




*Let your
Heart
shine through your
Smile*

The Butterfly Effect : Changing Dementia Care in Canada

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Chief Executive/Founder Dementia Care Matters

Visiting Senior Fellow, University of Surrey, UK

A photograph of a man in green and black patterned shorts performing a backflip into the ocean. He is captured mid-air, with his arms and legs extended. The ocean is a vibrant turquoise color, and the sky is a clear blue with scattered white clouds. In the background, a dark, forested coastline is visible under a bright sky. The foreground shows the dark, jagged rocks of the cliff from which he jumped.

My biggest adventure in
life



going from
this

A photograph of four female healthcare workers standing in a room. They are wearing short-sleeved polo shirts in two colors: dark green and light blue. Each worker has a name tag on their chest. The room has a white wall, a floral patterned curtain, and a window looking out onto a brick building. The text "and going from this" is overlaid in white on the lower half of the image.

and going from this

*and arriving at
this...*

*Let your
Heart
shine through your
Smile*



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



**We spend life as a human being
not as a human doing**





Life is an emotional journey



**Every person is different but
we have much in common**



**Feeding the spirit with hope
keeps us strong**



**All of us need to feel
free and not controlled**



**Everyone needs to have
purpose so as not to feel lost**



We all crave real human connection



**Having loving relationships
maintains our well being**



**A positive attitude to life
and disease will guide our path**



Feelings matter most in all of us



Live with dementia – dance your heart away



Move on from feeling lost



Give me something to hope for....



