



# Caring for people in a hospice setting who have or may develop difficulty communicating their needs due to dysphasia, cognitive impairment or extreme frailty

IMPROVEMENT INSIGHTS

**Project leader:** Jane Chatterjee  
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**Keywords:** Person-centred care, cognitive impairment, pain and distress, assessment, ‘Helping Us Understand You’ tool

**Project background**  
 St. Gemma’s Hospice, in Leeds, provides an integrated palliative care service. Studies show that many patients with palliative care needs experience some degree of cognitive impairment that may affect their ability to report, describe and interpret their symptoms, and/or understand assessment questions or recall previous experiences of symptoms.

**Aims and objectives**  
 The aim of the project was to improve the skills of healthcare professionals in caring for palliative care patients who have difficulty expressing their needs and to provide resources and tools to aid communication, symptom assessment and promote personhood. To achieve this aim, the objectives identified were to:

- Develop an adapted form of the *This is Me* leaflet to meet the needs of hospice patients
- Develop and deliver a workshop on ‘Understanding cognitive impairment’ for hospice staff involved in patient care
- Implement the use of the adapted form of the *This is Me* leaflet along with resources to aid communication, occupation, relaxation and reminiscence

- Implications for practice**
- Providing an interactive workshop to allow staff to spend time to understand cognitive impairment alongside creating a vision for person-centred care is important prior to the introduction of a tool such as the *Helping Us Understand You* booklet.
  - Tools such as the *Helping Us Understand You* booklet should be thought of as aids to use over time to make care more person-centred, rather than as one-off, tick-box exercises
  - Claims, concerns and issues can be used as an evaluation tool

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**Key activities and outcomes**

• **Claims, concerns and issues**

Initially the project group, an existing multidisciplinary group, wanted to explore thoughts and ideas and develop an action plan. To do this, it conducted a claims, concerns and issues exercise and agreed on the following priorities: developing and launching an adapted *This is Me* leaflet and organising study days for staff on the experience of cognitive impairment.

• **Developing the *Helping Us Understand You* booklet**

The project leader developed a questionnaire for the team to establish what sort of information could help staff improve care and how. Based on the responses, the *Helping Us Understand You* booklet was designed by the project leader in consultation with the project team, with the aim of capturing some of the little things that might make a person feel more comfortable, such as who they might want to speak to if they are upset.

• **Interviews with patients**

The project leader approached patients who were able to express their needs and had good insight into their illness for comments on the booklet. There was positive and negative feedback; for example, one relative said she didn’t like filling in forms, so would need support, but others could see the booklet’s value for when patients became less well.

• **Staff workshops: experience of cognitive impairment**

Two study days were held, one for healthcare assistants only and one multidisciplinary. The main aims were to: explore values and beliefs about person-centred care to develop a shared vision around care for people with cognitive impairment; improve understanding of cognitive impairment and its likely effects on function and behaviour; understand the common difficulties experienced by people with cognitive impairment; and recognise ways to support them to improve symptom management, quality of life and end-of-life care.

Staff were asked to consider improving care for fictional patients using the *Helping Us Understand You* booklet. Then the participants were asked to complete a booklet themselves to help them think about information that would support them if they needed care. The use of the booklet was supported by resources such as memory bank books, day/night calendar clocks, PictoComm – (pictorial communication aids; [tinyurl.com/pictocomm-tool](http://tinyurl.com/pictocomm-tool)) and items to look at and fiddle with in a ‘rummage and reminiscence box’. These resources could help orient a person to time and to their environment and provide achievable and meaningful activity and occupation. Evaluation after nine months found the participants valued their greater understanding of the needs of people with cognitive impairment.

• **Evaluation**

While this project is still in its early phase, a claims, concerns and issues exercise used to evaluate it pointed to many successes, including the value of the booklet and its contribution to improving care. Concerns expressed led to proposals for further actions, such as making the booklet itself more robust and the importance of celebrating success.