

# The experiences of caregivers of patients with delirium and their role in its management in a palliative care setting

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## Background

Delirium remains the most common and distressing complication in patients with advanced cancer. Up to 62% of patients during a palliative care inpatient admission and up to 88% of patients in the days or hours preceding death experience delirium<sup>1</sup>.

## Aims

- 1) To explore the experiences of caregivers of patients with delirium.
- 2) To explore the role of caregivers in management of delirium.
- 3) To explore evidence for interventions to improve support for caregivers and to help caregivers to support the patient.

## Method

An integrative review was undertaken. Twenty five papers were included in the final review. Four databases were searched using the terms:

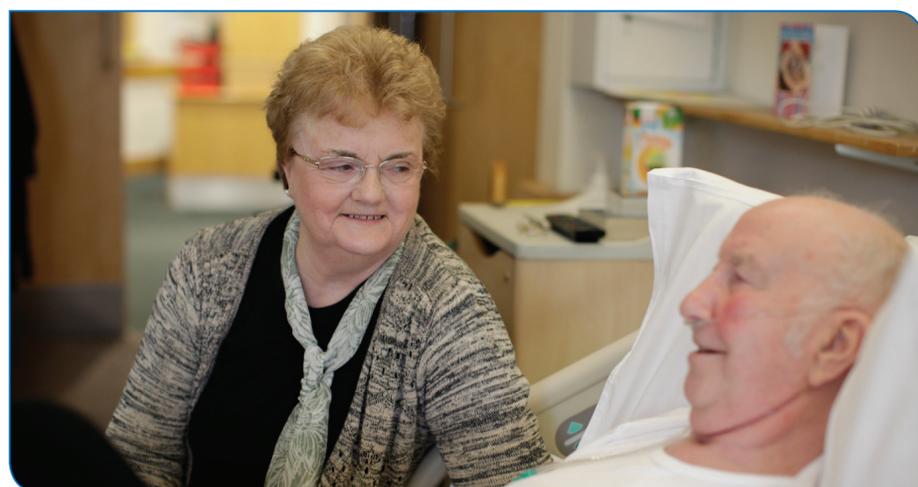
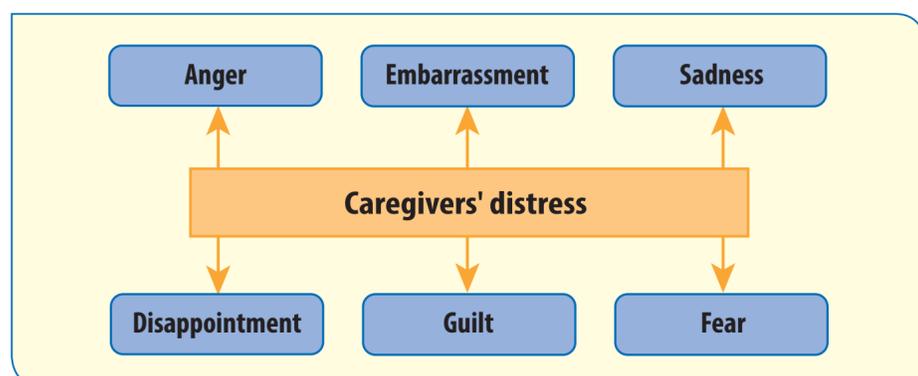
- Delirium
- Terminal restlessness / agitation combined with;
- Family / carer / caregivers

## Results

### 1) Distress is common in caregivers of patients with delirium.

- Distress is sometimes greater in caregivers than in patients themselves.
- There are a range of distinct negative emotions which can be experienced by caregivers during patient delirium.
- Deteriorating relationships are common when delirium occurs.

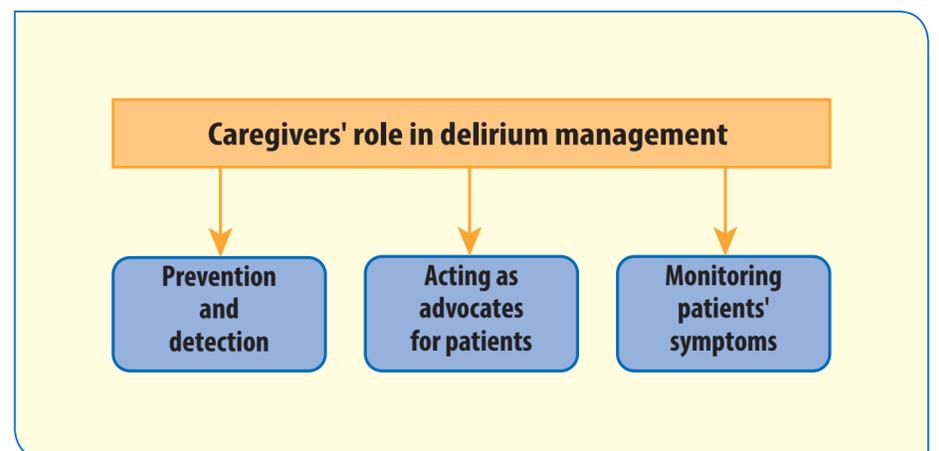
**Figure 1:** Distress and negative emotions experienced by caregivers during patient delirium.



### 2) Caregivers could potentially play an important role in the management of delirium in palliative care settings.

- Recent studies suggest that caregivers could potentially play a role in the detection of delirium; symptom monitoring and acting as advocates for the patient who is experiencing delirium.

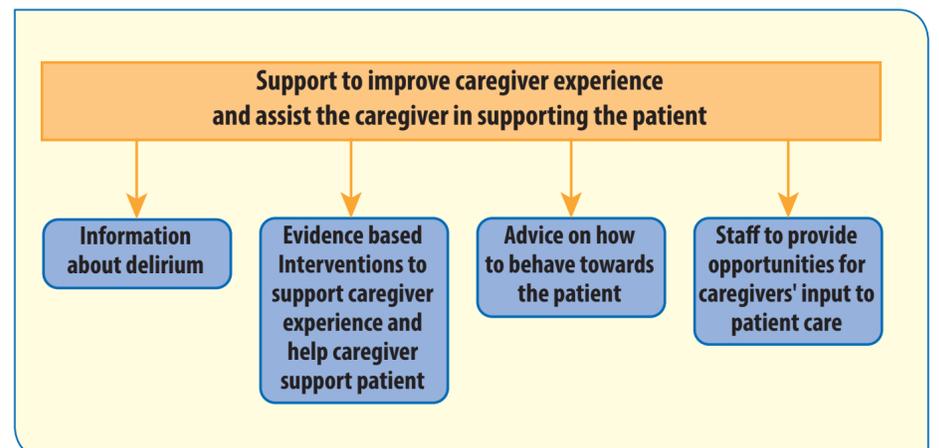
**Figure 2:** The role of caregivers in management of delirium.



### 3) There is a need for evidence based interventions to improve support for caregivers of patients with delirium, and to help the caregiver support the patient during delirium.

- Caregivers would like information and advice on how to help the patient with delirium and are keen to input into patient care.
- Interventions such as information leaflets in conjunction with a discussion with a staff member are effective in improving caregiver wellbeing and confidence in helping patients with delirium.

**Figure 3:** Support to improve caregiver experience and assist the caregiver in supporting the patient.



## Conclusions

- High levels of distress and negative emotions are experienced by caregivers of patients with delirium.
- Many caregivers would like an opportunity to play an active role in the management of delirium.
- There is a need to design and test new interventions to help caregivers support the patient experiencing delirium and to improve the wellbeing of caregivers themselves.



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