‘Can anyone fix dementia care homes? – quality of life matters’

Dr David Sheard  Director, Dementia Care Matters
Visiting Senior Fellow, Division of Health and Social Care,
University of Surrey, UK
10 Steps

1. Beginning with the truth
2. Confirming core beliefs re what matters most
3. Focusing on what person centred dementia care looks, sounds and feels like
4. Being person centred towards staff
5. Joining up the management pieces – the picture on the box
6. Recognising the destination – from one model to another
7. Linking beliefs to outcomes
8. Setting clear operational targets – the 50 point checklist
9. Turning staff training into real action
10. Translating into dementia design

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Step 1
Beginning with the truth
Is there an acceptance that care homes need fixing?
Can Gerry Robinson Fix Dementia Care Homes?
Enabling
quality of life – an evaluation tool

David M Sheard
The Reality of Exclusion in Care Homes for People with a Dementia

Dementia Care Matters Study (c) - 500 Audits Across UK - Average Results

Ref: Dean, Proudfoot & Lindesay: QUIS - Int J of Geriatric Psychiatry Vol 8:819 - 826
Step 2
Confirming core beliefs re what matters most
Being an approach to life and dementia

David M Sheard
Our Sense of ‘Being’

Being

Enabling

Inspiring

Nurturing

Growing

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The key aim of the books is to demonstrate:

• the real meaning of being person centred.
• the importance of focusing on ‘Being’ rather than ‘Doing’.
• that being person centred applies equally to everyone in life.
• a way forward in developing a person centred approach.
PUBLICATIONS

- **Being** – An approach to life and dementia
- **Enabling** – An evaluation approach to dementia services
- **Inspiring** – A tool kit focusing managers on best practice
- **Nurturing** – A guidance pack on providing emotional support
- **Growing** – A strategy to maximise learning in dementia care

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PUBLICATIONS PROMOTING
A SERIES OF MOVES

i) moving from seeing oneself as a carer to being an enabler / a supporter

ii) moving from providing care to being a care partner

iii) moving from delivering person centred care to being person centred

iv) moving from sounding person centred to being feeling based
OVERALL THEMES

The books comprises of a set of overall themes which are fundamental to achieving feeling based support for people living with a dementia, families and friends, managers and staff.
THE TEN THEMES

• A person enters and leaves this life as a human being not a human doing.
• The meaning of life is individual to each of us.
• Each of us has an inner spirit that needs to be kept strong.
• Having hope and a purpose in life is critical as a human being.
• Feeling physically and emotionally free to express ourselves is fundamental.
THE TEN THEMES

- Loving relationships maintain our well being.
- Everyone needs to feel a sense of togetherness and community with one another.
- Faced with difficulties in life recovery of the spirit and of oneself inside is always possible.
- A person centred approach has to look, sound and be heartfelt.
- Being person centred requires congruence – a merger in life and at work between oneself and these overall themes.
APPROACHES TO BEING

1. Being Person Centred
2. Being Feeling Based
3. Being Self Aware
4. Being Positive
5. Being Supportive
6. Being Congruent
7. Being Together
8. Being Passionate

© Dementia Care Matters 2010
“We are not human beings on a spiritual journey, we are spiritual beings on a human journey.”

[Stephen R Covey]
Step 3

Focusing on what person centred dementia care looks, sounds and feels like
Favourite areas
Presentation of corridors

- Colour
- Fabrics and items on hooks
- Lighting
- Front door

© Dementia Care Matters 2010
Get Rid of ‘Them’ and ‘Us’

- Uniforms
- Badges
- Staff Toilets
- Staff Mugs
- Trolleys
- Not eating with people with a dementia
- Hovering over people with a dementia
Step 4

Being person centred towards staff –developing an Emotions at Work Framework (NOSE)
Evidence

Taken from interviews and questionnaires with over 100 staff on:

Emotional Labour

Emotions at Work in dementia care

David Sheard.

© Dementia Care Matters 2009 Nurturing our emotions at work.
Nurturing our emotions at work in dementia care

David M Sheard
Evidence

‘The key to solving the riddle of person centred dementia care lies in nurturing emotions at work.’

