The “Butterfly Model”: Person-Centered Dementia Care

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My biggest adventure in life .......
going from this .........
and going from this ......
and arriving at this...
and being like this...
‘Achieving person centred dementia care cannot be simple. Otherwise by now it would have just happened

Somehow the most important part of achieving person centred care has been missed out. It is presumed people actually know what ‘it’ is. How many people really know what person centred care looks, sounds and feels like?

The false presumption has been made that managers and staff have, in their mind’s eye, a clear picture of ‘it’. People know only what they know.
• The reason people struggle to describe person centred care is that in order to know what ‘it’ is you also have to have a clear idea of what it is not.

• You need a vision of the key differences that a person centred care culture has from what previous models of care have been like.’

• ‘Achieving’, David Sheard, Dementia Care Matters 2011
First in the Feelings Matter Most series

Being
an approach to life and dementia

David M Sheard

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Being with not doing to

- Travelling the emotional journey
- Making parallels in feelings
- People first, tasks second
- Being real
- Valuing assertive feelings
- Responding constantly to well-being and ill-being
- Freeing up emotions
- Realising feelings matter most in all of us

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Not being close

• Not engaging fully.
• Creating a distance.
• Being wooden
• Minimal participation
• Looking for tasks.
Not being close (Cont...)

- Emphasising cleanliness, tidiness.
- ‘Escaping’ from contact.
- Being a spectator.
- Superficial banter filling empty spaces.
A care home needs wiring with emotional intelligence
“As we become more emotional and less cognitive, it’s the way you talk to us, not what you say, that we will remember.

We know the feelings, but don’t know the plot. Your smile, your laugh and your touch are what we connect with. Empathy heals. Just love us as we are. We’re still here in emotion and spirit, if only you could find us.”

Christine Bryden (2005)
Person Centred Recruitment

Would you share your life history with a stranger in a bus queue?

What has been the most painful emotional moment of your life

Show me how you can change this moment now
Emotional Competency

Emotional Intelligence ‘the primary competency’ in Dementia Care.

David Sheard
“As a nurse in the past I was taught to keep a professional distance, not to show emotions and most definitely not to show physical affection, even a cuddle to someone in distress. This new way of working has enabled me to be a person at work and inspire the team to show emotions, be themselves and be truly person centred whilst still maintaining their clinical responsibilities.”

Lyanne Raven
Clinical Team Leader
Alternative Futures Group
Being Close

- Travelling the emotional journey
- Making parallels in feelings
- People first, tasks second
- Being real

- Valuing assertive feelings
- Responding constantly to well-being and ill-being
- Freeing up emotions
- Realising feelings matter most in all of us
Seventh in the *Feelings Matter Most* series

*Loving*
the essence of being
a butterfly in dementia care

*Sally Knocker*
The Eternal Triangle

- Group Living
- Task Orientation
- Person Centred Care

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The Reality of Exclusion in Care Homes for People living with a Dementia

Average results from 500 Dementia Care Matters audits across the UK

The lived experience of people with dementia during the audit period

Ref: Dean, Proudfoot & Lindesay: QUIS – Int J of Geriatric Psychiatry Vol 8:819 - 826

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Evidence - Which Model are you?

Model 1

The Clinical Service: a traditional old culture organisation

CLINICAL SERVICE

- Philosophy of care based 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

© Dementia Care Matters 2015
Evidence - Which Model are you?

Model 2
The Confused Service: an adapted old culture organisation

CONFUSED SERVICE

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

© Dementia Care Matters 2015
Evidence - Which Model are you?

Model 3
The Creative Service: a muddled new culture organisation

Dementia care awareness training

Philosophy of care based on feelings and emotions

Attached professionalism

Person centred beliefs

Qualitative observation of service

Confused task based care

No emotional labour strategy

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Evidence - Which Model are you?

Model 4
The Congruent Service: a new emotion-led organisation

CONGRUENT SERVICE

- Staff well being tool
- Philosophy based on feelings
- Attached professionalism
- Person centred beliefs
- Qualitative observation of service
- Service run by people living there
- Emotional labour supported
- Model of emotional intelligence
Enabling
quality of life – an evaluation tool

David M Sheard

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Average results from 700 Dementia Care Matters care home audits across the UK

- Positive Social Interaction
- Positive Personal Care
- Neutral Care
- Negative Protective
- Negative Restrictive

The lived experience of people with dementia during the audit period

© Dementia Care Matters 2015
• Modern leadership and coaching
• Quality of life measurement
• Energised staff
• New model of care
• Removal of institutional features and practices
• Filled up environments
• Meaningful occupation
• Compulsion to happen
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
What does positive person-centred care in dementia care look, sound and feel like?

