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Person-Centred Dementia Care Research

**Global Action on Dementia
Tokyo November 2014**

**Professor Dawn Brooker
Association for Dementia Studies
University of Worcester UK**





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Thanks to....

- G7 Legacy Events Team
- The Japanese Society for Person-centred care
- The Alzheimer's Society
- Alzheimer's Europe
- Alzheimer's Disease International
- The ExtraCare Charitable Trust UK
- InterDem
- The Association for Dementia Studies Team



The Association for Dementia at Worcester University



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We provide research,
education and scholarship
to deliver evidence-based
practical ways of working
with people living with
dementia and their families
that enables them to live
well.

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





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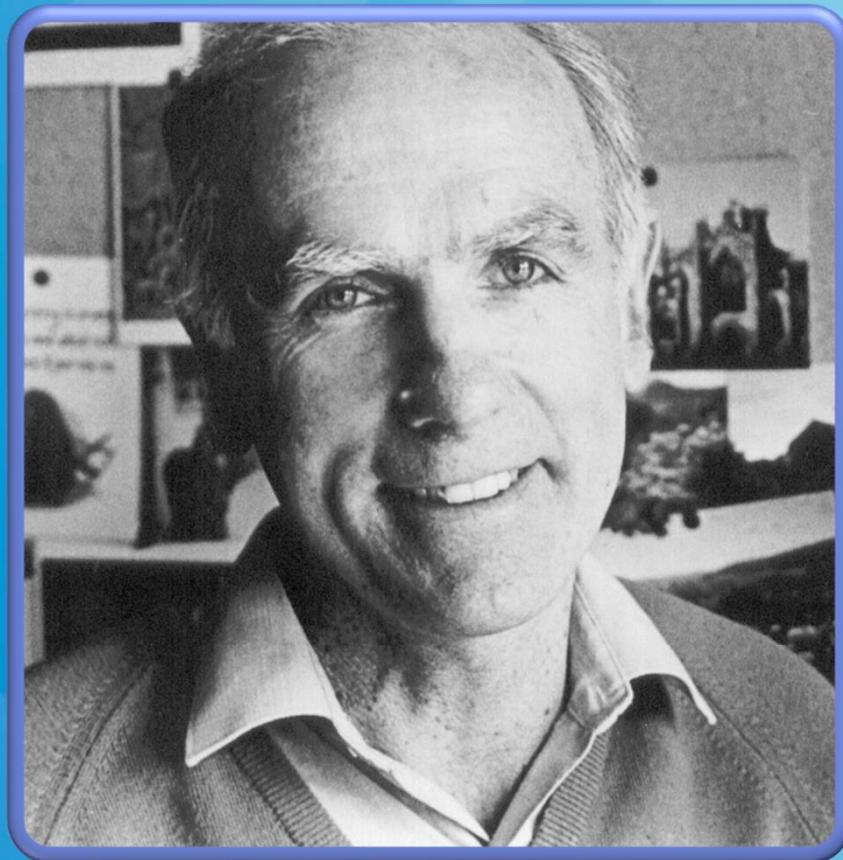
Hoping to cover

- What we mean by Person-Centred Care
- Overview of RCT's in the area
- The FITS into Practice Implementation study
- A case study from the Enriched Opportunities Programme

Person centred dementia care

Professor Tom Kitwood

- Person centred approaches to dementia care; 1989-1997 drawing on Martin Buber and Carl Rogers
- The enriched model of dementia
- Supporting personhood through the eradication of malignant social psychology
- Dementia Care Mapping



Kitwood, T. (1997). *Dementia Reconsidered: the person comes first*. Buckingham: Open University Press.