David Sheard.

© Dementia Care Matters 2009 Nurturing our emotions at work.
Evidence

Cultures of care are revealed by how staff display emotions at work.

• ‘I feel comfortable enough to be able to wear my heart on my sleeve. My manager loves me – what you see is what you get.’
Evidence

Cultures of care are revealed by how staff display emotions at work.

• ‘My direct line manager hasn’t got an emotional bone in their body. Our own personal issues should be left at home and should not influence the care we give.’
Evidence

Cultures of care are revealed by how staff display emotions at work.

• ‘My manager is unable to respond to emotions. I think that the emotional cost is high if you work in a place where feelings don’t matter’
Evidence

Cultures of care are revealed by how staff display emotions at work.

• ‘Many places do not want staff sat talking to people. Relationships are unprofessional.’

• ‘My manager ignores emotions at work and has no understanding of the feelings of others.’

© Dementia Care Matters 2009 Nurturing our emotions at work.
Evidence

Cultures of care are revealed by how staff display emotions at work.

- We are often made to feel that we should leave our personal issues or feelings at home and become a different person at work.’
Evidence

Disguising emotions at work is rife.

• to not upset people with a dementia in their presence
• to comply with family expectations about staff being upbeat
• to manage to switch emotionally from one task to another with sufficient speed

© Dementia Care Matters 2009 Nurturing our emotions at work.
Evidence

Disguising emotions at work is rife.

• to meet manager’s expectations in appearing positive.
• lack of time given for debriefing emotions at work,
• tangible suppression of sadness in the workplace
Evidence

Disguising emotions at work is rife.

- poor human responses to staff facing loss, grief and death very regularly at work

- reluctance to talk about how staff from other cultures respond to emotions at work

© Dementia Care Matters 2009 Nurturing our emotions at work.
Evidence

Disguising emotions at work is rife.

• subtle pressures at work to ‘not get involved’

• lack of training in how to respond to ‘angry’ families

• lack of physical space, opportunity or training to reflect on emotions at work.

© Dementia Care Matters 2009 Nurturing our emotions at work.
Nurturing our emotions at work.
Evidence

The suppression of emotions at work is predominant.

• Disguising emotions is purely a misguided social construction in dementia care.

• The historical emphasis on older people has been on bodies and not emotions.
Evidence

The suppression of emotions at work is predominant.

• The ‘old rules’ about emotions in dementia care originate from the asylum

• Old professionalism equalled ‘acting’, new professionalism requires authenticity.
Evidence

The suppression of emotions at work is predominant.

• Dementia care has suffered from the masculinisation of emotions.

• An accelerated pace of change is required, this will inevitably cause deep anxiety to ‘masked professionals.’
Evidence

The suppression of emotions at work is predominant.

• The emphasis on dementia design is in danger of only improving physical structures rather than prioritising feeling-based care.

• Task based dementia care was and is a way to avoid the management of feelings.
Evidence
The suppression of emotions at work is predominant.

• IQ and competencies in people have been overvalued when in dementia care emotional intelligence and awareness is needed.

• Emotional awareness in dementia care involves moving oneself away from being ‘anaesthetised’ to being more spiritual.

© Dementia Care Matters 2009 Nurturing our emotions at work.
Evidence
The need to tear up Old Rules on Emotions at work.

© Dementia Care Matters 2009 Nurturing our emotions at work.
Step 5

Joining up the management pieces – the picture on the box
TOWARDS A DEMENTIA CARE STRATEGY

• New culture beliefs adopted
• Signed up model of care
• Clear measurable outcomes
• Quality of life focus on standards
• Operational targets set
• Targets translated into action

© Dementia Care Matters 2010
TOWARDS A DEMENTIA CARE STRATEGY

Compatible:

- Design brief
- HR practices
- Learning and development plan
- Emotional labour approach
- Staffing ratio
- Fee levels
- Support services
- Qualitative observational methodology

© Dementia Care Matters 2010
Step 6

Recognising the destination – from one model to another
Inspiring leadership matters in dementia care

David M Sheard
Evidence - Which Model are you?

Model 1
The Clinical Service: a traditional old culture organisation.

