Person Centred Leadership in Dementia Care

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The Association for Dementia Studies
University of Worcester, UK
Hoping to cover

- Understanding what good looks like.
- Why *person-centred* leadership?
- Tools to help

THANKS TO

- All the team at the Association for Dementia Studies
- The Oak Pub, Ramsbottom
- Portsmouth NHS, The Limes
Association for Dementia Studies (est 2009)
Developing evidence-based person-centred practical ways to help people live well with dementia
The experience of people living with dementia and their families inform the work of Association for Dementia Studies at all stages.
What does good look like?

• Dementia covers a complex range of different syndromes, some very rare, that often happen to people who are also experiencing other health and social changes at the same time.

• Our health and social care services aim to support people and their families through targeted case detection, timely diagnosis, post diagnostic support and adjustment, progressive and unpredictable loss of functioning, adjusting to help at home, changing lifestyle needs, hospitalisations, housing support, care home admission and complex end of life issues.

• All of this needs to be done with due respect and sensitivity to the person’s lifestyle, family context and the context of the community in which they live.
We all need to work together to help the boat keep afloat

CLEAN & CALM WATERS

**Communities** that are dementia friendly, where “dementia” is not stigmatised, using the same facilities as everyone else, having equal rights as a citizen, having fun, having family life, schools, businesses, employers, churches, temples, synagogues, mosques

NAVIGATING the river

**Social care**, providing sensitive good quality care that supports the whole family to carry on and not get overwhelmed, information, education, finances, legal, signposting, technology, adjusting, support, hugs, counselling, peer-support, getting a break, getting help at home, care homes, housing, extra care, MEETING Centres Support Programme......

The BOAT hitting the rocks

**Health**, timely diagnosis, co-morbidities, therapeutic interventions, pharmacological and non-pharmacological, specialist support in a crisis, difficult histories, specialist care in complex families, there’s often more than 1 person in the boat

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Clean & Calm Waters
Community Awareness Initiatives

- The Dementia Action Alliance
- Carers call to action
- Dementia Friends
- Dementia Friendly Communities
- Schools programmes
- Faith groups
- Pop-up shops
- Banks, businesses
- Public awareness campaigns
Dementia Friendly Community

- Pubs, restaurants, cafes
- Hotels, Spa breaks, dances
- Supermarkets, charity shops, garden centres
- Cinemas, theatres, libraries
- Personalised TV streaming, radio
Navigating: Living well Initiatives

- Post diagnostic support initiatives
- Dementia Cafés
- Dementia Advisors
- Peer support
- DEEP
- Day opportunities
- Home based support

- Community Arts programmes
- Singing for the brain
- Cognitive stimulation groups
- Life-story work
- Technology & design
- Meeting Centres Support Programme
Keeping the boat afloat; complex care

- Complex diagnosis
- Co-morbidities physical health interventions
- Co-morbidities mental health interventions
- Specialist health and social care workforce
- Admiral Nursing
- Care homes
- Hospitals, acute and community
- End of life care
- Palliative care
- Emergency services
Why Person-Centred?
Modern dementia care

- The move from
- The death that leaves the body behind
- to
- Living well with dementia
Person Centred Care in front-line services

- People with dementia have a high risk of not being treated as full citizens, of being ignored, disparaged, abused
- People with dementia often have particular disabilities around communication, strong emotional responses and a major need for continuity and to feel connected to others
- Services need to respond to both these needs
- Person-centred services respond to these needs in a proactive fashion
Value us, give us our dignity

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. Christine Bryden
Really tough problems

• Funding
• Structure of health and social care not designed to cope with long-term conditions
• Prejudice, fear & stigma (which increase in times of austerity)
• A PERFECT STORM WHICH IS VERY DIFFICULT TO NAVIGATE........
Prejudice, Fear & Stigma

- Dementia – ism
- Often difficult to talk about
  - for ourselves, our families, our employees
- Balance of rights and needs
- Often prejudice is deep-seated and not always in conscious awareness, We are a product of our culture.
- Organisations take on the character of their leaders.

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Some underlying attitudes that block progress

• What is the point?
• Waste of resources
• Blocking beds (for more important patients?)
• “They” are not “our” patients/residents/clients/funding responsibility
• Not enough time, too busy saving lives.....
Tools to help
Person centred care fit for VIPS

V = Values people
I = Individual needs
P = Perspective of service user
S = Supportive social psychology
NICE-SCIE Guidelines on Dementia
2006 Person centred care

- Values and promotes the rights of the person
- Provides Individualised care according to needs
- Understands care from the Perspective of the person with dementia
- Social environment enables the person to remain in relationship
Guiding Principles

• Do my actions show that I respect, value, and honour this person?
• Am I treating this person as a unique individual?
• Am I making a serious attempt to see my actions from the perspective of the person I am trying to help? How might my actions be interpreted by them?
• Do my actions help this person to feel socially confident and that they are not alone?
The Person-Centred organisation. How are we doing?