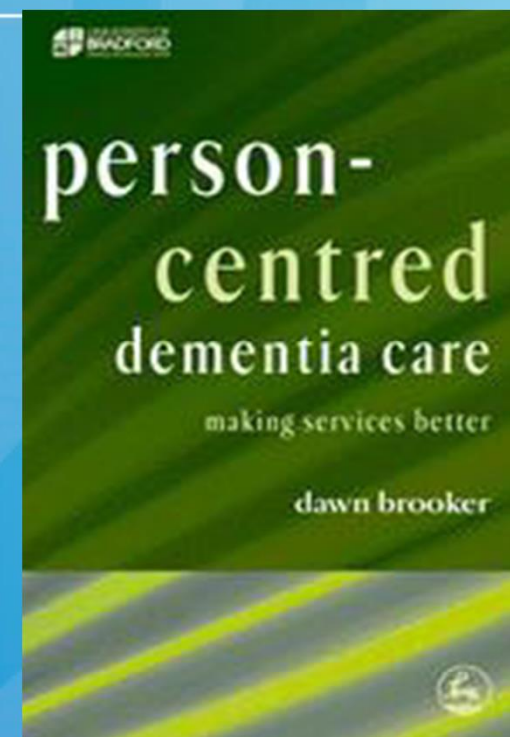
Person-centred care fit for VIPS

- V = Values people**
- I = Individuals needs**
- P = Perspective of service user**
- S = Supportive social psychology**

Brooker, D. (2004) What is Person Centred Care for people with dementia?
Reviews in Clinical Gerontology 13 (3). 215-222.

Brooker, D. (2007) *Person Centred Dementia Care: Making services better*
London, Jessica Kingsley Publications

<http://www.nice.org.uk/guidance/cg42/resources/guidance-dementia-pdf>



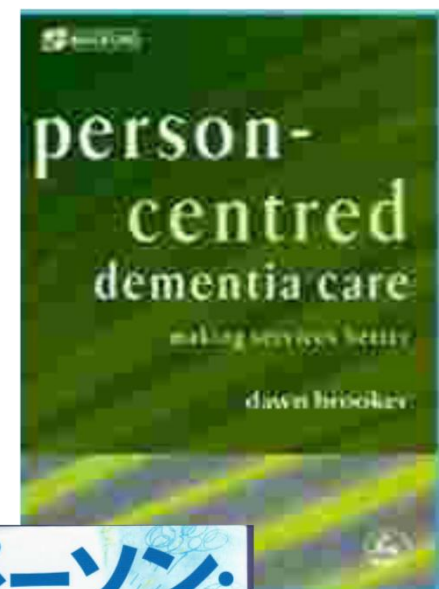
人々の価値を認めた パーソナル・センタード・ケア

V = 人々の価値を認める

I = 個人の独自性を尊重する

P = サービス利用者の視点に立つ

S = 相互に支え合う社会的環境



research evidence?

- Person centred care provides a set of guiding principles to apply across service settings and countries.
- In itself it is not a single intervention
- The challenge is to enable practitioners, professionals and services that can provide interventions in a person centred manner.
- Cluster randomised controlled trials evidence shows this is possible.....

a complex intervention

- UK MRC (Medical Research Council) framework for complex interventions
- www.mrc.ac.uk/complexinterventionsguidance

1. Theory, proof of concept
2. Exploratory pilots
3. Definitive multicentre RCTs
4. Implementation studies

centred RCTs for people amilies living at home

- Brooker D., Argyle, E., Clancy, D. & Scally A. (2011) Enriched Opportunities Programme: A cluster randomised controlled trial of a new approach to living with dementia and other mental health issues in ExtraCare housing schemes and villages. *Aging and Mental Health*. 15 (8); 1008-1017
- Graff, M.J., Vernooij-Dassen, M.J., Thijssen, M., Dekker, J., Hoefnagels, W.H. & Rikkert, M.G. (2006). Community based occupational therapy for patients with dementia and their care givers: Randomised control trial. *British Medical Journal*, 333, 1196
- Logsdon, R., Pike, K., McCurry, S., Hunter, P, Mather, J., Snyder, L., & Teri, L. (2010). Early stage memory loss support groups: Outcomes from a randomised controlled clinical trial. *Journal of Gerontology B; Psychological Sciences and Social Sciences*, 65B, 691-697
- Mittleman, M., Brodaty, H., Wallen, A. and Burns, A. (2008). A three-country randomized controlled trial of a psychosocial intervention for caregivers combined with pharmacological treatment for patients with Alzheimer disease: effects on caregiver depression. *American Journal of Geriatric Psychiatry*, 16 (11), 893-904.

