The Art of the Heart in Person-centred Dementia Care.

Introduction and Welcome

Hello, my name is Mike Phillips, an Associate Trainer and Consultant with *Meaningful Care Matters*.

It feels odd not to meet you person-to-person, so before the presentation, I thought I'd introduce myself.

I've been working and training in dementia care for over 15 years: in hospitals, care homes, day centres, nursing homes, domiciliary and home care.

Every time, I ask the question: do you get paid a million pound or dollar bonus every year? I've yet to meet anyone, say yes!

That might seem a flippant question; however, we all know that, sadly, care-work is often under-valued and underpaid. Most, if not all, care-workers I meet, do this work because **they want help others**. In other words, they **do it from the heart**, they want to have **a purpose** and that is to **make a difference in the lives of others**.

At *Meaningful Care Matters*, we believe that if care-workers can **connect on a feelings level** with people with dementia and their carers/relatives, then **true person-centred care is possible**.

I daily meet people in all kinds of settings - from a supermarket to a coffeeshop - who I know would make amazing dementia care workers, because it feels like we **truly connect, person-to-person**.

I've observed care-workers, over the years, who make *meaningful connections with people with dementia* seemingly effortlessly. Not necessarily talkative; they sometimes can be very quiet and reserved. Yet there is something powerful about the quality that care-worker has that enables them to **connect on a feelings level**. Words are unnecessary, *they simply enter the world of the person with dementia and can see it from their perspective*.

Another characteristic I have notice about care-workers who are *truly person-centred*, is that they are willing to *share their own vulnerability*. This often comes from a place within their own life history. They **work from the heart**, because at some time they have felt the *vulnerability, emotional pain or loss that people with dementia often feel*.

Take Sue for example who I met whilst training for *Meaningful Care Matters* – she was a housekeeper in the home and I soon knew that she would make a fantastic **'Butterfly'** as we call them. She was very quiet, incredibly sensitive - and, sadly, very unconfident with low self-esteem.

During our life story session, Sue shared that she had a difficult upbringing (often being criticised as a child and labelled 'fat,' 'stupid' etc. by her mother). This had a profound effect on her life in many ways, she had other tragedies in her life and yet she came across as a survivor.

I had a gut feeling on first meeting with Sue, that despite her lack of confidence, she would be a fantastic dementia care-worker. In other words, my gut reaction was that **she could work from the heart.**

Not all care-workers can work from the heart, however, some just *'do the job.'* Perhaps that is fine – although would you want that if you were living in a dementia in the future? **Remember, none of know what lies ahead of us – one in three people watching this presentation will have dementia if you all live to 80-plus.** So, if we don't like things as they are, we have to be the ones to change them.

Nevertheless, at *Meaningful Care Matters*, **working from the heart is essential** – it's the difference between **doing** person-centred care and '**being' person-centred'**.

This presentation is divided into describing **the brain approach** (knowing the brain, knowing the theory, having the qualifications etc.) and **the heart approach** (bringing our own life story, feelings, empathy and compassion) to create the *'Art of the Heart in Person-centred Dementia Care'*.

If care isn't coming from the heart, I believe, it isn't true person-centred care at all. **We need the passion in our heart to make a difference in the future**.

At *Meaningful Care Matters*, *we encourage all staff to share their life story*. Not to be nosy or intrusive: it simply means that we value everybody's individual story as human beings. When we share those stories, we often find things in common, above all, our shared humanity.

I'm going to share a little of my story, not to be self-indulgent – simply to demonstrate that our personal story is often what helps us to connect on a feelings level with people with dementia and their carer/relatives.

I was born in Wales and, despite what I said earlier, I've actually been working with people with dementia since I was three months old. Yes, three months old. For that was when I first visited a place called The Court – what was then called an Old People's Home, where my grandmother worked as what was then called the Matron.

It was a manor house and I spent much of my childhood there. It had a grand staircase, secret passages, huge grounds with summer houses and a priest hole. In other words, a great place for a kid to explore.

I would arrive soon after breakfast most mornings and insist on giving a concert (I'm not sure if the residents wanted one, looking back), I was the de facto Entertainments Officer!

Even better for me, was the people that lived there:

- Mr Nurton who had a shrapnel wound from World War I, causing a huge lump on his head

- Miss Drayton who was blind and deaf who I'd sit with for hours, writing messages on each other's hand
- Mrs Schofield who was approaching 100 and would ask me to get her apples from the shop – she'd run upstairs to get the money and run back down – today she wouldn't be allowed to as it would be seen as too much of a risk.

And then there was one lady whose name, sadly, I can't seem to remember. Yet I remember her well. I remember running into the lobby of the grand house and she was sat sadly with a suitcase. She looked so lonely, sad and almost afraid. I pestered the care-workers about where she was going. One finally told me "She's gone to Whitchurch." In later years I realised that 'Whitchurch' was then the local asylum, the place where people with dementia were sent away to be forgotten.

My Dad as I grew up had long periods of mental health problems, so I saw what it was like to be on the inside on the rare times he was allowed visitors.

I share these parts of my life, not because my life experiences are more dramatic than other people's (although I've had a few traumas in my life). Each person's story is unique – no better or worse than the next person.

Yet we all have life experiences that can help us connect with people with dementia.

So, welcome to *'The Art of the Heart in Person-centred Dementia Care'*

Setting the scene

About this Module

The theme for this module is 'The Art of the Heart in Person-centred Care.' Please read through the **Meaningful Reflections Learning Journal** before you start your learning journey.

