

## Box 1: Patient, family member and clinician quotes about delirium-related distress

### The experience

- "I did not dare go to sleep. When they told me to go to sleep and rest, I was afraid that if I fell asleep, I would never wake up again." (Patient)<sup>1</sup>
- "I could not think. My speech was so stupid and wrong. I thought something but said something else. It did not connect in my brain." (Patient)<sup>1</sup>
- "The whole thing was terrible, it was very stressful." (Patient)<sup>2</sup>
- "I am very embarrassed regarding the people who cared for me. I was such a bad egg. I really feel guilty." (Patient)<sup>1</sup>
- "He was suffering, absolutely" (Family member)<sup>2</sup>
- "The hate and anger that was coming out of him. I'd be quite honest, I was scared stiff. I did not know what to expect next." (Family member)<sup>2</sup>
- "The change in her was massive and it was really quite hard to relate to her." (Clinician)<sup>2</sup>
- "Patients with delirium often experience distress. Family of patients with delirium always experience distress." (Clinician)<sup>3</sup>

### What helped

- "I can remember the nurse ... rubbing her hand over my head ... and she was smoothing my hair down, her words were so kind. Even when I was in that state, I could feel someone taking care of me." (Patient)<sup>1</sup>
- "She loved playing Yahtzee. . .the staff member knew that she liked it so they would take it out and they would play with her." (Family member)<sup>2</sup>
- "The nurse always had patience and a smile. . .That human way of relating, that the patient isn't a chart but a person, even if he is at the end of his life." (Family member)<sup>2</sup>
- "After reading many articles on the subject in the nursing press, I now speak calmly, quietly, slowly and clearly...Use closed, 'yes' or 'no' questions. Ensure I am speaking to the patient at eye level - not standing over them. Involve family where practical and safe to do so. Try to make the patient understand that I am listening to their worries and taking them seriously." (Clinician)<sup>4</sup>
- "Compassion is really important and involving those closest to the patient helps." (Clinician)<sup>4</sup>
- "Utilise family and friends to help keep patient orientated and to endeavour to gain their trust" (Clinician)<sup>4</sup>

<sup>1</sup>Reference 11; <sup>2</sup>Featherstone I, et al. Risk factors for delirium in adult patients receiving specialist palliative care: A systematic review and meta-analysis. *Palliat Med* 2021; 02692163211065278. DOI: 10.1177/02692163211065278.;

<sup>3</sup>Personal communication to AM; <sup>4</sup>Reference 18