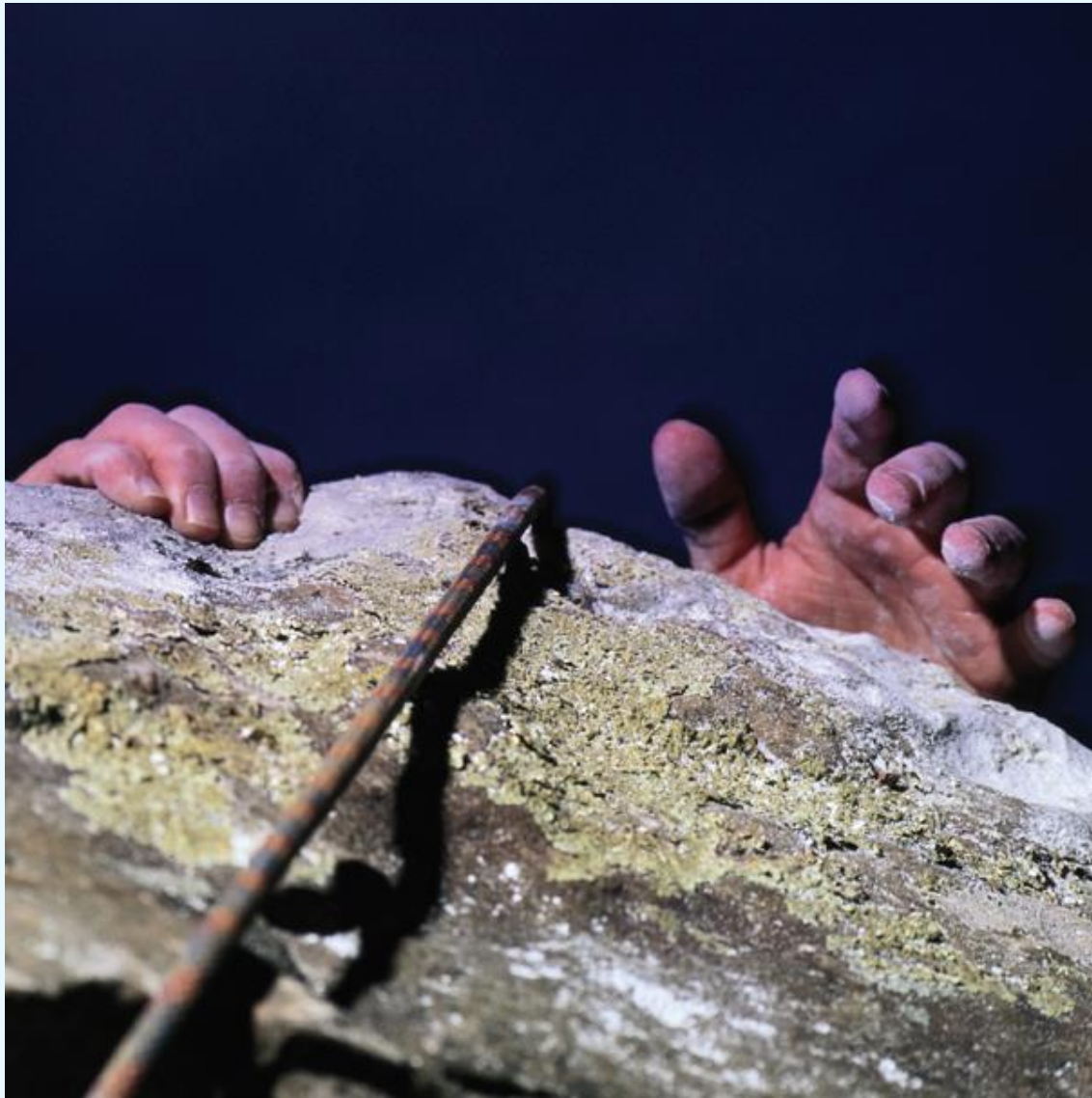
Take each day as it comes



Never be lonely – stick together



Focus on feelings not facts



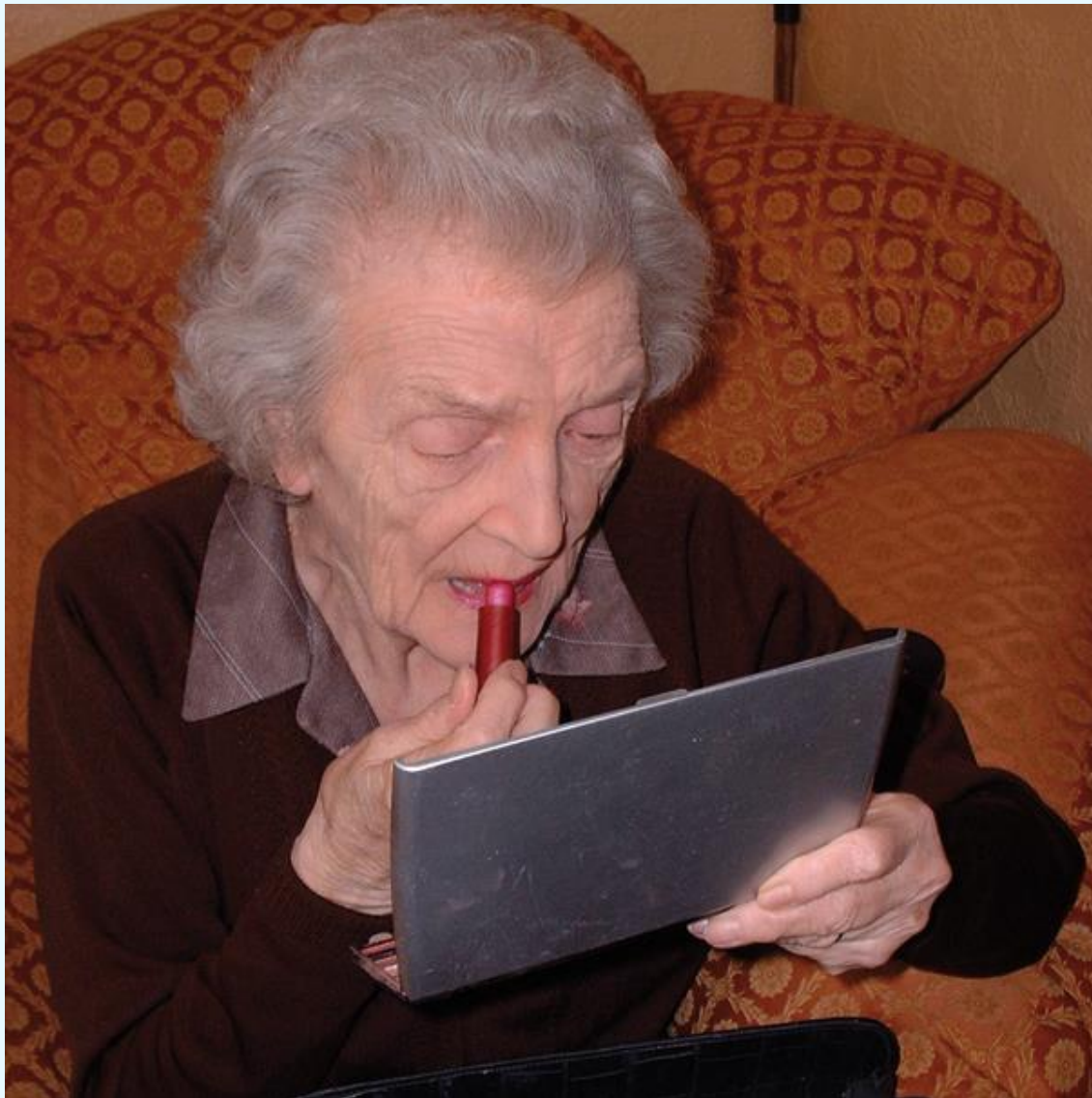
**Having a purpose involves
a lot of will power**



Find the motivation to fight on



Choose how you want to live



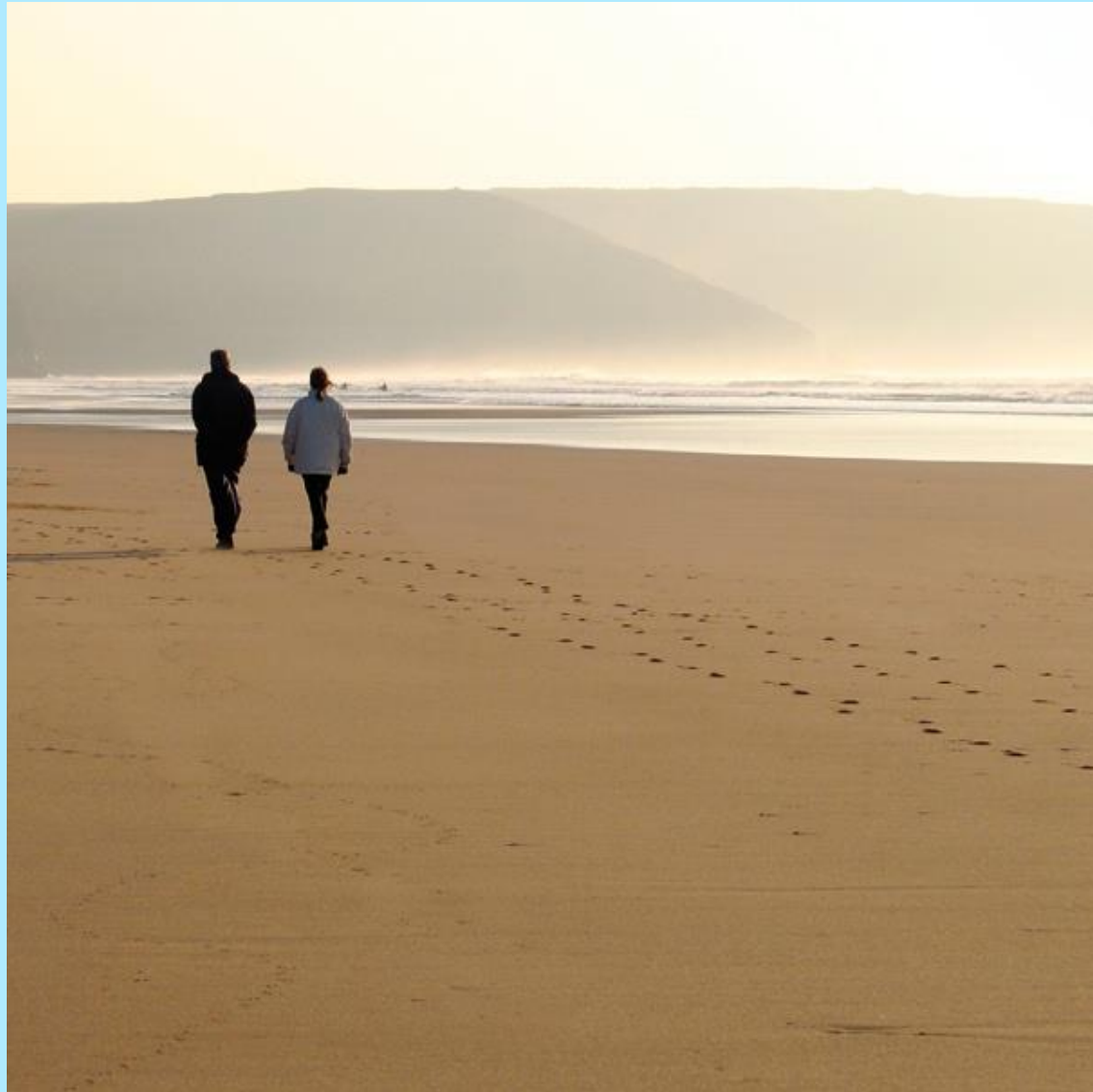
**Feel good about what
is important in life**