The module is self-directed, so you can complete each segment and relevant section of the journal in the order that you wish, these include:

- Segment 1: **Listening/watching this presentation: "The Art of the Heart in Person-centred Dementia Care"**
- Segment 2: **Reading *Meaningful Words* (a selection of articles and other writing relating to the theme)**
- Segment 3: **Listen/watch *Meaningful Sights and Sounds* (specially selected multi-media relating to the theme)**
- Segment 4: ***Learning into Practice* (Completing a project to strengthen your learning and put it into practice)**

Learning Outcomes

By the end of this presentation you will be able to:

☑ List words and phrases associated with the words 'brain' and heart.'
☑ Explore various definitions for person-centred care
☑ Describe the origins of person-centred dementia care and at least 4 models of dementia care as they have emerged over time
☑ Distinguish between working from the brain and working from the heart in dementia care
☑ Describe the barriers to person-centred dementia care
☑ Recognise the toxic words and labels, toxic environments and malignant social psychology that still exist in dementia care

- ☑ Name 5 personal enhancers and 5 personal detractors, as described by Tom Kitwood.
- ☑ Explain the elements of caring from the heart
- ☑ Discuss the elements of leading from the heart

The brain and the heart: or hearts and minds?

So, let's think about the brain. Take a moment to think about the words and phrases that come to mind……

Perhaps you came up with some of these words….

I wonder what words you'd list, if I said: "Write the words you'd associate with the brain in dementia care" and "Words you'd associate with the heart in Dementia care?" Don't worry I'm not going to ask you to do it again!

However, I believe that this is one of key conflicts in achieving true person-centred dementia care. Whilst things on the left (the brain/logic stuff) is undeniably important. It can get in the way of the ***heart in person-centred care***.

Let's not forget, that people with dementia are often robbed of cognitive skills: logic, memory, understanding and what we perceive as reality.

Their experience is much more feelings based. Therefore, **our approaches must come from the heart**: we need to provide compassion, acceptance, love and empathy.

First, we need to revisit the brain stuff, the theory of person-centred care to truly feel and work from the heart.

Whilst qualifications and knowledge are important, **just knowing it, doesn't mean we can do it – or more importantly, be it**! Just think of those teachers you had in school that knew all the facts and figures, etc. However, they couldn't make the topic interesting, exciting and manage a classroom.

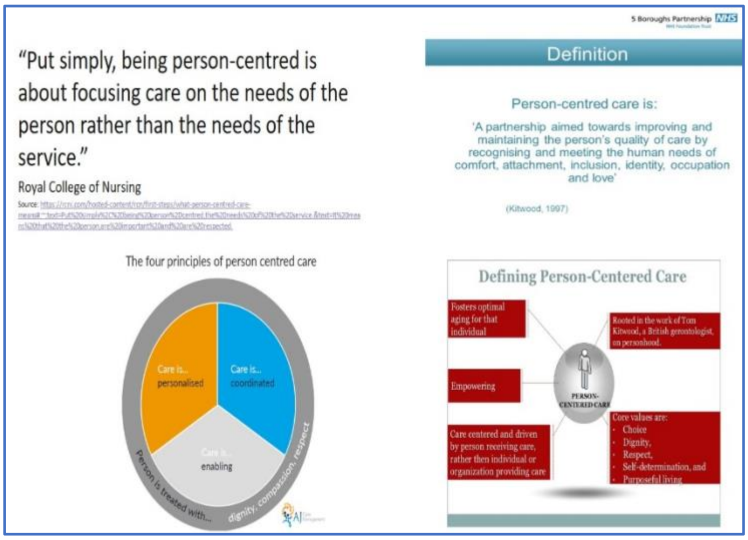
Exploring Person-centred Care: An Overview

It is even within my lifetime that people with dementia, were sent away to asylums, later called mental hospitals to be locked away, unseen and forgotten. These institutions were little short of prisons, often physically remote, austere buildings, with 'inmates' often sleeping with many others in impersonal dormitories. It wasn't unusual for the inmates to have their clothes swapped and to suffer many indignities and, at worst verbal, sexual and physical abuse.

It was to such a place that the lady I remember as a child was being taken to. I look back in horror at what might have been her fate.

Definitions

There are *many definitions of person-centred care* and a tendency for person-centred care to mean different things to different people.



"Put simply, being person-centred is about focusing care on the needs of the person rather than the needs of the service."

Royal College of Nursing

Source: [illegible]

The four principles of person centred care

5 Boroughs Partnership NHS

Definition

Person-centred care is:

'A partnership aimed towards improving and maintaining the person's quality of care by recognising and meeting the human needs of comfort, attachment, inclusion, identity, occupation and love'

(Kitwood, 1997)

Defining Person-Centered Care

Many of us use the words person-centred care, many care providers use them in their promotional materials.

However, as Dawn Brooker writes: *"although the words sound good, the lived experience of care for people with dementia – particularly for those living in long-term care – is anything but person-centred."*

Person-centred Dementia Care Theories

The origins of person-centred care come from the work of the psychologist **Carl Rogers** who introduced his ideas of **empathy**, **congruence** and **unconditional positive regard**.

The term Person-centred Care was first used in dementia care by Tom Kitwood in 1988, in many ways the **father of person-centred dementia care**. Although the mental institutions were starting to see their demise; there was still very much a focus on the **medical model of care**.

At the same time, people with disabilities were campaigning for change - away from the medical model of disability to the **social model of disability**.

By 1997, with **'Dementia Reconsidered,'** Tom Kitwood had written extensively and introduced to two models with which many of you will be familiar. **Tom's equation** helped us to understand that the experience of a person with dementia, is not just influenced by their Neurological Impairment, but many other factors.

Crucially what he calls – the **social psychology** – how others perceive us and treat us - can have a huge impact on the person with dementia.

Person-centred care is simply just that, putting the person with dementia at the centre of what we do, requiring us to **see the world from the perspective** of the person with dementia.

His psychological needs of people with dementia model (often called the flower), could in many ways be seen as universal: all of us have a need for comfort, we all need occupation (a feeling of having a purpose and worth) and in life we all become attached to people and things in different ways. For example, I have many pens, however, when my father died, it was important that I had his fountain pen, as it always reminds me of him – that's **attachment**.

This informed the transformation agenda and many person-centred care models since. There are many of these, so I will select three more.

At the core of Tom Kitwood's work is that we should treat each person, not only as we would want to be treated, but also recognising that every person is unique and valuable. As he said himself:

"When you've met one person with dementia, you've met one person with dementia."

Building on her work with Tom, Dawn Brooker introduced the **VIPS Model.**

The **Senses Model**, is a **Relationship Centred Care Model**, extending these principles to, not just people with dementia, but also relatives and staff themselves.