Features

- Philosophy of care based on science, function, rationality and bodies.
- Detached professionalism
- Lack of person centred beliefs
- No qualitative observation of service
- Task based care
- Suppression of Emotions at Work
- Clinical training in dementia: causes, signs and symptoms.

This is an emotion-less organisation promoting clinical services with a powerful and controlling defence mechanism of limiting the emotional impact throughout the service.

© Dementia Care Matters 2009/Alzheimer’s Society Nurturing our emotions at work.
Evidence - Which Model are you?

Model 2
The Confused Service: an adapted old culture organisation

Features

- Philosophy based on hierarchy of needs from physical to spiritual.
- Detached professionalism
- Dementia care awareness training.
- Suppression of Emotions at Work.
- Task based care.
- Person centred beliefs
- No qualitative observation of service.

This is a confused service with no effective defence mechanism of limiting the emotional impact throughout the service. The service exposes staff to new beliefs in person centred care without effective means of implementation as the service is still task based and run on an old culture of professionalism leading to elements of staff stress, disillusionment, ill being and burn out.

© Dementia Care Matters 2009/Alzheimer’s Society Nurturing our emotions at work.
Evidence - Which Model are you?

Model 3
The Creative Service: a muddled new culture organisation

Features

- Philosophy of care based on feelings and emotions
- Dementia care awareness training.
- Attached professionalism
- Expression of Emotions at Work but no strategy.
- Confused task based care.
- Person centred beliefs
- Qualitative observation of service.

This is a creative service which has many new culture beliefs and approaches in place but these are mixed in with old culture actions. The service is likely to have no clarity that lack of effective training and lack of applying person centred approach to staff teams is defeating its intended purpose. This leaves staff exposed with no defence mechanism to handle the lack of congruence in the service between the service’s intentions and its muddled daily approach.

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Evidence - Which Model are you?

Model 4

Features

- Philosophy of care based on feelings and emotions
- Attached professionalism
- Implementation of staff well being tool.
- Person centred beliefs
- Dementia care training which is focused on self-awareness and action.
- Evidence of an Emotions at Work framework.
- Service run by individuals for individuals – free flowing.
- Qualitative observation of service.

This is an emotion-led organisation providing congruent services with its beliefs, training, and action compatible to people living and working together. It is effective in promoting and valuing emotions at work and supports these in formal and informal means on a regular basis.

© Dementia Care Matters 2009/Alzheimer’s Society Nurturing our emotions at work.
Step 7
Linking beliefs to outcomes -
Dementia Care Matters
36 outcomes approach
# LEADING: Outcomes in dementia care

## 36 OUTCOMES

<table>
<thead>
<tr>
<th>Quality of Service Outcomes</th>
<th>Quality of Life Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Managers have high levels of self awareness.</td>
<td>1. Guaranteed quality of life</td>
</tr>
<tr>
<td>2. Managers have passion in their work.</td>
<td>2. Increased well being.</td>
</tr>
<tr>
<td>3. Managers communicate a person centred vision.</td>
<td>3. Life histories are valued and reinforced.</td>
</tr>
<tr>
<td>4. Attitudes are valued most in recruitment.</td>
<td>4. Us and them features removed.</td>
</tr>
<tr>
<td>5. Emotional labour is supported.</td>
<td>5. Controlling care reduced.</td>
</tr>
<tr>
<td>6. Appraisals measure capacity to be person centred.</td>
<td>6. Positive interactions increased.</td>
</tr>
<tr>
<td>7. Families/friends are significant partners in the home.</td>
<td>7. People grouped with common needs.</td>
</tr>
<tr>
<td>8. &quot;Home and family learning sessions&quot; are regularly held.</td>
<td>8. Peoples functional capacity is assessed.</td>
</tr>
<tr>
<td>9. Families and friends have clarity on model of care.</td>
<td>9. Specialisms within dementia care are created.</td>
</tr>
<tr>
<td>10. Personal reflection is prioritised in training.</td>
<td>10. Disability and home-like needs met.</td>
</tr>
<tr>
<td>11. Training includes emotional appraisal.</td>
<td>11. Engaging rooms set up.</td>
</tr>
<tr>
<td>12. Training is turned into action.</td>
<td>12. Life skill areas created.</td>
</tr>
<tr>
<td>13. Task orientation substantially removed.</td>
<td>13. Five star dining is dementia specific.</td>
</tr>
<tr>
<td>15. Mutual regard is evident.</td>
<td>15. Engaged, positive mealtimes.</td>
</tr>
<tr>
<td>16. Rights are upheld to taking measured risk.</td>
<td>16. Occupation is staffs key purpose.</td>
</tr>
<tr>
<td>17. Care Plans focused on strengths.</td>
<td>17. 'Activity' repertoire has increased.</td>
</tr>
<tr>
<td>18. Feelings are assessed before 'behaviours'.</td>
<td>18. Butterflies are seen in action.</td>
</tr>
</tbody>
</table>