Hold onto hope – each journey is individual



Become care partners to weather the storm



**Being supportive involves deciding
on your purpose together**



Closeness is what counts



Dive into the hidden depths – look beneath the surface



Learn about dementia – collect strategies



Become an interpreter, learn the language



Accept someone as they are – embrace their reality



Using logic and reason generally won't work



Being person centred with oneself is important



Leadership is a felt experience



Reflect on your congruence in being person-centred



Breaking down institutional barriers is essential



Start with getting rid of control



Putting together the jigsaw of a person centred approach is a leadership skill



Find in staff the instinctive feeling based stars



Accept no half measures – live your passion



Demonstrate what a person centred approach looks, sounds and feels like



Realising feelings, training and action need to be intertwined



Model as a leader support for emotions at work



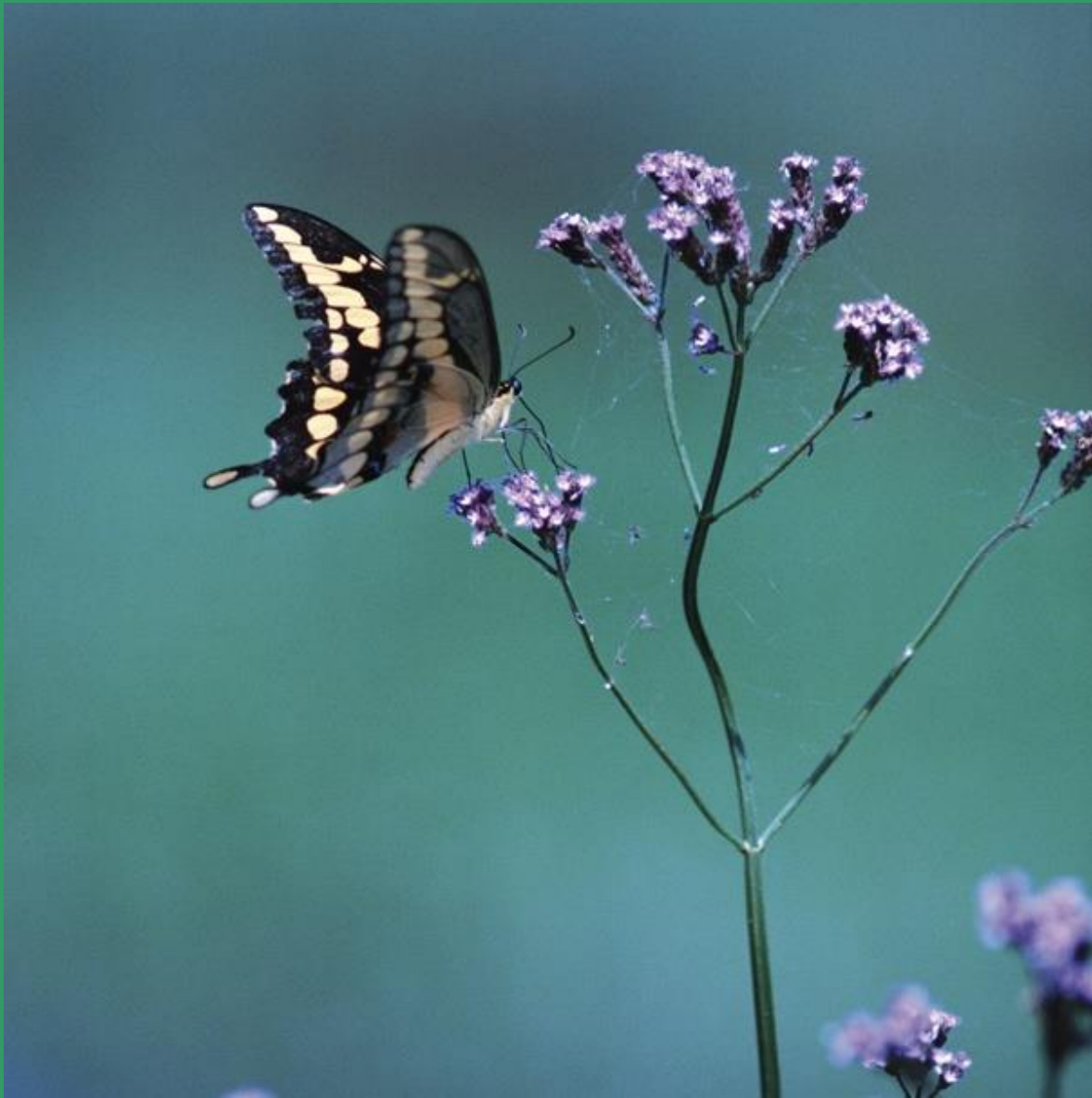
Start with being heartfelt as a person centred worker



Search for the treasure in each individual



Enable people to make sense of themselves



Become like a butterfly – change the moment



Enable first, care second



Make it your purpose to enable others to find purpose



Build close friendships with no barriers



**Be yourself at work and celebrate
the giving of special gifts**



Come to work to be part of a family



Realise it is all about your feelings from now on

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



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 house 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. ”

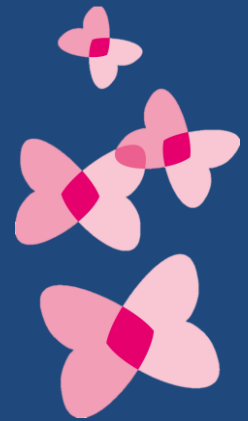


Lyanne Raven
Clinical Team Leader
Alternative Futures Group



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



"Dementiaville : positioning quality of interactions at the Core of Care "



dementiaville



Dementiaville: Poppy Lodge – A BUTTERFLY HOUSEHOLD MODEL™ Care Home

- Rare opportunity to show public what real person centred dementia care looks, sounds and feels like
- Jo-Anne Wilson Matron / General Manager followed DCMs work for over 15 years
- Became a one year Butterfly Care Home Project on opening
- Implements DCM's model of care - the Butterfly Household Model
- Holds DCM's National Quality of Life Butterfly Kitemark



Dementiaville: Key concepts in Butterfly Care Homes

** Billed as controversial in the Dementiaville series*



- bringing out the best in people, accepting people as they are, going with a person's reality
- valuing people's life history and the importance of people's emotional memories
- filling the place up with the stuff of life to prevent emptiness inside people



Dementiaville: The Controversy ? – taking back to specific moments

- **peoples ' behaviour ' not due to symptoms of dementia**
- **people searching from the past to make sense of the now**
- **people searching inside themselves to be who they were**
- **helping people therefore to be who they were as people not always in the present**
- **accepting the language of dementia is not literal**