Finally, the SPACE Model was developed by the Royal College of Nursing, particularly focussing on hospital care.

So, there are many models of person-centred care. Observational tools such as Dementia Care Mapping and *Meaningful Care Matters* QUIS have evolved to assess the impact of person-centred dementia care and the lived experience of people with dementia.

Indeed, people with dementia themselves and carers, are now strongly advocating for themselves as **Experts by Experience**. One of those voices is Christine Bryden.

The Brain in Care

Before we come to the art of the heart in person-centred care. I'd like to take some time to focus on **the brain in care**. For I believe that *it's our brain that sometimes gets in the way of the heart in person-centred dementia care*.

The Brain in Care: Knowing Dementia

Traditional training tends to focus on the brain, the different diseases and disorders of the brain that fall under the umbrella term 'dementia' and the various signs and symptoms.

I'm not saying that knowing these things are not important, however, does that knowledge really improve person-centred care?

Of course, **it's helpful for us to have some basic knowledge of the brain**, and how it may be affected by the type or types of dementia a person has. I have had many conversations with staff, activity workers and relatives where they complain about the fact that they can't motivate a person with dementia to get involved with an activity they want them to engage with.

Knowing that when the front lobes of the brain, if malfunctioning, can cause a lack of motivation to do things, might help.

However, if we work from the heart and feelings, it is equally likely that the person is unmotivated because they are bored, perhaps they don't feel like being with a group of people at this time, or perhaps the activity is beyond their current capability, which increases their feeling on failure and sadness.

A recent example was a friend who wanted his mother to play scrabble, not realising that she was unable to follow the game as well as she used to. However, recognising Kitwood **identity** petal, my friend used it as an opportunity to talk about her late husband with whom she regularly played the game. Getting the words spelled correctly was secondary to boosting her feeling of identity. As a result, she did better than she expected. After the game she felt validated and much happier. My friend kept **focussing on what she able to do rather that what she was unable to do**.

The Brain in Care: Systems, Policies and Procedures

The logic of systems, structures, policies and procedures, are as important as knowledge.

- Care Plans and other Processes
- Control versus Freedom
- Corporate Image, philosophy and Business Demands
- Day-to-day operations: getting up, mealtimes, what time people go to bed.
- National Care and Inspection Standards
- Policies: infection control and safeguarding Infection Control

I believe that all of these are important. Though again, I ask, **do they improve the quality of life for residents?** Often, they are about our logic and we expect people with dementia to fit within them, often reducing their freedoms as a result.

I've been to many a luxury/corporate image care homes – stunning – alike to a 5-star hotel; yet, there's **no heart and soul**.

I don't know about you, but whenever I've been lucky enough to stay in a lovely hotel, no matter how luxurious, I eventually wanted to **go home**.

And there's many a hotel in which I've passed my room lost amongst the similarly anonymous doors which all look the same.

I remember one such care home, I call them the **"fur coat and no knickers"** type. Beautiful website and glossy brochures espousing their commitment to person-centred care. It was immaculate (a hairdressers, a cinema room, a restaurant-style dining room) – all empty! The people who lived there either **stayed in their rooms** or were at the door wanting to **go home**.

What does that say? For me, there was no heart to the place, despite the best efforts of the care-workers and the place looking like The Ritz. It simply **didn't feel like home**.

Take Angela, a very experienced, very person-centred care home manager who told me this:

> - *"It's a common experience in care home management. In their hearts, managers know what equals a good lifestyle for people living within their care. But their head overrules them because… I don't know.*
>
> - *Some are definitely driven by ambition and financial reward - owners value high company achievers. The managers who make money and have good ratings. Regulators like to see nice shiny care plans, tidy, all well-organised on a shelf, which they believe translates to a good experience for the person whose care plan it is.*
>
> - *Some years ago, as a manager of a care home, where I can honestly say our people were truly loved, I was instructed to sort out the care plans. The care plans were up to date albeit lots of the pages had hand-written additions. Some of the plans were rather tatty looking and that was because they were frequently picked up and used. The team members could have sat themselves at a computer every shift and written page updates but instead of that they spent time with our people.*
>
> - *I was instructed by my boss to rewrite all the care plans and put them into shiny new folders. This presented a good picture to regulators. But was that a sign of good quality care or quality of life for the people with dementia?"s*

Patience, a visionary and enthusiastic leader told me:

> - *"We'd turned a big open space into a lovely village green, with a pub, hair salon, fruit and veg stall (where our residents would collect the vegetables to make soup together for the evening meal), a sweetshop and a chemist. It was great and residents and relatives were involved in creating it.*
>
> - *Someone came from Head Office and hated it. They said: "What if the people with dementia drink the shampoo? What if they touch the vegetables and pass on infections? What if they pick up a sweet and choke on it? I know it's important to manage risk, I really do. However, I felt like all our efforts had gone to waste. We had worked hard to create a meaningful and engaging environment and all he could think of was the potential harm, rather than the good it was giving people. The residents loved it and now it has to be taken away."*

I was once in a care home, doing some Dementia Care Mapping. I noticed that one-by-one from 4p.m., the people with dementia would leave the main lounge and return in their bedclothes. I enquired why? The answer: *"it makes it easier for the night shif"t.* Where was the **choice**, where was the **freedom** for the people **whose home it was**?

In the same home, I observed residents being served tea from a huge teapot – milk already added, - whether individuals wanted milk or not.

I could give so many more examples. The point I wish to make is we **work in homes of people with dementia**, we should fit around them; not them have to fit into our policies, procedures and systems which come from our brains – not their feelings.

The Brain: Working from our World Reality and Logic

Years ago, I was training at a hospital on the topic of behaviour and dementia. We had talked about **seeing things from the perspective of people living with dementia** and that **all behaviour has meaning** – usually as an expression of how they are **feeling**.

