

MANAGEMENT

While we know the usual approaches may not be of benefit often carers/families ask what they can do. Here are some ideas:

- ❖ If the person is able to speak encourage them to say what they are thinking and feeling.
- ❖ Use non-verbal cues, e.g. showing and offering them a cup rather than asking if they are thirsty.
- ❖ Remember everyone responds differently.
- ❖ Talk in a gentle reassuring, manner, touching them gently e.g. holding their hand.
- ❖ Provide reassurance by explaining what is happening.
- ❖ Consider if the person may be in pain.
- ❖ ...Use of music the person likes.
- ❖ Reposition the person to increase comfort.

DRUG THERAPY

When psychological approaches have had a limited effect medications can be introduced where medically indicated to ease distress.

More information is available from:

mariecurie.org.uk
alzheimers.org.uk
alzscot.org



www.careopinion.org.uk

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Pub. date:	December 2023
Review date:	December 2025
Issue No:	03
Dept:	Advanced Dementia & Terminal Agitation
Clinical Lead:	

PIL.TRMAGT.19_32881.L
23_32008



Advanced Dementia and Terminal Agitation

Information for families and carers

WHAT IS ADVANCED DEMENTIA?

Advanced dementia will be unique to each person and is dependent on factors relating to underlying health.

Defining the point at which a person has reached advanced dementia is difficult.

Advanced dementia can last many months or years depending on the presence of other health issues, the point of diagnosis as well as other factors.

It would be more appropriate to think about the level and complexity of the person's needs in understanding when advanced illness is being experienced.

WHAT IS TERMINAL AGITATION?

This is also known as terminal restlessness, pre death restlessness, or terminal anguish. This is a form of delirium that sometimes occurs in a dying person and in people experiencing advanced dementia. This can last for days, weeks or many months.

HOW DO I KNOW IF SOMEONE HAS TERMINAL AGITATION?

People experience different symptoms and often these symptoms can be managed. However when our usual approaches, for example using medications are not helping with symptoms, we may suspect that the person could be experiencing terminal agitation.

SOME SYMPTOMS THAT MAY BE PRESENT IN A PERSON:

Distressed behaviour sometimes including anger and possible aggression.

- ❖ Calling out, shouting or screaming.
- ❖ Hallucinations. (where people can hear, feel or see things that may not be there but feel real to the person)
- ❖ Constant agitation, walking, wandering, restless.
- ❖ Being unable to concentrate or relax.
- ❖ Recurrent infections

Palliative care for end stage dementia

Good person centred dementia care supports an approach that places the person and relationships at the centre of healthcare. Key to this is involving the carer. Staff such as psychiatric nurses, district nurses and palliative care nurses have the skills and knowledge to support others to provide fundamental care needs for their relative.

Carer's Role

Using the knowledge of family and friends of the person experiencing dementia is important. This knowledge will be used to enhance the health, wellbeing and sense of self of their loved ones and of themselves.