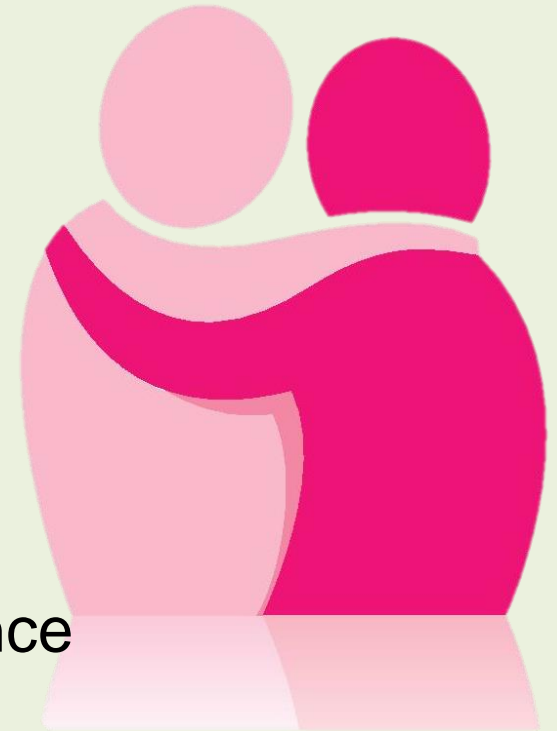


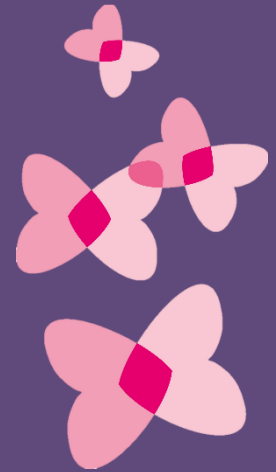
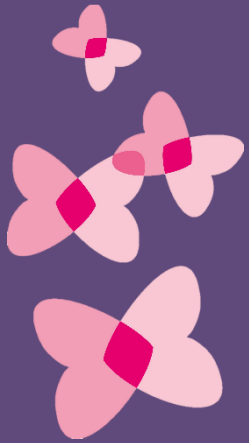


- **focusing on the emotional intelligence in staff to enable people to be reached**
- **removing all signs of an institution and creating households for people to really live in**
- **occupying people with both who they were in the past and living in the moment**

Dementiaville: Basic simple ideas in complex organisations

- dismantling features of an institution
- ensuring no 'them and us' features
- creating family - like relationships
- recruiting staff with emotional intelligence





- **finding staff who know what matters in life**
- **moving away from a disease, symptom behaviour model**
- **believing people are more feeling beings than thinking beings**



- relying not on facts logic or reason
- focusing on emotional connection and quality with a person
- filling the place up as the world shrinks inwards
- establishing closeness of self and the ' stuff ' of life





Dementiaville: Accepting the loss

- leaving past training behind
- going through a pain barrier to accept this approach
- letting go of wanting the person back
- loving someone as they are




Dementiaville: Reaching people

- people show where they are on the bridge of realities
- people seek to be re-found not pushed to the edges of being a person
- people come alive again once their spirit is reached
- people need to shed their mask and feel vulnerability to reach others
- people need to become 'attached' professionals not detached
- people need to want to engage in what is emotional labour



Key messages - Supporting Families

- *people living with a dementia are more feeling beings than thinking beings*
 - *joining a person in their reality involves crossing the bridge into their world loving the person as they are and not trying to 'fix' them as this reduces stress*
 - *focusing on emotional memories is one key to reaching the person on the inside*
 - *helping a person to be who they were and to live in the moment works*
- 



Key messages - Supporting Families

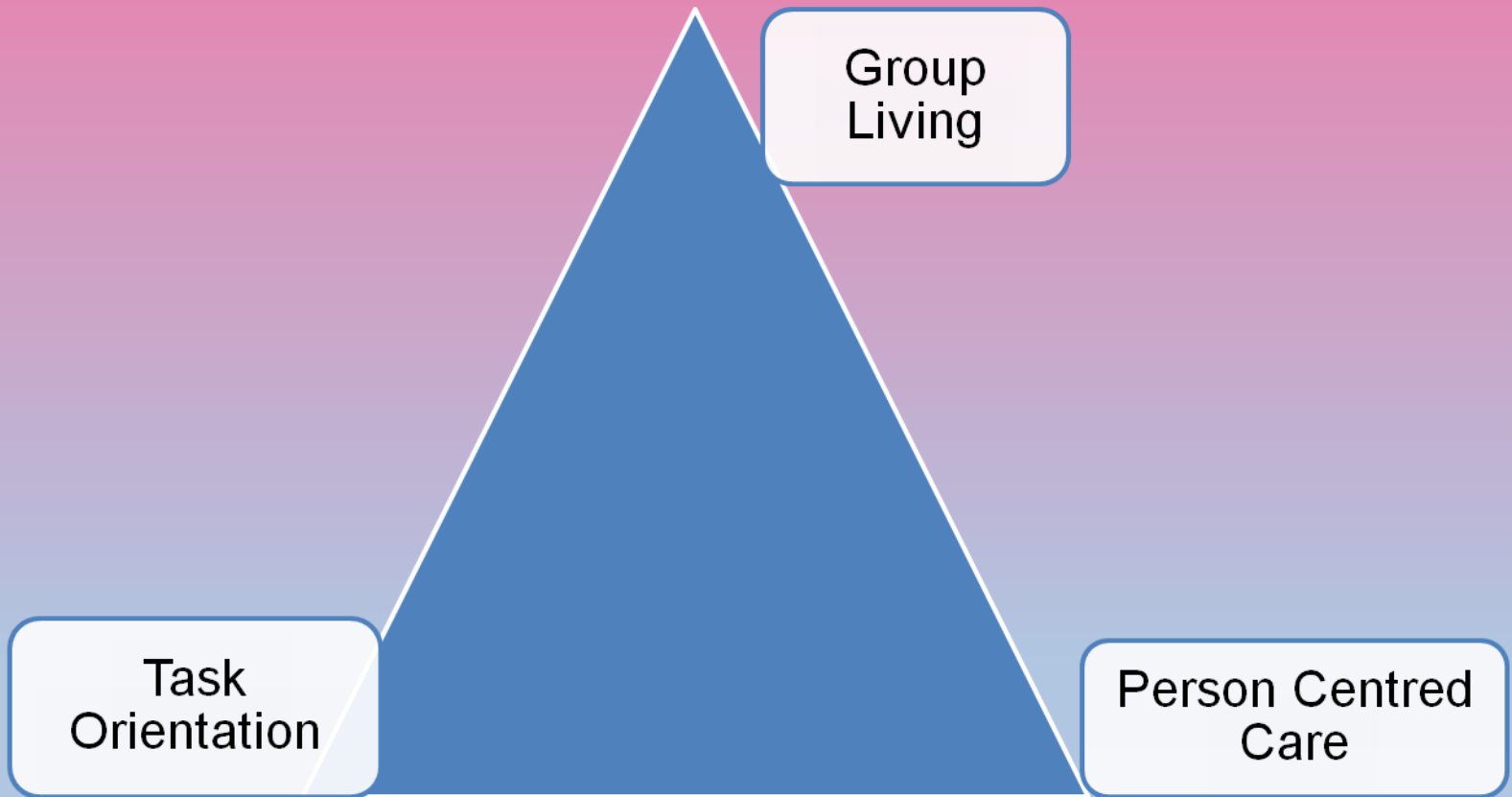
- *everything a person says or does has some meaning and is about a feeling*
- *the person is still there if only we can find them*
- *searching beyond the literal in words or actions to the meaning is important*
- *there are no experts in dementia care it's just about thinking outside of the box*
- *remember you are doing your best and you too are only human.*