At the next session, a few people told me that the techniques we'd discussed had been helpful. Then, one nurse said: *"I'm worried about one patient though. She's non-compliant with personal care."* I bristled slightly at the word non-compliant, so I asked: *"So how have you been responding to her, what sort of things have you said?"* The nurse replied: *"Well we've tried to be patient with her and reason with her"*. I explained, *"we just want to clean you up, you've made a mess of yourself and you're all dirty."*

I gently, questioned the nurse concerned: *"I appreciate you're trying your best. So, let's imagine that, for whatever reason, you had a bad stomach and you'd been incontinent because you couldn't get to the toilet in time. How would you feel if somebody told you that you had 'made a mess' and that you were 'dirty?' Honestly, how would you feel in your heart? The nurse quietly responded: "I'd feel humiliated and ashamed."*

- You may see several things in this picture.
- A perception is just that, it isn't necessarily reality.
- Yet our brains are hardwired to think that our perception is the right and only way of seeing things.

My next question was: *"So, how might your response to this woman have been unhelpful?"*

I hope she understood. Sometimes **our words can make people with dementia feel worse**. Firstly, because we are trying to **force them to see our logic and perspective**, rather than **theirs**. Secondly, because **our words can unintentionally reinforce the acutely negative feelings they are experiencing**.

Barriers against the Art of the Heart in Person-centred Dementia Care

There continue to be many barriers to person-centred dementia care, ranging from poor leadership, staff-turnover to poor pay and recognition of front-line care workers.

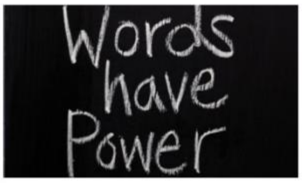
- Financial and other resources
- Form filling and 'red tape'
- Lack of consistent care-workers
- Lack of leadership by the senior manager (head office)
- Lack of staff consultation and poor communication in implementing change
- Lack of time to engage in meaningful ways
- Lack of understanding of person-centred care and how to implement it = continued focus on task-centred care
- Learning and training opportunities for staff
- Poor pay and recognition of the value of care-workers
- Regulations, policies and procedures
- Staff shortages and reliance on 'agency' staff
- Staff turnover and difficulties recruiting staff
- The apathy and inflexibility of some front-line staff
- Time and task-focussed commissioning practices
- Time and work-pressures leading to task-orientation appears as a significant barrier to sustaining relationships
- Time pressure and conflicting demands on this time

The Words We Use - A Toxic and Socially Malignant Language

Words have power. Anyone who comes from a marginalised community: women, indigenous peoples, Black and Ethnic Minorities, the LGBT community, people of faith and people with disabilities can **empathise** with this. They all have experiences of having language used against them, to create stigma, discrimination and, sadly in some cases, hatred and violence. These people know how **words can disempower**.

- Words have power
- Can create stigma
- Dehumanise
- Create a them and us – 'othering'
- At the most extreme can lead to abuse

In 1963 Erving Goffman referred to stigma as "spoiled identity."



Personally, being diagnosed HIV+ 30 years ago, I've experienced this: we were described as 'victims,' suffers, 'dirty,' 'riddled' etc. We were exposed to conspiracy theories, stories of fake miraculous cures, stigma and hatred. People thought they could 'catch' HIV just by sharing a mug or cutlery with us. No different to staff using different cups to people with dementia today.

- **Dementia clients/patients/residents**
- **Dementia people**
- **"Frank is an attention-seeker"**
- **"Mary is aggressive"**
- **"Maggie isn't the person she used to be"**
- **"Mr Khan can't communicate with us...verbally...properly"**
- **"Mr O'Sullivan is non-compliant with his medication/personal care again"**
- **"She doesn't understand"**
- **"She isn't with us any more"**
- **"We've got to change you Mrs Simpson – you've made a mess again."**
- **Challenging Behaviour**
- **Feeding**
- **Toileting**
- **Wanderer**

That's why I can empathise with people with dementia and their carers: media around the world used phrases like *'victim'* and *'sufferer,'* promoting **conspiracy theories** and **miracle cures.** Today, in the language of care, there are phrases like *'dementia people'*, *'demented,' 'wanderer,'* or *'room 24 is in need of 'toileting'* etc. This simply serves to **dehumanise people**.

Often on training courses, I ask learners to raise their hand if they have the word 'care' in their job title or involved in 'care work' – most do. Then, I ask people to raise their hand if they have the word *'butcher'* in their job title. Nobody does.

That's because **butchers move around dead lumps of meat**. Those is health and social care work are involved in **caring for fellow human beings**. So why is it that some, and I admit they are a minority, treat the people they work with like they are dead lumps of meat?

I know the vast majority don't – I've met some incredible doctors, nurses, care-workers, cleaners, gardeners and others who **really understand what working from the heart in dementia care means**.

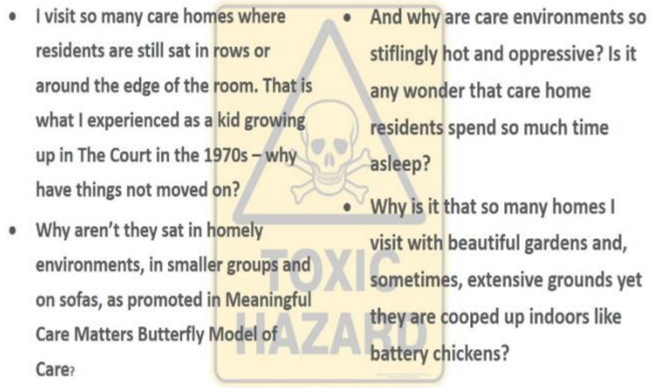
However, **when a minority of care staff don't treat people in their care as if they are equal human-beings deserving of respect, dignity and love**, this results in two things:

- **The needs of the person (a fellow human being) are neglected**
- **Emotional, psychological, financial, sexual and physical abuse is a possible**

True, **this is rare and the extreme**. Nevertheless, once the language we use to describe the vulnerable and people with dementia becomes **dehumanising** and we label them as **'other,'** then we are ignoring the fact that those people are fellow human beings – **no different** – no better or worse - **than us**.