This is an extract from Dementia Care Matters new publication commissioned by Barchester Healthcare ‘LEADING: Outcomes in dementia care’ shortly to be published by Dementia Care Matters.
Step 8

Setting clear operational targets—
the 50 Point Checklist
<table>
<thead>
<tr>
<th>Item</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Uniforms have been removed and staff look like ‘best friends and not like nurses in charge.</td>
</tr>
<tr>
<td>2.</td>
<td>All toilets are communal and there are no separate staff toilets.</td>
</tr>
<tr>
<td>3.</td>
<td>Staff do sit to each meals with people with a dementia.</td>
</tr>
<tr>
<td>4.</td>
<td>All use of trolleys has been stopped – medication is given out individually from locked cupboards in people’s own rooms. Drinks and meals are served individually.</td>
</tr>
<tr>
<td>5.</td>
<td>There is a relaxed ‘go with the flow’ feel to the day with no sense of the routines that occur in hospital.</td>
</tr>
<tr>
<td>6.</td>
<td>Evidence can be seen of Managers modelling person centred care ‘on the floor’ daily.</td>
</tr>
<tr>
<td>7.</td>
<td>Staff see management as feeling based leaders towards them and use words which describe this when talking about managers.</td>
</tr>
<tr>
<td>8.</td>
<td>Labelling language in care plans has been removed i.e. words such as wanderer, challenging, aggressive, are banned and staff do not use this language nor ‘talk about’ people in communal areas in front of people.</td>
</tr>
<tr>
<td>Feelings Matter Most Approaches</td>
<td>Yes</td>
</tr>
<tr>
<td>-----------------------------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>9. On arrival people would see, hear and feel immediately it is a feeling based Home within 5 minutes of walking in.</td>
<td></td>
</tr>
<tr>
<td>10. Lots of feelings based communication by staff can be seen occurring.</td>
<td></td>
</tr>
<tr>
<td>11. Love, comfort and hugs can be seen to be visibly happening when needed.</td>
<td></td>
</tr>
<tr>
<td>12. Staff can be seen at times sitting and just ‘being with’ people who live there.</td>
<td></td>
</tr>
<tr>
<td>13. Staff demonstrate they know when people with dementia talk about Mum, Dad, kids, school, home and work, it is often not literal but about how people are feeling now.</td>
<td></td>
</tr>
<tr>
<td>14. Staff express positive comments about why they work there and the feelings working there creates for them.</td>
<td></td>
</tr>
<tr>
<td>15. Staff are able to express the care setting's one key belief, its one purpose about dementia care.</td>
<td></td>
</tr>
<tr>
<td>Evidence of Physical and Emotional Freedom</td>
<td>Yes</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>-----</td>
</tr>
<tr>
<td>16. People are freely able to go outside into safe enclosed private areas without needing locks unlocked or having to be accompanied.</td>
<td></td>
</tr>
<tr>
<td>17. Families seem to be ‘at home’ rather than as visitors or guests and are visibly significantly involved in the daily life of the setting.</td>
<td></td>
</tr>
<tr>
<td>18. Families are visibly accepting people with a dementia’s different realities and appear not to try to force their own reality when they visit. Clear evidence exists that families have been educated in the philosophy of the setting.</td>
<td></td>
</tr>
<tr>
<td>19. Staff are not obsessed with risk prevention and health and safety - they meet legal requirements but evidence during the day that their approach is in the context of promoting rights.</td>
<td></td>
</tr>
<tr>
<td>20. Staff clearly recognise the importance of people’s emotional memory and their treasured emotional possessions and demonstrate this in their contact with people.</td>
<td></td>
</tr>
<tr>
<td>21. Regular use of the outdoors is ensured where outdoors and indoors merge together as one area to occupy people with for example a busy garden, an old car on blocks, washing lines, ‘activity’ based sheds etc.,</td>
<td></td>
</tr>
<tr>
<td>22. Limited use exists of anti-behaviour medication – neuroleptics – where this is only as a last resort to relieve acute distress.</td>
<td></td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Item</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>23.</td>
<td>People with a dementia are seen regularly doing domestic activities throughout the day.</td>
</tr>
<tr>
<td>24.</td>
<td>Some people with a dementia are helped in their reality to ‘do’ a part of a work like job they did in the past.</td>
</tr>
<tr>
<td>25.</td>
<td>Sensory calming and sensory stimulating items and a variety of their approaches are alternated at different periods of time during the day.</td>
</tr>
<tr>
<td>26.</td>