“ Emerging research from InterDem
members

<http://www.interdem.org:8085>



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Person-centred care in care homes: cluster-randomised controlled trials

- Chenoweth, L., King, M.T., Jeon, Y-H., Brodaty, H., Stein-Parbury, J., Norman, R., Haas, M. and Luscombe, G. (2009). Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *The Lancet/ Neurology*. 8, 317-325.
- [Cohen-Mansfield, J.](#), [Libin, A.](#) and [Marx, M.S.](#) (2007). Nonpharmacological treatment of agitation: a controlled trial of systematic individualized intervention. *Journal of Gerontology Series A: Biological Sciences Medical Sciences*, 62 (8), 908-916.
- Fossey, J., Ballard, C., Juszczak, E., James, I., Alder, N., Jacoby, R. and Howard, R. (2006). Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomised trial. *British Medical Journal*, 332, 756-761.
- Mork Rokstad, A.M., Røsvik, J., Kirkevold, O., Selbaek, G., Saltyte Benth, J and Engedal, K. (2013). The Effect of Person-Centred Dementia Care to Prevent Agitation and Other Neuropsychiatric Symptoms and Enhance Quality of Life in Nursing Home Patients: A 10-Month Randomized Controlled Trial. *Dementia and Geriatric Cognitive Disorders*, 36:340–353

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 **University of Worcester**
Association for Dementia Studies

FITS into Practice

Focused Intervention Training and Support

Oxford Health 
NHS Foundation Trust

 UNIVERSITY OF OXFORD

 **Newcastle University**

KING'S
College
LONDON



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The Original FITS Project

Objective: to reduce the use of antipsychotic medication in residents with dementia in a care home through the use of person centred care and supportive interventions in 12 care homes.

Fossey, J., Ballard, C., Juszczak, E., James, I., Alder, N., Jacoby, R. & Howard, R. (2006). Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: a cluster randomised trial. *British Medical Journal* 332. 756-58



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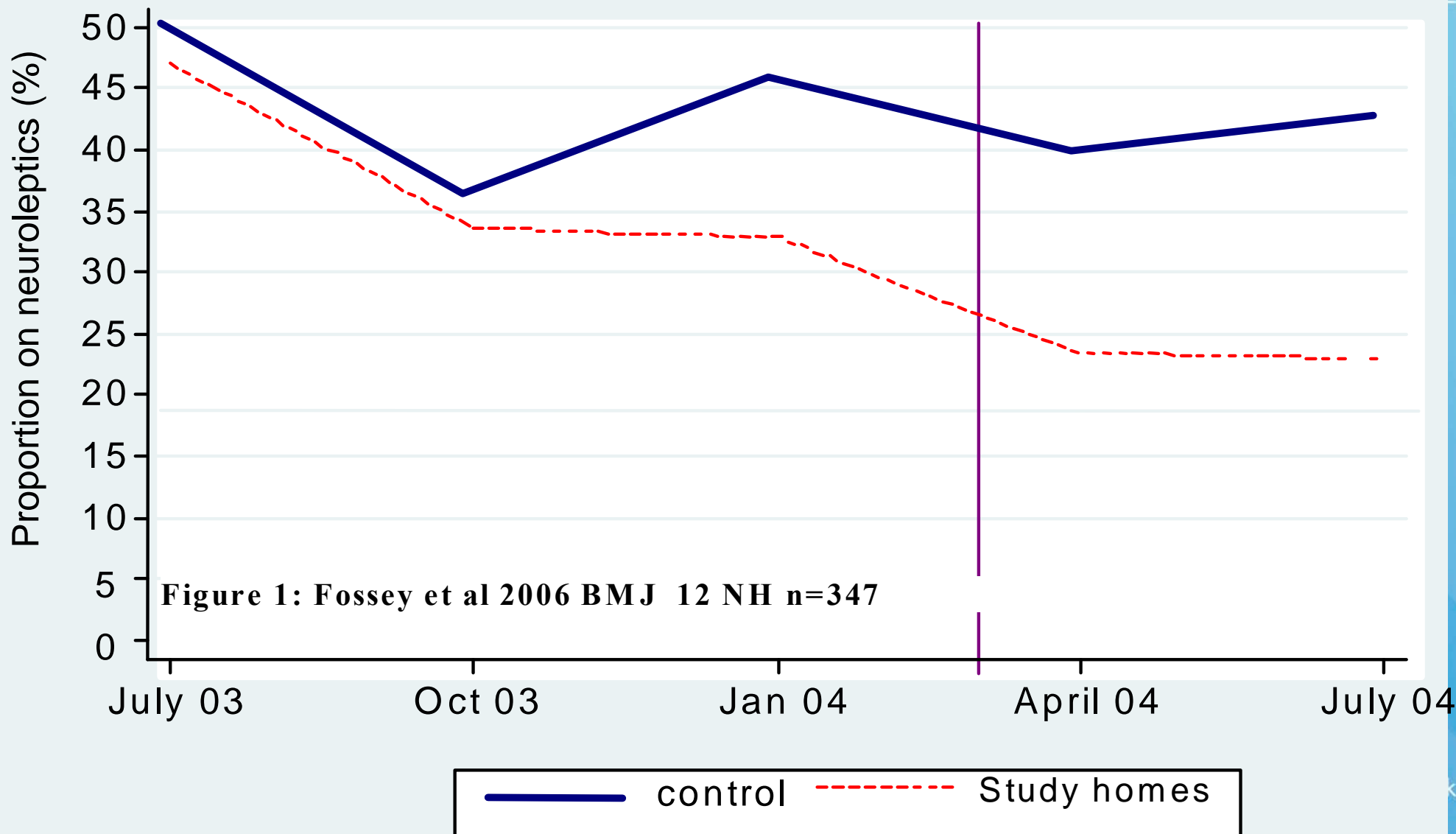
Acknowledgements

