is important. It is sometimes necessary to use sedative doses of medication. This will need careful consideration for older people with complex physical health care needs, frailty and dementia. You need to consider all medications the person is prescribed together with fluid and food being taken as these will impact on the body’s response. You may be administering medication as prescribed but because of slow absorption and elimination the person may have a build-up in their system that is causing the terminal restlessness. Adding additional sedation will just exacerbate their terminal restlessness.

Anticipatory Prescribing
When considering medication use it is recommended that you follow the Scottish Palliative Care Guideline for anticipatory prescribing for specific symptoms and for specific doses.

https://www.palliativecareguidelines.scot.nhs.uk/guidelines/pain/Anticipatory-Prescribing.aspx

For additional guidelines during COVID 19 please see-

Key considerations in relation to medication:
- There is less need for parenteral medication or medication by infusion or injection
- Often the person is unable to take medication orally and bolus subcutaneous is better as well as transdermal patches
- Be careful not to over diagnose pain- there is no evidence that pain suddenly increases as a person dies and discomfort may be relieved with non-pharmacological interventions
- Never give haloperidol or domperidone to someone with dementia with lewy bodies or Parkinson’s disease.
- Start medication dose low titrate slowly and where possible only change type of medication at a time.
- Opioids can cause toxicity in frail older people. This can happen suddenly and can mimic terminal restlessness. If this is the case a change to an alternative medication may be helpful.
- Opioids can also cause constipation/ nausea
- Benzodiazepines can cause confusion both on commencing and stopping!
- Benzodiazepine withdrawal can cause psychomotor agitation
- Sometimes withdrawing someone from an antidepressant can cause psychomotor agitation which can mimic terminal restlessness.