Seventh in the **Feelings Matter Most** series

Loving
the essence of being
a butterfly in dementia care

Sally Knocker

The Eternal Triangle



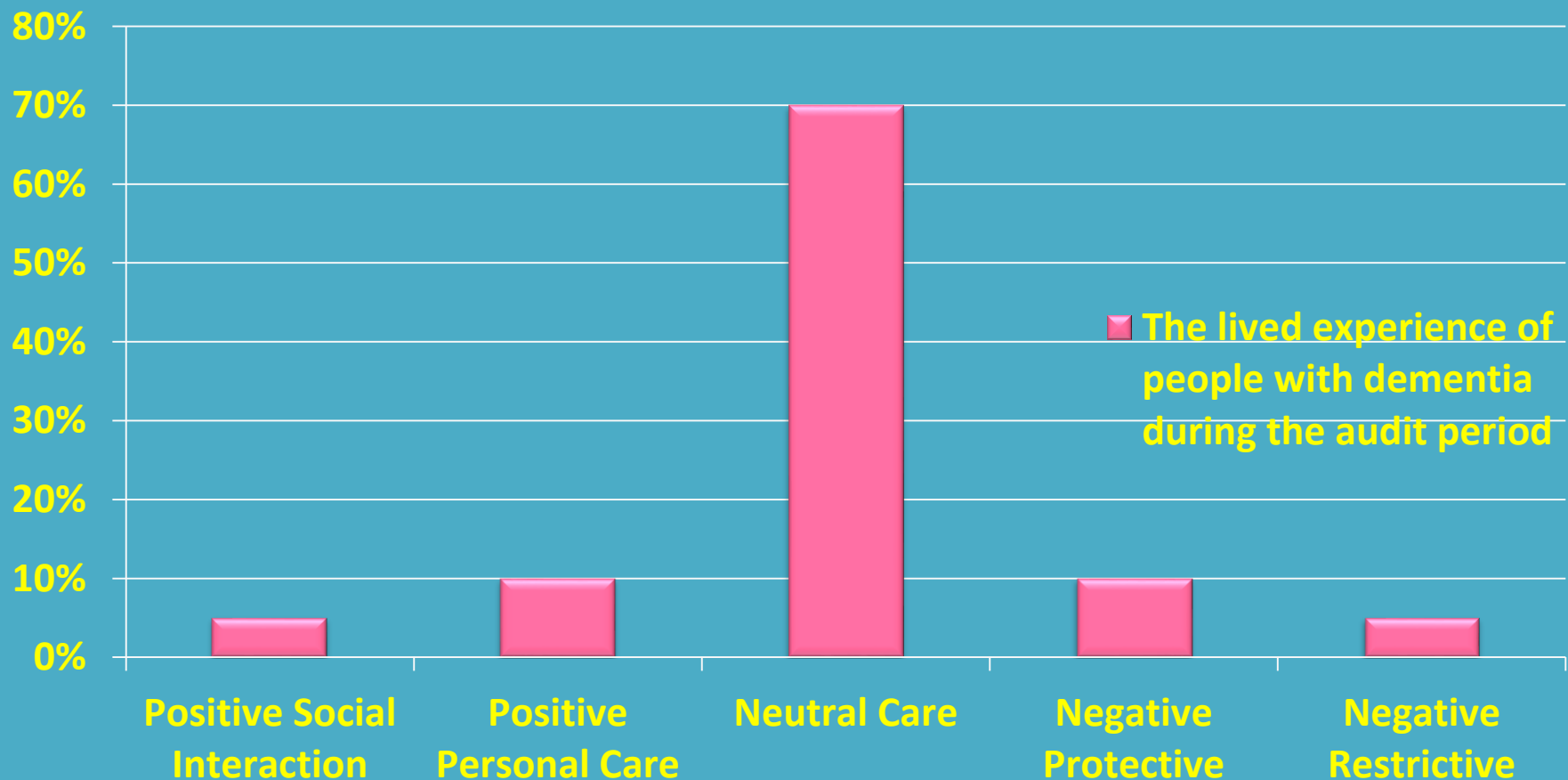




- **Modern leadership and coaching**
- **Quality of life measurement**
- **Energised staff**
- **New model of care**
- **Removal of institutional features and practices**
- **Filled up environments**
- **Meaningful occupation**
- **Compulsion to happen**