Language is important. Thankfully, around the world, there are efforts being made to reassess the language that we use in dementia care. Interestingly, this is often led by people with dementia themselves, in the same way that people with HIV/Aids fought against poor language and stereotypes from the 1980s onwards.

Toxic Physical Environments



- I visit so many care homes where residents are still sat in rows or around the edge of the room. That is what I experienced as a kid growing up in The Court in the 1970s – why have things not moved on?
- Why aren't they sat in homely environments, in smaller groups and on sofas, as promoted in Meaningful Care Matters Butterfly Model of Care?
- And why are care environments so stiflingly hot and oppressive? Is it any wonder that care home residents spend so much time asleep?
- Why is it that so many homes I visit with beautiful gardens and, sometimes, extensive grounds yet they are cooped up indoors like battery chickens?

Sadly, I visit so many care homes where residents are **still <u>sat in rows or around the edge of the room</u>**. That is what I experienced as a kid growing up in The Court in the 1970s – why have things not moved on?

Why are there still so many Toxic Physical Environments?

Malignant Social Psychology

It's many years since Tom Kitwood described **'Personal Enhancers'** and **'Personal Detractors.'** I hugely respect his messages. However, the language perhaps provides a barrier to his true message. Using the words **'Personal Detractors,'** he was simply **describing toxic care behaviours**.

When I first read about Malignant Social Psychology, I thought words like such as 'Infantilisation' and 'treachery' seemed extreme. Then I saw them played out before me during a Dementia Care Mapping observation. Two hours spent in the lounge, with a group of women with dementia watching diving on the television – all experiencing well-being.

Time came for the evening meal (so I discreely observed from a corner in the dining room) and the demeanour of one woman, May, visibly changed dramatically. By the time she was sat in the dining room, her shoulders and facial muscles were tense. As the residents were awaiting the arrival of the meal – May looked increasing anxious. Then there was a clattering of a medication trolley, pushed by the Team Leader into the dining area. May, by this stage, was looking increasingly distressed.

Faith, the team leader, went around the room saying: "Here's your medication darling." She spoke across the room to May – "now don't you give me any trouble today, May, you know what you're like." I was becoming concerned as Faith approached May: "Come on, be a good girl and take your sweeties, you know they are good for you. Take your sweeties." By this point, May had grown increasingly distressed, she had stood up. Breaking with the anonymity of the observation, Faith said across the room to me: “She’s aggressive you know, I think it’s because she’s racist.”

I don’t know if May was racist or not. However, what I observed, was a team leader that had made May’s anxiety so much worse – she didn’t even eat her meal. Racism against staff is wrong and unacceptable, yet I couldn’t help thinking that Faith’s approach was unhelpful and caused the problem.

- If May didn’t like taking her mediation in public; why couldn’t she have taken it in private (either before or after the meal)?
- The noise of the trolley was obviously a trigger? Was it necessary?
- There were so many ways in which Faith could have altered her approach? (So many examples of Kitwood’s ‘personal detractors’ were on display). How could she have done things differently?
- Why had May been blamed for the problem? The situation could have been changed so much easier then trying to force May into such a difficult position.

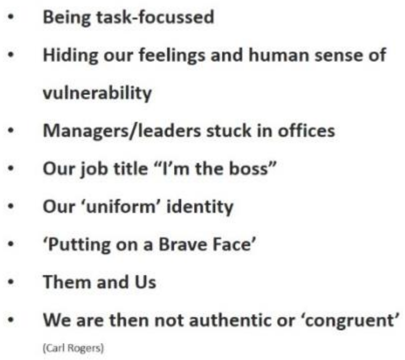
The Task is the Mask

Through the Covid-19 pandemic, we learned that having to wear masks **creates a barrier** between ourselves and others – **reducing the opportunity for meaningful connection**. Obviously, wearing masks and PPE was crucial to protecting lives.

Yet in 2010 David Sheard talked about “the mask of the task.” His premise is that we hide behind masks including the mask of the task, rather than connect as one human being to another.

Despite all the years since Tom Kitwood talked about person-centred care, there are still too many who are **task-focussed** rather than **person-focussed**.

There are so many masks we wear, including what David Sheard called **'detached professionalism'** that get in the way of meaningful connection with people with dementia from the heart. I despair at the number of staff on training who say 'we can't talk about our personal life: it's professional boundaries.'



- Being task-focussed
- Hiding our feelings and human sense of vulnerability
- Managers/leaders stuck in offices
- Our job title "I'm the boss"
- Our 'uniform' identity
- 'Putting on a Brave Face'
- Them and Us
- We are then not authentic or 'congruent'

(Carl Rogers)

Of course, boundaries are important. Nevertheless, **we cannot connect with people with dementia unless we share some of ourselves**: what the kids are doing in school, the programme we watched on TV last night, our upcoming wedding, our team won at the weekend, the fact we feel sad today because our pet has died. **None of these things should be 'off the table'** – they are part of our everyday lives. People with dementia, from my experience, are feelings-based, they know when we are feeling happy or sad, **for feelings are their new vocabulary**.

Of course, it wouldn't be right to unburden them with our problems. However, **boundaries are often seen from our logic of absolutes**, things are either right or wrong, when that is not the reality of life – **there is always more than one perspective**.

These masks only serve to create a **'them and us'** – othering. In reality, we share the same humanity with people with dementia, they are the same us, **so why do we create barriers between us? Is it to make ourselves feel better or superior?**

So, think about the masks that you wear and why? As a nurse once said to me, realising her uniform was a form of mask: *"I'm so scared to stop wearing a uniform. I studied all those years so that I can wear this. It's who I am?"*

The Art of the Heart in Person-Centre Care

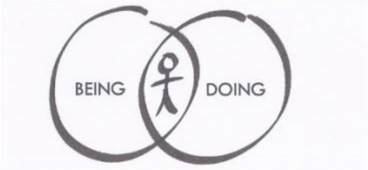
Start with Becoming a Human Being Again

In our modern society with busy home and work lives (why is it called work-life balance and not life-work balance?) we have so many pressures:

- Dealing with technology and social media
- Family and Care Responsibilities
- Financial concerns and job insecurity
- Having to have a good income and career success
- Increasingly fast pace of life
- Keeping up with our neighbours
- Our desire for perfection (the right body, the right clothes, looking good, having the best qualifications

So many of these things are external and about how others judge us or we judge ourselves. We have turned from **human beings** into **human doings**.