“ *The FITS into Practice programme was a research project led by the Association for Dementia Studies, University of Worcester and funded by the Alzheimer’s Society. It followed on from an original randomised controlled trial of the FITS programme which produced significant results in terms of antipsychotic reduction (Fossey et al, 2006. FITS into Practice is based on this original research conducted at King’s College London, in association with Oxford University, University of Newcastle and Oxford Health NHS Trust. Copyright of the original FITS manual is held by **Dr Jane Fossey** (Oxford Health NHS Trust) and **Dr Ian James** (University of Newcastle).*

Thanks to

- “ **The Association for Dementia Studies** at the University of Worcester: Prof Dawn Brooker, Isabelle Latham, Dr Simon Evans, Nicola Jacobson, Wendy Perry (report authors) also to Jen Bray, Michael Watts, Jenny La Fontaine and David Moore.
- “ **The Alzheimer’s Society**: Professor Clive Ballard, Dr James Pickett, Anne Corbett, Nicola Hart, Keara O’Connor, Barbara Woodward-Carlton.
- “ **The steering group**: Dr Jane Fossey (chair), Nia Golding (HC1), Professor Robin Jacoby, Dr Claire Surr, Paula Windmill, Karen Culshaw, Barbara Woodward-Carlton.
- “ **All the Dementia Care Coaches & care homes** who took part for the many examples of good practice, dedication, creative thinking, compassion and hard work implementing learning in their homes and making a difference to the lives of people with dementia in their care.

Results Fossey et al 2006





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Practice: an implementation study of the RCT

The original FITS programme was a high cost and intensive intervention, using an in-house 'FITS therapist' to support person-centred care and medication review in each care home.

The real challenge was how to translate the model into an approach that could be effective across a large number of care homes.

The Association for Dementia Studies (ADS) and the Alzheimer's Society worked together to design, implement and evaluate a programme to implement FITS into Practice across
100 care homes



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into Practice programme

- “ Two **Dementia Practice Development Coaches** were employed and supported by the Association for Dementia Studies
- “ They delivered training and supervision to **Dementia Care Coaches** – nominated staff from 100 care homes
- “ Dementia Care Coaches attended a **10 day training programme over 3 months** (meeting fortnightly in 2-day blocks)
- “ Following training, Dementia Care Coaches attended **monthly supervision sessions for 6 months**, whilst they implemented FITS in their home.
- “ **Dementia Care Coaches implemented their learning, supported by the Dementia Practice Development Coaches**

the FITS into Practice Project

- “ 106 homes were initially recruited. Care homes ranged in size, owning organisation and geographical location. 67 completed the programme.
- “ DCCs evaluated the intervention (training & supervision) highly; pre-post questionnaires demonstrated increased knowledge of dementia, increased confidence and improved attitude to dementia.
- “ 30.5% reduction in anti-psychotic medication with dose reductions being reported for additional residents.