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

Average results from 700 Dementia Care Matters audits across the UK

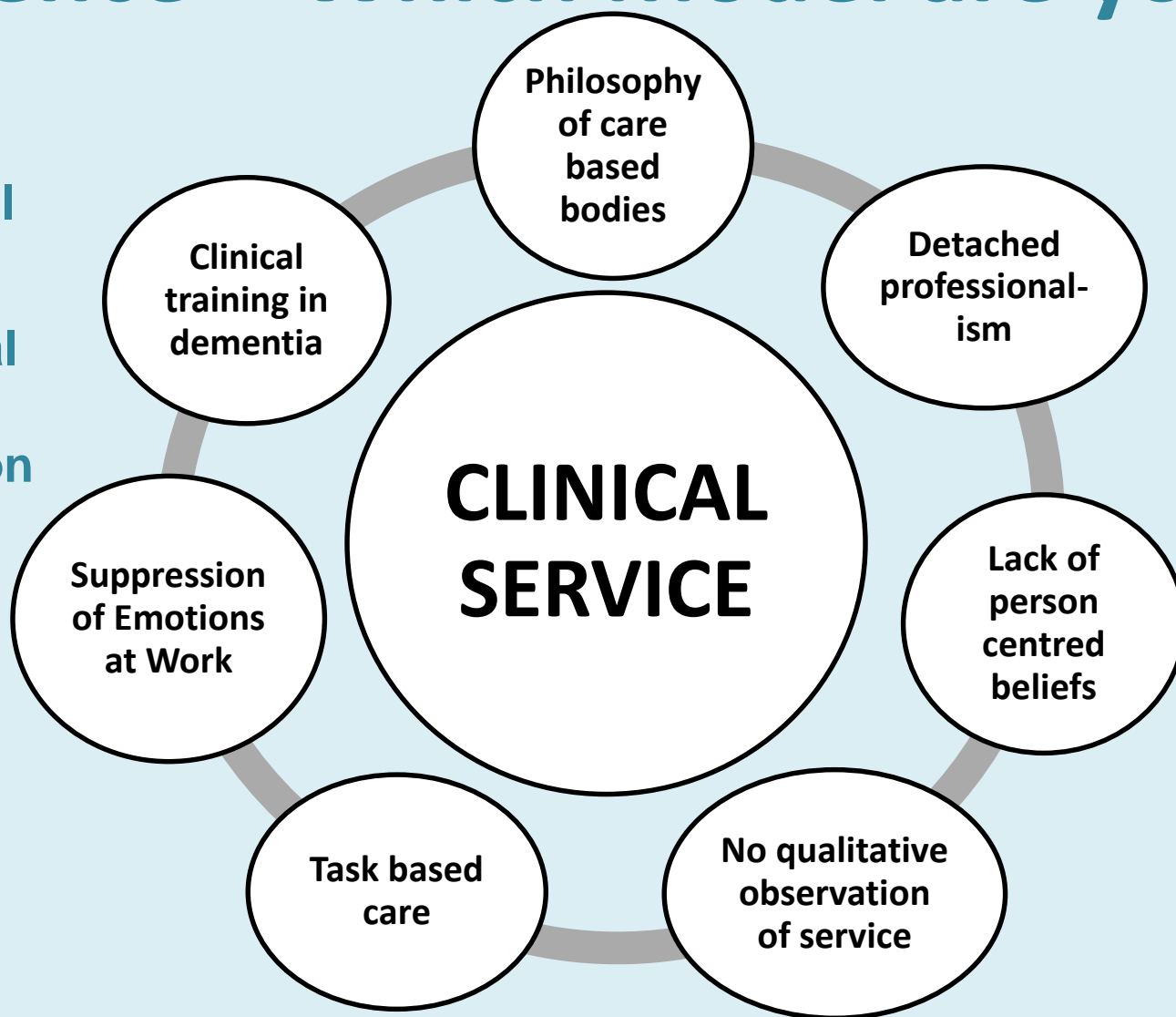


Ref: Dean, Proudfoot & Lindesay: QUIS – Int J of Geriatric Psychiatry Vol 8:819 - 826

Evidence - Which Model are you?

Model 1

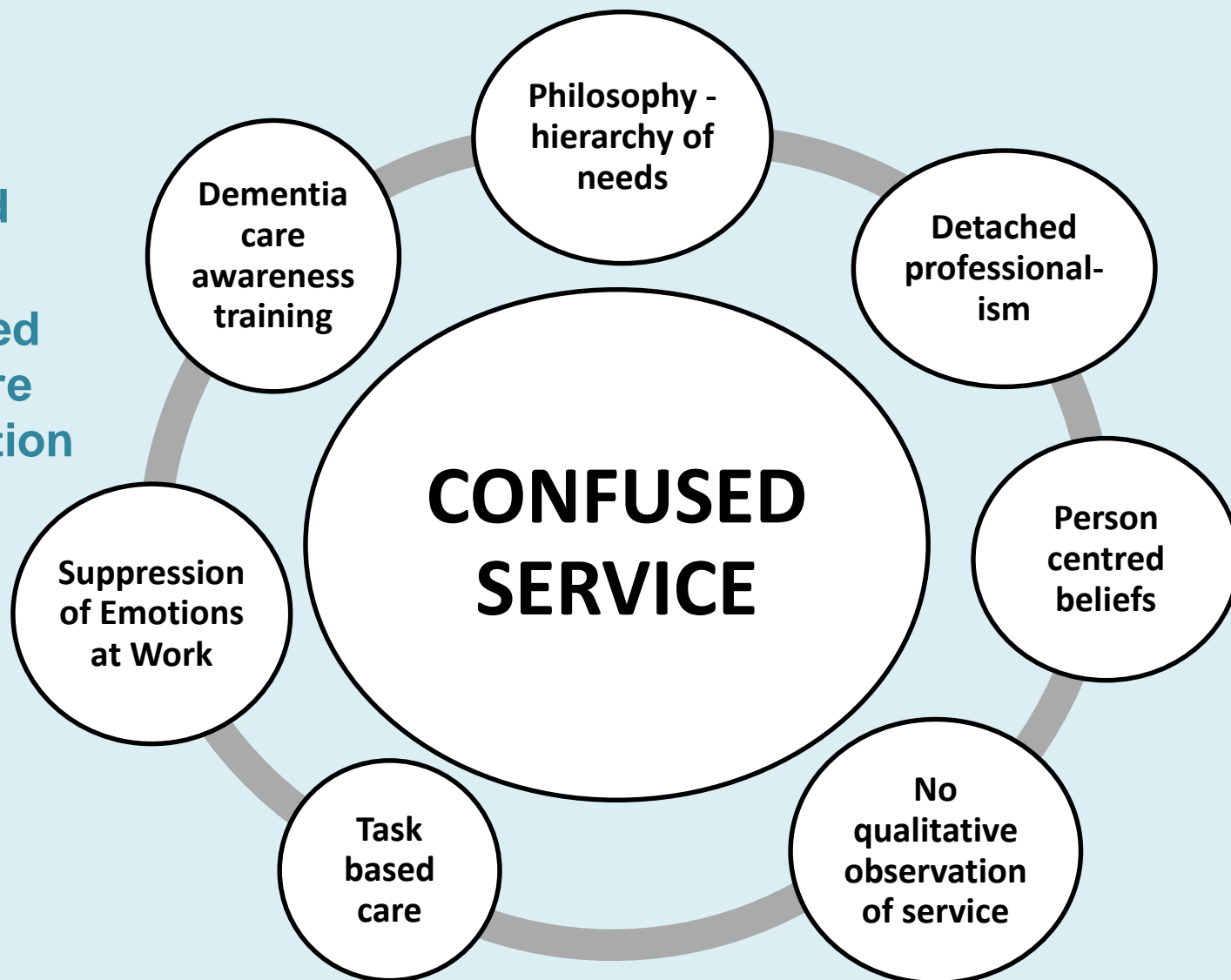
The Clinical Service:
a traditional old culture organisation



Evidence - Which Model are you?