<td>Attempts are made not to mix up people with a dementia at different ‘points’ of experience who are fearful of one another.</td>
</tr>
<tr>
<td>27.</td>
<td>Knowledge exists of how to ‘match’ the right level of activity and occupation appropriate to where an individual is in relation to their point of experience of a dementia.</td>
</tr>
<tr>
<td>28.</td>
<td>Dolls, prams, soft toys, comfort objects are all available and visible within the service.</td>
</tr>
<tr>
<td>29.</td>
<td>Massage and other physical therapies occur during the week.</td>
</tr>
<tr>
<td>30.</td>
<td>Use of sensory fabrics to touch and feel for example velvet, fur etc., are scattered about.</td>
</tr>
<tr>
<td>31.</td>
<td>Masses of 30 second connections between staff and people who are in the care setting occur – staff look like they know how to be butterflies creating lots of positive moments.</td>
</tr>
<tr>
<td>32.</td>
<td>Choices of individual music geared to individuals and natural sounds i.e. bird song are introduced.</td>
</tr>
<tr>
<td>Tick one box per item listed below</td>
<td>Yes</td>
</tr>
<tr>
<td>-----------------------------------------------------------------------</td>
<td>-----</td>
</tr>
<tr>
<td><strong>Focusing on the Mealtime Experience.</strong></td>
<td></td>
</tr>
<tr>
<td>33. Meal choice is shown at the time of the meal.</td>
<td></td>
</tr>
<tr>
<td>34. The mealtime experience is turned into a social occasion and not a task. Staff are clearly trained in how to keep mealtime conversations going using objects, items in their pockets, perspex boxes on tables which are full of things to talk about including photos.</td>
<td></td>
</tr>
<tr>
<td>35. 24 hour visible food is out in public areas and corridors – changed hourly to meet Food Hygiene Regulations, with the aim of encouraging people to eat when they feel like it.</td>
<td></td>
</tr>
<tr>
<td>36. Use of smells from cooking and food discussion, food pictures are actively used to orientate people 45 minutes prior to a meal with the aim of encouraging an increase in appetite.</td>
<td></td>
</tr>
<tr>
<td><strong>Person Centred Care Planning</strong></td>
<td></td>
</tr>
<tr>
<td>37. Care plans show they focus on people’s strengths and not lists of losses and dependency nor on problem based sheets.</td>
<td></td>
</tr>
<tr>
<td>38. Detailed life histories – books, memory boxes etc are being used daily by people working and living there.</td>
<td></td>
</tr>
<tr>
<td>39. Specialist skills in ‘later stage’ dementia care are evident.</td>
<td></td>
</tr>
<tr>
<td>Item</td>
<td>Description</td>
</tr>
<tr>
<td>------</td>
<td>-------------</td>
</tr>
</tbody>
</table>
| 40.  | Evidence of a Dementia Specific Environment  
Positive attempts have been made to reduce the impact of a hotel like environment whilst retaining a quality environment – it looks more like a home than a hotel. |
<p>| 41.  | Real small-scale domestic living exists i.e. Maximum lounge sizes of 10-12 people. |
| 42.  | Orientation aids i.e. colour and objects and appropriate signage throughout building exist to enable people to find their way through a range of cues. |
| 43.  | Corridors exists which are divided into coloured sections or divided up with objects and/or seating to prevent institutionalisation. |
| 44.  | Corridors are full of ‘activity items – things to occupy’ i.e. on tables and walls, activity boards, sensory areas – corridors seen as areas of stimulation. |
| 45.  | Untidiness exists with clutter, rummage items all out in lounges, corridors etc., Lounges are full of rummage boxes, open chests of drawers and the rooms are full with all these items out and being passed around. |</p>
<table>
<thead>
<tr>
<th>Evidence of a Dementia Specific Environment</th>
<th>Yes</th>
<th>No</th>
<th>Partly</th>
</tr>
</thead>
<tbody>
<tr>
<td>46. Bedroom doors look easily identifiable – very individual with either colour, notice boards or memory boxes by door, whatever works for each person.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>47. Pictorial signage on toilets exists.</td>
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<tr>
<td>48. Lounges have sofas.</td>
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</tr>
<tr>
<td>49. Lounges have artwork and pictures that denote the function of the room as a cue i.e. not confusing pictures unrelated to room function.</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>50. Bathrooms are not clinical but warm, inviting places to want to relax in – reduction of reflective tiling and glare, been actioned, they appear warm and friendly.</td>
<td></td>
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</tr>
</tbody>
</table>
Step 9