Results

- “ Increased activity and better staff-resident relationships
- “ Crucial for FITS into Practice to succeed was the allocation and protection of time for the DCC to attend training and carry out implementation tasks in addition to their existing job role. Evaluation data showed that this was a substantial barrier to implementation in a number of homes.



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9 Enriched Opportunities

1998- 2000

Between group comparison of nursing home residents participating in an activity challenge holiday and a matched control group.

2001-2003

The development of the EOP programme using qualitative enquiry and within group quantitative evaluation in four study sites

2005- 2009

Random cluster controlled trial in ten extra care housing schemes



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Enriched Opportunities published outputs

- Brooker D., Argyle, E., Clancy, D. & Scally A. (2011) Enriched Opportunities Programme: A cluster randomised controlled trial of a new approach to living with dementia and other mental health issues in ExtraCare housing schemes and villages. *Aging and Mental Health*. 15 (8); 1008-1017
- May, H., Edwards, P. and Brooker, D. (2009). *Enriched Care Planning for People with Dementia: A Good Practice Guide to Delivering Person-Centred Care*. London, Jessica Kingsley Publications
- Brooker D., Argyle, E. & Clancy, D. (2009) Mental Health Needs of people living in extra care housing. *Journal of Care Services Management*, Vol 3.3 March/April
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- Brooker, D., Woolley, R. & Lee, D. (2007) Enriching Opportunities for People living with Dementia in Nursing Homes: An evaluation of a multi-level activity-based model of care. *Aging and Mental Health* 11(4): 361-370
- Brooker, D. (2001) Enriching Lives: evaluation of the ExtraCare Activity Challenge. *Journal of Dementia Care*. (Research Focus) 9 (3), 33-37.



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ing”

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

Mrs May Williams , Lady Forester
Home



ing”

1 month later – baking

Mrs May Williams , Lady Forester
Home



ing”

1 month later – baking

Mrs May Williams , Lady
Forester Home



ing”

6 weeks later – Italian meal

.....



ing”

6 weeks later tea and teddy



ing”

2 months
later – head
massage .



ing”

2 months
later – old
skills
returning.....



ing”

2 months
later – silk
scarves.....



ing”

3 months
later –
dancing to
music....



ing”

3 months later Mexican celebration



Interventions to improve quality of life for May Williams?

- **Interventions:** Person centred animal therapy, baking, good food, special occasions, eating, knitting, teddy, dressing up, silk scarves, head massage, dancing
- **Outcomes:** Alive, weight gain, happy, active, having fun, no BPSD, no sedation





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Take home messages

- Person-centred care transforms lives.
- If we put person centred principles into practice globally we would save millions of people from misery. We do not need to wait until 2025 to have an impact.
- Prioritise robust implementation studies across the journey with dementia and in low and middle income countries
- Develop strong international networks for sharing data on what works, InterDem, Dementia-NET, International Person-Centred Values Network; ADI;.....



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Thank you for listening!

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



Photographs of people living with dementia taking part in
The Enriched Opportunities Programme

www.worcester.ac.uk



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Domicilliary
Care

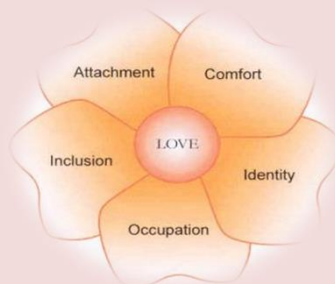
Care
Homes

Day
Care

ンタード・ケア関連情報Dawn Brooker 著書/講演他

D.ブルッカー「VIPSですすめるパーソン・センタード・ケア」

水野裕監修
村田康子他訳、2010
クリエイツかもがわ
TEL:075-661-5741



「パーソン・センタード・ケアを 実践する ドーン・ブルッカー 講演より」(日本語吹替)

水野裕監修
中川経子他訳、2012
シルバーチャンネル
TEL:048-711-7762



「パーソン・センタード・ケアとDCM 研修会」基礎コース年4回開催

問合せ先:

認知症介護研究研修大府センター
<http://dcnet.gr.jp> TEL:0562-44-5551

NPOシルバー総合研究所

<http://silver-soken.com/>

NPOその人を中心とした認知症ケアを考える会 —パーソン・センタード・ケアに関する学習会

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bsites

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