<table>
<thead>
<tr>
<th>VALUING; The directors, senior team</th>
<th>INDIVIDUALISED; dementia leads</th>
</tr>
</thead>
<tbody>
<tr>
<td>V1 the vision is clear</td>
<td>I1 care pathways and planning</td>
</tr>
<tr>
<td>V2 human resource management</td>
<td>I2 regular reviews</td>
</tr>
<tr>
<td>V3 management ethos</td>
<td>I3 personal possessions</td>
</tr>
<tr>
<td>V4 training &amp; staff development</td>
<td>I4 individual preferences</td>
</tr>
<tr>
<td>V5 the service environments</td>
<td>I5 life story work</td>
</tr>
<tr>
<td>V6 quality assurance, improvement &amp; governance</td>
<td>I6 activity &amp; occupation</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>PERSPECTIVE; shift leaders</th>
<th>SOCIAL/PSYCHOLOGICAL; everyone</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1 skilled communication</td>
<td>S1 inclusion</td>
</tr>
<tr>
<td>P2 empathy, risk &amp; decisions</td>
<td>S2 respect</td>
</tr>
<tr>
<td>P3 physical environment managed</td>
<td>S3 warmth</td>
</tr>
<tr>
<td>P4 physical health needs</td>
<td>S4 validation</td>
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<tr>
<td>P5 challenging behaviour, BPSD</td>
<td>S5 enabling</td>
</tr>
<tr>
<td>P6 advocacy</td>
<td>S6 family &amp; community</td>
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www.worcester.ac.uk
Indicators of valuing

1. Every life is precious?
2. Do staff feel valued?
3. Staff act in best interests of service users?
4. Skilled work-force?
5. Physical & social care environments?
6. QA processes service user focussed?

Excellent, Good, OK, Needs serious work?
Key personnel **THE BOSS**

**VALUING**
V1 vision
V2 human resource management
V3 management ethos
V4 training & staff development
V5 the service environments
V6 quality assurance

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Indicators of Individualised approach

1. Care planning across all needs?
2. Responsive to change?
3. Personal clothing and possessions?
4. Individualised preferences & routines?
5. Key stories of proud times?
6. Occupation & activities?

Excellent, Good, OK, Needs serious work?
Key Personnel “CARE LEADER”

- INDIVIDUALISED CARE
  - 1 care planning
  - 2 regular reviews
  - 3 personal possessions
  - 4 individual preferences
  - 5 life history work
  - 6 activity & occupation
Indicators of the taking the perspective

1. Skilled Communicators?
2. Empathy and risk balance?
3. Comfort needs managed?
4. Physical health needs anticipated?
5. “Challenging behaviour” seen as communication?
6. Advocacy?

Excellent, Good, OK, Needs serious work?
Key Personnel SHIFT LEADER

PERSPECTIVE
P1 communication
P2 empathy & acceptable risk
P3 physical environment
P4 physical health needs
P5 challenging behaviour
P6 advocacy
Indicators of providing social-psychological support

1. Included or talked over?
2. Respect or disregarded?
3. Warmth or coldness?
4. Distress taken seriously or ignored?
5. Helping to do, or doing to?
6. Community or institution?

Excellent, Good, OK, Needs serious work?
Key Personnel 

**FRONT-LINE STAFF**

**SOCIAL PSYCHOLOGICAL**

S1 inclusion
S2 respect
S3 warmth
S4 validation
S5 enabling
S6 part of family & community

**Association for Dementia Studies**
Care Fit for VIPS website

www.carefitforvips.co.uk
A three-part toolkit

What is Care Fit for VIPS?

Care Fit for VIPS is based on the nationally recognised VIPS model of dementia care, and is made up of:

- **Real-time Assessment Tool**: Assess and understand your home’s current strengths and weaknesses.
- **Searchable Toolkit**: Guiding you to many of the best resources available on and offline.
- **Improvement Cycle**: Helping you to make small, concrete changes and log improvements.
“all needs, no mobility, not eating”

6 days after admission to a care home.....

Mrs May Williams, Lady Forester Home
“all needs, no mobility, not eating”

1 month later – baking

Mrs May Williams, Lady Forester
Home
“all needs, no mobility, not eating”

1 month later – baking

Mrs May Williams, Lady Forester Home
“all needs, no mobility, not eating”

6 weeks later – Italian meal

.....
“all needs, no mobility, not eating”

6 weeks later

tea and teddy
“all needs, no mobility, not eating”

2 months later – head massage.
“all needs, no mobility, not eating”

2 months later – old skills returning…..
“all needs, no mobility, not eating”

2 months later – silk scarves.....
“all needs, no mobility, not eating”

3 months later – dancing to music....
“all needs, no mobility, not eating”

3 months later Mexican celebration
Useful websites

Association for Dementia Studies, University of Worcester
- http://www.worc.ac.uk/discover/association-for-dementia-studies.html

Interdem: European Early & Timely Interventions in dementia research network
- http://www.interdem.org/

Care fit for VIPS
http://www.carefitforvips.co.uk

Lifestory network
- http://www.lifestorynetwork.org.uk/

Memory Bridge:
www.memorybridge.org

Social Care Institute for Excellence: Dementia Gateway
- www.scie.org.uk/publications/dementia

Playlist for Life http://www.playlistforlife.org.uk
Thank you for listening!

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http://www.worc.ac.uk/discover/association-for-dementia-studies.html