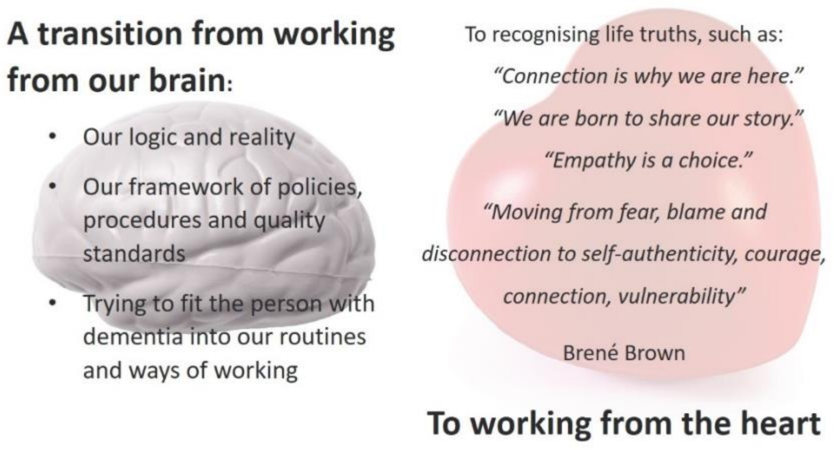
- Afraid to stop
- Always busy
- Anxious or Depressed
- Easily angered or upset
- Exhausted
- Outpacing others
- Overwhelmed
- Poor sleep
- Running Around



Is it any wonder then that those of us working in dementia care are so focussed on **doing person-centred care** that we have forgotten to **be person-centred**? Have we forgotten the stillness and silence that many people with dementia crave, particularly in the later stages of the disease?

So what is working from the heart?

Caring from the heart is a transition from **Working from our brain**, to **Working from our Heart**.



A transition from working from our brain:

- Our logic and reality
- Our framework of policies, procedures and quality standards
- Trying to fit the person with dementia into our routines and ways of working

To recognising life truths, such as:

"Connection is why we are here."

"We are born to share our story."

"Empathy is a choice."

"Moving from fear, blame and disconnection to self-authenticity, courage, connection, vulnerability"

Brené Brown

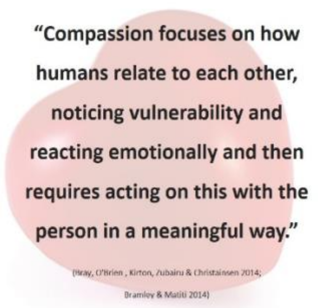
To working from the heart

Using Heart Skills

- Authentic, active listening
- Being congruent
- Being truly 'present'
- Compassion
- Dignity
- Dignity
- Empathy
- Empowerment
- Enabling, not Disabling
- In touch with our own feelings and sense of vulnerability
- Love
- Respect
- Unconditional Positive Regard
- Willing to recognise that we can't always fix things or make someone 'feel better.'

Defining Compassion

Compassion can be defined in many ways, here are two examples:



"Compassion focuses on how humans relate to each other, noticing vulnerability and reacting emotionally and then requires acting on this with the person in a meaningful way."

(Bray, O'Brien , Kirton, Zubairu & Christainsen 2014; Bramley & Matiti 2014)

"Compassion is how care is given through relationships based on empathy, respect and dignity and is dependent on how people relate to each other. Integral to compassionate care is the recognition of the patient as an individual and the way in which nurses and midwives communicate with each other, their patients, families and carers."

(Dewar 2013)

Genuine **Caring from the Heart** requires

- Authentic communication
- Being alongside - not **doing to** or **doing for**
- Being in harmony as **one human being with another**
- Being in touch with our personal life story and feelings, in order to create **meaningful connection**

- Bringing your **whole self** into the relationship, positive and negative feelings and all
- Bringing **your emotions into the room**
- Emotional Intelligence

- Removing the mask
    - The task as the mask
    - Removing them and us features

- Seeing dementia as a disability to be lived with, rather than a disease process to be managed
- Using words that enable, not disable people with dementia
- Working as a human being not a human doing
- Working together as a team

Empathy and Behaviour

If we approach behaviour as a gift – an expression of what the person with dementia is feeling inside, it is no longer a problem, it's a solution to be found on a feelings level:

> "Don't interpret behaviour in terms of how you feel about it."
>
> (Dawn Brooker)

It's about how the person with dementia feels about it. See things from their perspective and ask yourself:

- The person is sharing a gift – how they feel on the inside?
- What is the gift they are trying to share with me?

What about Time and Resources?

Care-workers are incredibly busy and work hard, I know. They will often ask: *"But won't person-centred care take more time, we've already got so much to do"*. Or they will say, *"we need resources, we need more funding."* I understand that perspective and they aren't wrong.

My response is to say **we must see things from a different perspective**, and I give two examples:

First, an amazingly creative male care-worker called Shahid. It was approaching lunchtime and all the staff were busy. A woman with dementia in the lounge had not been engaging for over an hour with no signs of well-being. In between his tasks, Shahid brought some photos of cats for the woman (she'd been a cat-owner) – **it took him less than 30 seconds**.

After leaving the photos with her, Shahid set about his tasks. He didn't see what I observed: the woman started to smile, after staring at the floor for an hour, she started to look around the room – **for a whole 25-minutes, she was in a state of well-being**. All thanks to the 30 seconds Shahid spent on enabling her well-being. I think he was amazing.