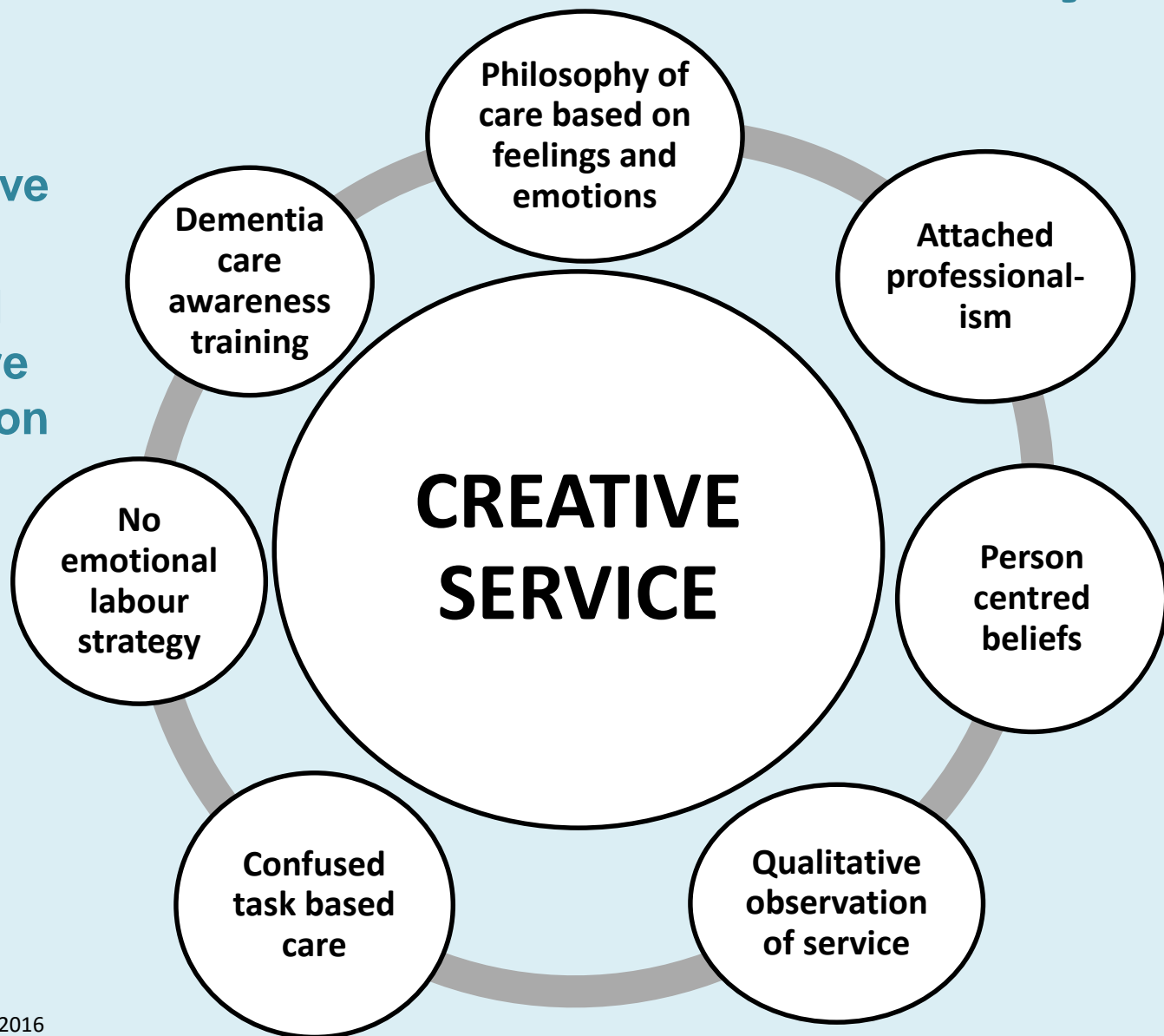
Model 2

The Confused Service:
an adapted old culture organisation



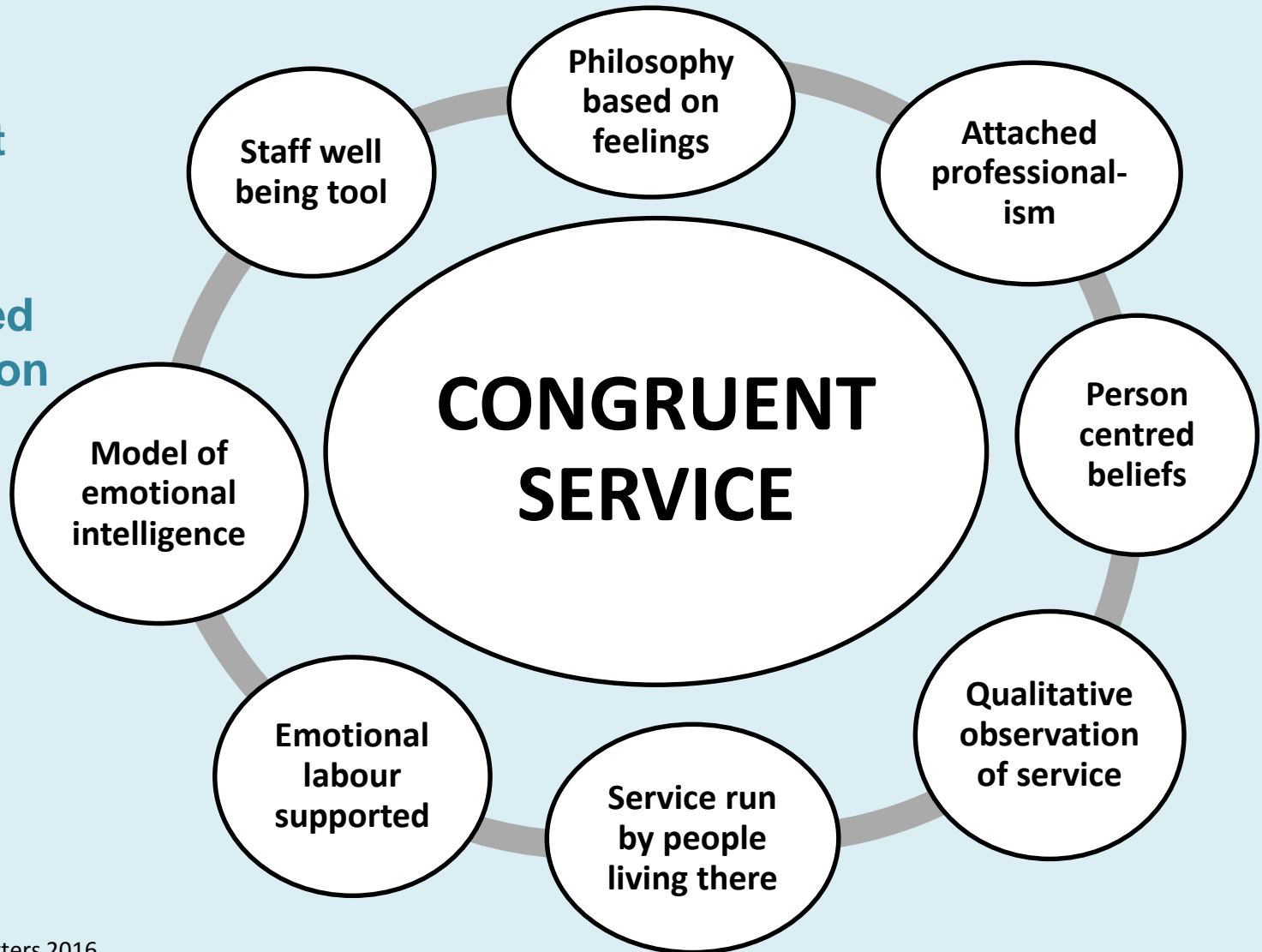
Evidence - Which Model are you?