Turning staff training into real action
Fifth in the Feelings Matter Most series

Growing training that works in dementia care

David M Sheard
‘What works’ in changing practice and care cultures:

• A multi faceted approach which embraces adult learning models as well as incorporating skill development and the role of leadership in culture change appears critical to maximising impact (Moniz-Cook, 1998; Lintern et al, 2001).

• Management support and backing may be critical in maintaining new practices over a longer period of time and in sustaining motivation of the workforce.

Brooker (2007)
Professional development and dementia care:

“...dogs are trained, children are taught and adults learn from experience....most forms of training have a weak impact on practice, especially if they are classroom based and factually oriented...the most effective learning is work place-based, problem solving in character and resource intensive”

(Iliffe and Wilcock, 2009)
‘What works’ in changing practice and care cultures:

• Commitment to professional development
• Appropriate skill acquisition and practice
• Identify and acknowledge what’s going well
• Self disclosure
• Empathy
• Modelling / mentoring

Dr Mo Ray 2010
Domains of ‘Being a Star’™ Training Framework
Independent evaluation – Dr Mo Ray

Organisational factors

Leadership and mentoring

Experiential Learning; problem focused; use of self, skill development
Findings of the programmes pointed not to training as the answer but to ..........
• Modern leadership and coaching
• Quality of life measurement
• Energised staff
• New model of care
• Removal of institution
• Filled up environments
• Meaningful occupation
• Compulsion to happen
Step 10

Translating into dementia design
DEMENTIA DESIGN
12 KEY PRINCIPLES

- Small group living
- Sensible way finding
- Limiting disorientation
- Visible domestic function
- Increased light levels, increased colour differentiation, limiting use of patterns
- Matching groups

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DEMENTIA DESIGN
12 KEY PRINCIPLES

• Space to fill the environment up
• Softening of bathrooms
• Bed position to ensuite
• Visual outlook
• Dementia specific gardens
• Provision of quiet areas

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Arriving at your destination-

Measuring quality of life above quality of service
LAUNCH OF NATIONAL SCHEME

Dementia Care Matters Quality of Life “kitemark”

• Participating in a national dementia care Quality of Life ‘kite mark’
• Providing the Care Quality Commission with independent evidence
• Being recognised for quality dementia care
• Gaining external validation
• Receiving an independent qualitative evaluation
• Focusing on quality of life outcomes

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‘Quality of Life Matters and is the only real indicator of quality of service in person centred dementia care’

David Sheard
Director, Dementia Care Matters