

See it, hear it, feel it

It's time for less dissociation, more facing up to the truth, says David Sheard, describing Dementia Care Matters' approach, Enabling, which helps care services to focus on the real lived experience of people with dementia through the use of a qualitative evaluation tool

*I was quite mortified because I thought we were a good home. Sometimes we're afraid to see what is actually happening.**

In life we do not always see what is staring us in the face. We walk around not hearing what is obvious. We manage to avoid feeling the very real experiences going on around us. Deep down we may know, really, how things are. However the enormity of the truth can be overwhelming.

In a dementia care service there is a high risk of this occurring. The core purpose of a care service – enabling people to have a positive day – can become lost in systems, paperwork and processes, although there may be no evidence that these enhance quality of life. The lived experience of people can too readily become secondary to busy work agendas.

The true quest for quality in a service begins with a staff team really seeing, hearing and feeling minute by minute the quality of interactions in people's lives. This can be done through an observation technique such as the one

described below. However, embarking on this quest is not for the faint hearted.

You need to expect challenges and be prepared to search your soul – there will be tears. Embrace this approach but be prepared to have a big shock.

The truth is out there

Opening up a care service to minute by minute recorded observation is brave. It asks that staff lower their defences and allow themselves to share the lived experience and feelings of others. Afterwards, reading the report of this observation can give a very different picture from the general impressions formed by management, visiting families or inspectors. The whole experience can be profoundly unsettling. What in passing always appeared a reasonable day looks quite different when its full impact on each person living there is made clear: the subtle reactions, the missed moments, the repetitive nature of events, the stultifying boredom. A whole new picture is opened up to staff which can

feel too brutal to face up to, too honest and too challenging. Measuring people's level of boredom and its consequences strips a service back to its core.

It was an eye opener... staff were in denial. Deep down you know don't you?

Enabling insight

The aim of an observation is for the observer to become the eyes, ears, heart and voice of people with a dementia.

(David Sheard)

The book *Enabling* (see below) describes a methodology known originally as QUIS – the Quality of Interactions Schedule. This qualitative observational approach measures quality of life through a time sampling technique in which the quality of interactions between people living and working within a service are estimated. This is done through a series of five-minute observations in group living areas (lounges and dining rooms) across a minimum period of two hours.

Key thoughts

- Recording a day in the life of people experiencing 'care' is powerful.
- Feeling the boredom of social warehousing is a shock.
- Seeing evidence of positive interactions is uplifting.
- Turning positive personal care into positive social interactions is a skill.
- Removing controlling care is the place to begin.
- Measuring individuals' experiences in group living is at the heart of being person-centred.

At five-minute intervals the overall level of interactions and quality of care being experienced by the group is observed and coded using one of the five codes set out in Figure 1 below.

In addition a 'script' is written which captures:

- significant quotations from people living in the service, reflecting their feelings and experience



- quotations from staff in the course of their work which reflect the culture

- additional positive or negative experiences of individual which are exceptions to the observed and recorded group experience

- written summaries: these always identify positive aspects of care but also set out a developmental action plan.

We undertook observations in 100 care services and analysed these. The results showed that

Positive Social Interactions	Positive Personal Care	Neutral Care	Negative Protective / Controlling Care	Negative Restrictive Care / Subtle Abuse
Interaction, ie time spent during the 5 minute period where for the observed group it was principally a 5 minute period of:				
positive social and/or emotional interaction with staff, family, visitors or other people living there	positive personal care with good attention to one's physical and personal care needs	neutral care with the main experience being one of lethargy, boredom, staring into space, etc	controlling care where the staff decide what's best for people living there or take this further to actually stopping, preventing, restricting and controlling what people can or cannot do in their own living and dining areas	subtle forms of abuse, ie negative restrictive care where the level of controlling care is part of the culture of service

Fig 1: Codes used in a QUIS observation to rate the level of interactions and quality of care.