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The ‘Household Model’ identifies three components that support a home:

- renewal of the spirit
- reframing the organisation
- renovating into home

USA the ‘Household Model’ pioneered by LaVrene Norton, Action Pact and Steve Shields
Accepting that homes have front doors while institutions have ‘units’
Dementia Care Matters turns 10 key household beliefs into action

• A home needs the right name
• A house needs a front door
• A home needs heart
• A house needs a leader
• A home needs a housekeeper

• A house matches people together
• A home brings out the best in people
• A house needs visiting partners
• A home creates mutual regard
• A house needs wiring with emotional intelligence
<table>
<thead>
<tr>
<th>Positive Social Interaction</th>
<th>Positive Personal Care</th>
<th>Neutral Care</th>
<th>Negative Protective Care</th>
<th>Negative Restrictive Care/Subtle Abuse</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talking about how you love the smell of toast, your own memories of eating toast, chatting about the smell of marmalade and oranges and where oranges come from etc.</td>
<td>Offering to help them butter the toast or asking if they need it cutting up, offering a choice of jam or marmalade.</td>
<td>Just putting the extra toast down in front of the person without speaking.</td>
<td>Telling the person to wait for the toast, that they’ve had their ration, saying ‘don’t you remember you’ve just had 3 slices’, telling someone they’ll be too full up.</td>
<td>Sighing, treating it as a bother, talking about them in the room and why they are a nuisance always wanting more toast with other staff and saying that the person has no idea really if they want it so ignore them.</td>
</tr>
</tbody>
</table>
INSPIRING ACTION
Leadership Matters in Person Centred Dementia Care

The 50 Point Action Checklist

Name of person completing checklist: .........................................................

Care setting: ...................................................................................

Date of completion: ........................................................................

This Checklist is a rough guide to some of the key features in Inspiring Action in Person Centred Dementia Care. The checklist will require further team discussion to ascertain if all team members have the same opinion. The checklist can also be used to create discussion amongst team members on each other’s understanding of the items. The items 1 – 50 are listed in priority order in terms of the headings. The purpose of this checklist is not to be definitive or comprehensive nor to create another version of institutionalised approaches. All of the points on the checklist need to be considered in terms of their relevance to each individual. The purpose of the Checklist is to focus on inspiring and improving culture change in dementia care. Work quickly through the Checklist on the basis of:

“if I came to your care setting today would I see evidence of .......................................................... being provided / offered to people with dementia?”
<table>
<thead>
<tr>
<th>Tick one box per item listed below</th>
<th>Yes</th>
<th>No</th>
<th>Partly</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Removal of Them &amp; Us Barriers leading to Culture Change</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Uniforms have been removed and staff look like ‘best friends and not like nurses in charge.</td>
<td></td>
<td></td>
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<tr>
<td>2. All toilets are communal and there are no separate staff toilets.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Staff do sit to each meals with people with a dementia.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>4. 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>
<td></td>
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</tr>
<tr>
<td>5. There is a relaxed ‘go with the flow’ feel to the day with no sense of the routines that occur in hospital.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>6. Evidence can be seen of Managers modelling person centred care ‘on the floor’ daily.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>7. Staff see management as feeling based leaders towards them and use words which describe this when talking about managers.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. 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>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
One Butterfly Care Home’s Evidence – Wren Hall, Nottinghamshire, UK

- 43% Reduced incidence of falls
- 58% Reduced incidence of displays of behaviours
- 1.7% Reduction in staff sickness
- People living and working together satisfaction increased
- More laughter and fun is shared

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“Contact with dementia or other forms of severe cognitive disability can – and indeed should – take us out of our customary patterns of over busyness, hypercognitivism and extreme talkativity, into a way of being in which emotion and feeling are given a much larger place....

.....inviting us to return to aspects of our being that are much older in evolutionary terms: more in tune with the body and its functions, closer to the life of instinct"

T. Kitwood. Dementia Reconsidered
“Feeling you matter is at the core of being a person, Knowing you matter is at the heart of being alive, Seeing you matter is at the centre of carrying on in life”

David Sheard
BEING NOT DOING IT

“When you know who you are, what you can be and where you can lead; when you can be vulnerable and unafraid, laugh, cry and dance a dance you do not know. When you can be in the moment with another person, only then do you have the beginning of being the best that you can be in dementia care.”

Claire Peters, RMN nurse
Alternative Futures Group

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Real Person-centred Care

“Its about helping, being their friend, being everything to them. I can't explain it – you’re just here – I’ve been everyone to them – I’ve been a husband, a brother and a father. I’ve had to be that person for them. I find it easy”. Its interaction that matters – keeping them human, keeping them feeling ‘human’ “.
NURSES AS LEADERS:
Starting from self

“You can’t lead a person-centred approach if you are not attuned to who and what you are as an individual. Only with that kind of congruence will the message resonate convincingly enough to be adopted by the rest of the team.”

Mark Bailey
Fairways Care Ltd
Messages to Nurses in dementia care in Canada

- Accept that a Nurses Licence in the past has attached a professional mask that needs to be shed
- Offer inspirational leadership as a nurse – go back to why you came into nursing – your spirit identity and feelings
- Model new culture nursing that you believe, feel and can show
- Lead the vanguard in removing controlling, de-humanising humiliating and abusive care
- Return to compassion by ‘being with’ not ‘doing to’ the person

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Five Practices of Effective Leaders in Person-centred Dementia Care

1. **CHALLENGE** the care setting

2. **INSPIRE** a dream of dementia care

3. **MODEL** and achieve small wins

4. **EMPOWER** staff to try things out

5. **GROW HEARTS** – set expectations on every individual and reward stars

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Can Anyone Robinson Fix Dementia Care Homes?

Evelyn: “I’m not a nice person!”
What do you feel proud of about dementia care in Canada?

For more information about David Sheard and Dementia Care Matters, please go to

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