Model 3
The Creative Service:
a muddled
new culture
organisation

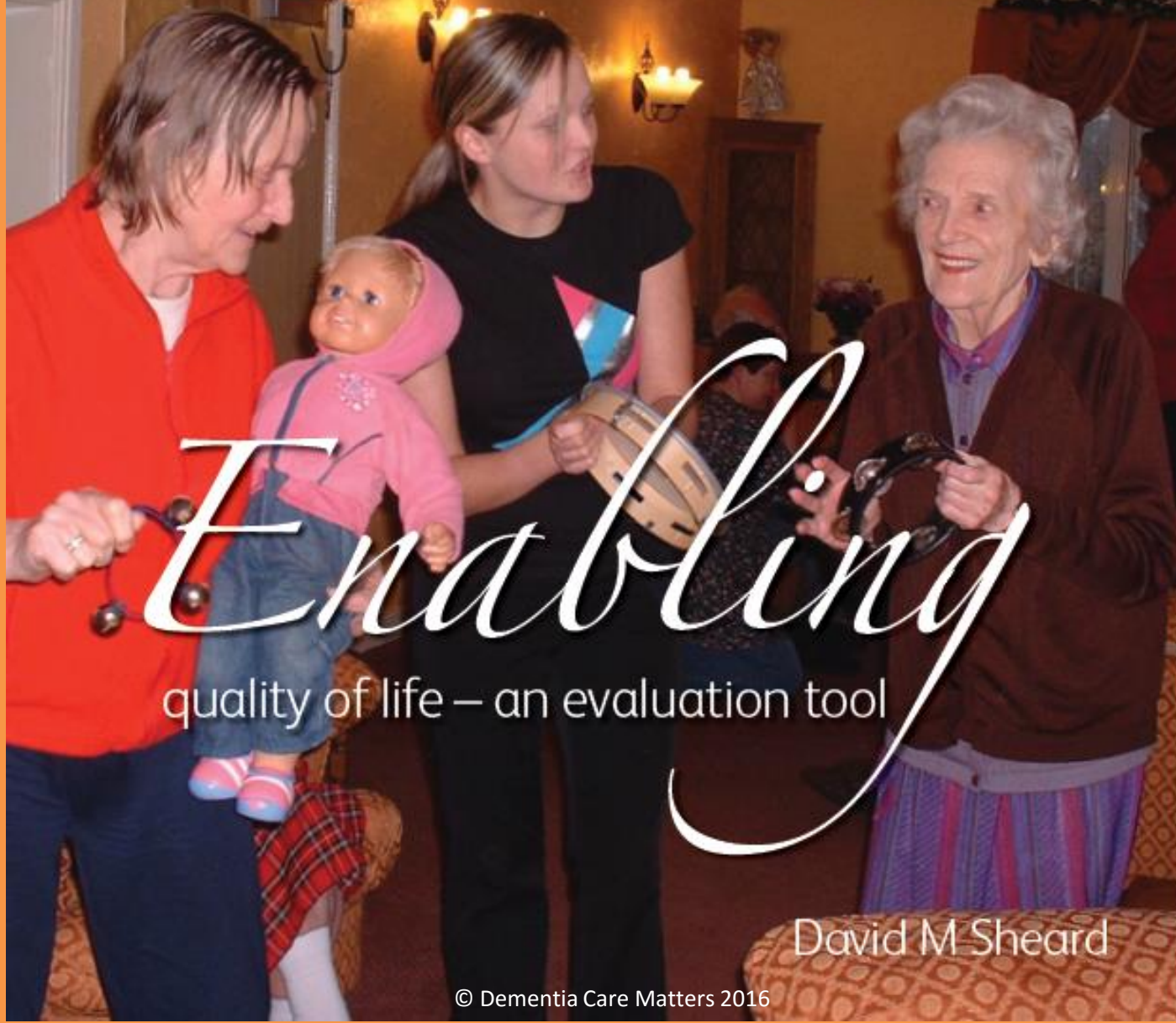


Evidence - Which Model are you?

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



Second in the **Feelings Matter Most** series



Enabling

quality of life – an evaluation tool

David M Sheard



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
dementia care
look,
sound
and
feel like?**





The 'Household Model' identifies three components that support a home:

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

Ref: 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

MAKING TOAST

Positive Social Interaction	Positive Personal Care	Neutral Care	Negative Protective/ Controlling Care	Negative Restrictive Care/Subtle Abuse
<p>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.</p>	<p>Offering to help them butter the toast or asking if they need it cutting up, offering a choice of jam or marmalade.</p>	<p>Just putting the extra toast down in front of the person without speaking.</p>	<p>Sighing, treating it as a bother, talking about them being a nuisance in the room. Telling them they will have to wait for toast as you have other people to 'deal with' and it might be at least 40 minutes.</p>	<p>Telling the person 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 and put on too much weight and they must wait until its lunchtime.</p>

Inspiring

leadership matters
in dementia care



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?"*



Tick one box per item listed below		Yes	No	Partly
Removal of Them & Us Barriers leading to Culture Change				
1.	Uniforms have been removed and staff look like 'best friends and not like nurses in charge.			
2.	All toilets are communal and there are no separate staff toilets.			
3.	Staff do sit to each meals with people with a dementia.			
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.			
5.	There is a relaxed 'go with the flow' feel to the day with no sense of the routines that occur in hospital.			
6.	Evidence can be seen of Managers modelling person centred care 'on the floor' daily.			
7.	Staff see management as feeling based leaders towards them and use words which describe this when talking about managers.			
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.			



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**





“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



Mattering ®

“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*



Real Person-centred Care

“ Its about helping, being their friend, being everything to them.

I cant 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**



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

Can Anyone Fix Dementia Care Homes?

Evelyn: “ I’m not a nice person! ”

PROUD

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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twitter.com/DCmatters