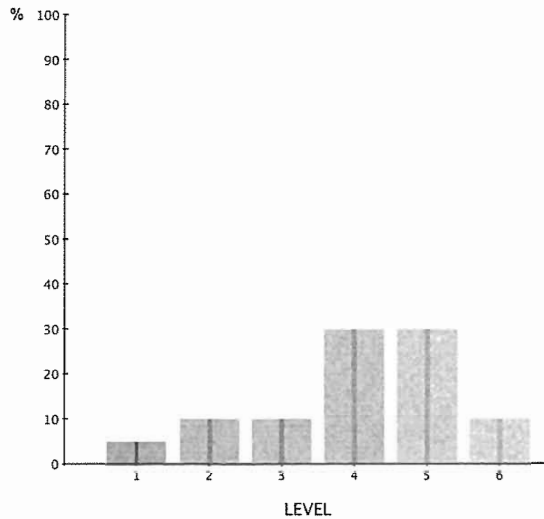
Measuring person-centred care

The methodology also enables a service to be 'rated' from Level 1 to Level 6 against other care services which have experienced the same observation approach. Level 1 is exceptional person-centred dementia care and Level 6 is a service at crisis level.

This bar chart (Figure 2) shows the outcome of 100 observations conducted across the UK in terms of the level achieved.

These figures give a clear indication of how far person-centred dementia care still has to travel: only five per cent of homes are achieving Level 1 (exceptional person-centred dementia care) and 70 per cent of homes are below average to a crisis level. It should be remembered that these 100 services were services enlightened enough and brave enough to place themselves under this level of scrutiny.

Our data also showed that services with a good reputation, where the focus is on policies, procedures, standards and systems, can have a very different rating when measured on the quality of interactions and the observed lived experience of people with a dementia. The truth is out there if we want to see, hear and feel it.



while negative care/abuse was rare, and there were some instances of positive social interactions, the predominant experience by far is of neutral care. Services signing up to less dissociation and more facing of the truth have to acknowledge that boredom, lethargy and staring into space are what most people experience, most of the time, in care settings.

Enabling and inspiring action

I defy anyone to put the report in the bottom drawer and sleep well at night. It will change the way you view people with a dementia forever.

Findings from a large number of observations have identified common themes needing to be addressed:

- establishing a clear model of dementia care
- developing team leadership
- enabling staff to learn through their own observations
- skills in 'grouping' people living together
- getting rid of controlling care
- reducing long periods of neutral care
- creating an environment that works
- increasing positive social interactions
- improving the mealtime experience
- enabling more emotional

connection between people living and working together.

What do people learn about a person-centred approach from the experience of having a qualitative observation? Answer – the truth!

It opens us up emotionally and challenges us to get out of the box. It's an enormous opportunity to open people's eyes to the possibilities.

Further reading

- Dean R, Proudfoot R, Lindsay J (1993) The Quality of Interactions Schedule (QUIS): Development, Reliability and Use in the Evaluation of Two Domus Units. *International Journal of Geriatric Psychiatry*, 8, 819-826
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- Bruce E (2000) Looking after wellbeing: a tool for evaluation. *Journal of Dementia Care*, 8(6) 25-27
- Sheard D (2007) the Feelings Matter Most series, published by the Alzheimer's Society, UK: *Being: an approach to life and dementia* (2007)
- Enabling: quality of life – an evaluation tool* (2008)
- Inspiring: leadership matters*

- in dementia care* (2008)
- Nurturing* (due September 2008)
- Growing: training that works in dementia care*
- Brooker D, Edwards P, Benson S (eds) (2004) *Dementia Care Mapping: experience and*

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* Grateful thanks also to those staff whose feedback gave us the quotes included (in italics) here.

David Sheard is director of Dementia Care Matters, a training consultant with Alzheimer's Society and a visiting senior fellow in the Division of Health and Social Care, University of Surrey. David Sheard's book 'Enabling' is the second book in his Feelings Matter Most series published by Alzheimer's Society.

Enabling quality of life - an evaluation tool

Part of the innovative Feelings Matter Most series, *Enabling* challenges traditional methods of delivering dementia care by introducing an enabling approach that places an emphasis on empowerment, rights and on the lived experience of people with dementia.

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