The second example is around resources. Some time ago, I had the good fortune to work with **Dementia South Africa**. I got to visit Cape Town's 3 tiers of care:

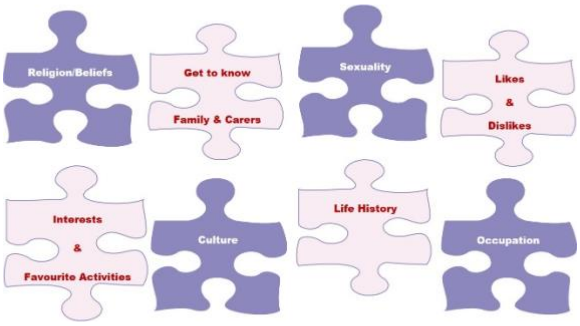
- the **top tier** - for the very wealthy white people - no expense was spared
- the **middle tier** a mixture of races, with fewer resources and
- the **lowest tier** in the poverty-stricken township of Khayelitsha with virtually no resources.

Where were the happiest people with dementia? Yes, Khayelitsha, the township. Here people with dementia were laughing, receiving and offering love to those looking after them. This was the happiest group of people with dementia I have ever met**. And why?**

More than anything, despite the poverty, **the place was filled with love**. That word at the heart of Tom Kitwood's flower was so evident. Resources help, of course, yet **person-centred care that comes from the heart can happen in any or all environments, no matter rich or poor.**

Being truly person-centred

Getting to know the whole person



Only through putting the pieces together can we really get to know the whole person and understand how best to meet their needs, interests and respond appropriately to their communication and behaviours.
In the absence of relatives, this can sometimes be difficult, admittedly. However, this is where communication between staff and effective care planning is so important.

Take Gwen. I was in the middle of training one day at a care home, when she started to come in and out of the training room. Eventually, I asked her to join us. She was quite a character and liked being up the from with me (the staff soon let me know that she used to be an actress). The next time she came into the room I invited Gwen to sit up the front with me – centre-stage if you like.

I was explaining **semantic memory** – how we remember and name things through our senses – e.g. for example, we look at a flat surface on four legs and we know it's called 'a table'.

I was playing some sound effects as a game to see if participants could recognise and name the sounds. Inadvertently, I played the sound of a donkey braying.

Gwen suddenly said: *"We used to have a donkey come to our gate, but it doesn't come any more."* I was delighted that Gwen had demonstrated the theory of **auditory semantic memory**, whilst the staff were agog at this new information about Gwen.

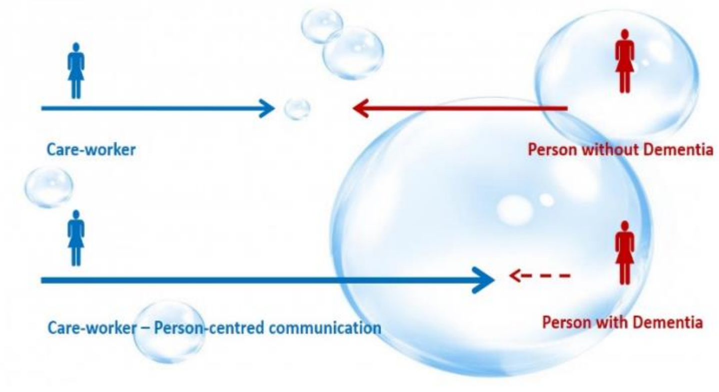
I then played the sound effect of a steam train leaving a station. The staff and I were all surprised when Gwen signed: *"Mummy took us on the train to the seaside whilst Daddy was away at the war to cheer us up. He never came back."*

We'd learned two gems of information about Gwen, which could facilitate future conversations and indeed, potentially influence her care. It also showed that emotional memories can remain intact, despite dementia. So, I hope those **gems of information were recorded**, for they told us a little bit more about Gwen **as a whole person** that nobody realised before.

Communicating from the heart: reaching out to the Person

Bernie McCarthy says:

> *"Communication is the food of relationships. Good communication is nourishing, delightful and memorable. It creates intimacy, enriches us and we become better people. Poor communication is like bad food – poisonous and harmful."*
>
> Bernie McCarthy



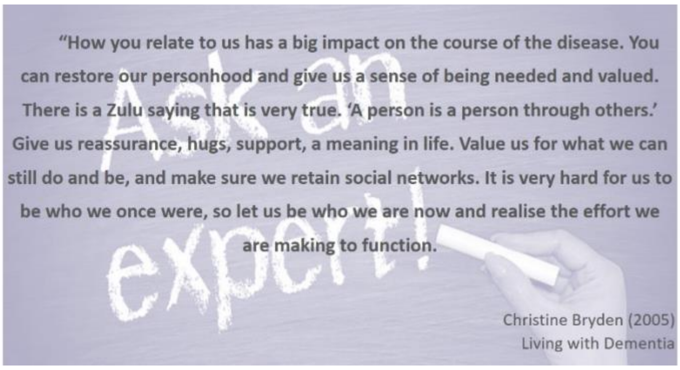
When people with dementia reach a point when they are unable to communicate through words, they are often described as **'no longer there.'** I find this heart-breaking, for they are still there, just not able to communicate through the **vocabulary of words or within the logic of our expectations.**

Rather, they communicate through the **vocabulary of feelings**: body language, gestures, sounds and facial expressions. I'm not suggesting they are babies. However, would we say a baby is 'no longer there' because they can't yet speak? We know this is untrue and we **adapt our communication accordingly** in order to reach that much further to connect.

To do this, we use innate **'heart-based' skills**. I truly believe, therefore, that we can still reach people with dementia if we are prepared to **put logical barriers aside**. To truly reach from our heart and **connect with that person with dementia**.

Ultimately, people want (as Tom Kitwood identified with his flower all those years ago) – **love and belonging**.

As Christine Bryden says…



"How you relate to us has a big impact on the course of the disease. You can restore our personhood and give us a sense of being needed and valued. There is a Zulu saying that is very true. 'A person is a person through others.' Give us reassurance, hugs, support, a meaning in life. Value us for what we can still do and be, and make sure we retain social networks. It is very hard for us to be who we once were, so let us be who we are now and realise the effort we are making to function.

Christine Bryden (2005)
Living with Dementia

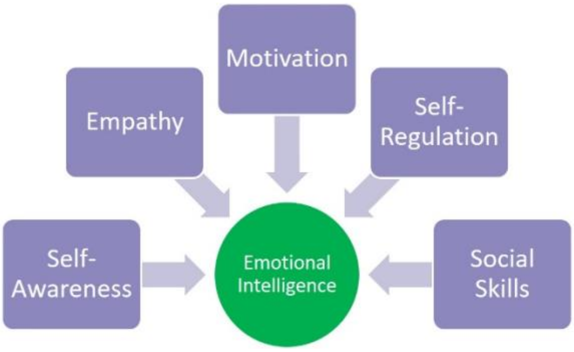
Working with Emotional Intelligence

Daniel Goleman, said the **Emotional Intelligence** is equivalent to, if not more important that IQ. Emotional Intelligence (EQ) has been defined as being:

> 'The ability to express your emotions appropriately and clearly in a way that enables you to achieve harmonious and effective outcomes with others.'

Emotional intelligence is a series of skills, starting with self-awareness and empathy. The art of the heart of person-centred dementia care, has Emotional Intelligence at its core.

Emotional intelligence is a combination of intrapersonal (knowing and understanding ourselves) and interpersonal skills (the ability to understand others)

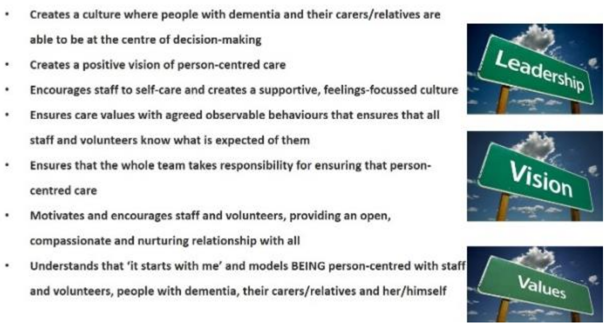


Leading from the Heart in Person-centred Dementia Care

The best Managers and Leaders work from the heart, understanding that every single person (regardless of their job title), plays a part in leading the culture change required to put the 'Art of the Heart into Person-centred Dementia Care'. The best leaders win over people's hearts, much more than their minds.

An effective dementia care leader, working from the heart knows what person-centred care looks, sounds, feels, tastes and smells like.

They make it a vision that everyone can grasp and wish to follow.

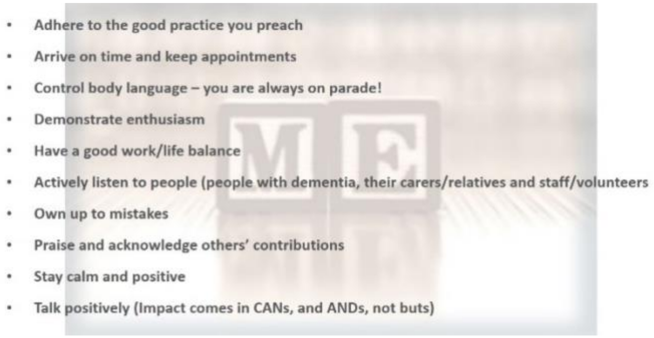


- Creates a culture where people with dementia and their carers/relatives are able to be at the centre of decision-making
- Creates a positive vision of person-centred care
- Encourages staff to self-care and creates a supportive, feelings-focussed culture
- Ensures care values with agreed observable behaviours that ensures that all staff and volunteers know what is expected of them
- Ensures that the whole team takes responsibility for ensuring that person-centred care
- Motivates and encourages staff and volunteers, providing an open, compassionate and nurturing relationship with all
- Understands that 'it starts with me' and models BEING person-centred with staff and volunteers, people with dementia, their carers/relatives and her/himself

They motivate a time that supports each other on a practical and feelings level.

An emotionally intelligent leader knows that they must model the behaviour they wish to see in staff and volunteers. They know that: **"It Starts with ME!"**

Teams work together to PEFORM, to ensure *'the Art of the Heart in Person-centred Dementia Care.'*



- Adhere to the good practice you preach
- Arrive on time and keep appointments
- Control body language – you are always on parade!
- Demonstrate enthusiasm
- Have a good work/life balance
- Actively listen to people (people with dementia, their carers/relatives and staff/volunteers
- Own up to mistakes
- Praise and acknowledge others' contributions
- Stay calm and positive
- Talk positively (Impact comes in CANs, and ANDs, not buts)

SUMMARY

- There are many definitions of person-centre care
- Have we yet achieved true person-centred care that comes from the heart? Probably not, it's **always a work in progress**.
- We work in homes of people with dementia, **we should fit around them**; not them have to fit into our policies, procedures and systems which come from our brains – not their feelings.
- Working from the heart requires: empathy, compassion, connection, self-authenticity, creating belonging, emotional intelligence and to stop controlling that which cannot be controlled.
- We are human-beings, not human-doings, so instead of trying to **DO person-centred dementia care**, we need to **BE person-centred**.
- It means **sharing our vulnerability** (based on our own life story and experiences) as a fellow human being, to connect with the feelings and vulnerabilities of people with dementia and their carers/relatives.
- The *Heart in Person-centred Care* is not easy (it requires us to remove the mask of the task and make ourselves emotionally vulnerable).
- It is about supporting each other as care-workers, **we have to be person-centred with ourselves, before we can be person-centred with others**.
- However, this is the only way we can truly meet the person with dementia, for they are now feelings-based. Meeting them from our logical, cognitive world, doesn't support them.
- It's similar to when we have a 2-year-old child who is feeling upset about something - our logic doesn't make them feel any better. It doesn't mean that a person with dementia is the same as a 2-year-old child or that we should treat them like that.
- However, it does mean that we need to **understand things from their perspective**, we know instinctively how to respond on a feelings-level.
- So, whilst, dementia care is hard work, it isn't difficult - the potential lies within each of us to respond on an instinctive, feelings-based level.

Thank you for listening and participating in this self-directed learning module. I hope you found it interesting and that the remaining segments help you understand more about *'The Art of the Heart in Person-centred Dementia Care'*.

We can all be a part of changing the lives of people with dementia and their carers/relatives.

As Barak Obama once said:

"Change will not come if we wait for some other person or some other time. We are the ones we've been waiting for. We are the change that we seek."