

# IHS

Institute of  
Health & Society

# Person- and carer-centred respite care

Claire Bamford

Institute of  
Health & Society

# Background



- Respite care is a key support service for people with dementia and their carers
- Carers express high levels of satisfaction with respite care
- Significant investment to encourage new models of respite care/short breaks
- Limited evidence of the effectiveness of different models



# Defining respite care



- Any formal service with the purpose of providing a break from the usual routine for the person with dementia and/or their carer



# Shifting priorities



Institute of  
Health&Society

- *“It’s all centred around the ambulance drivers, it’s all centred around staff, it’s all centred around activities [...] it might not fit in with the work pattern of the person at home, there’s no flexibility, there’s no weekends, there’s no night time.”*

Manager (ESMI home providing respite care and day care)

*“I think it’s about how you organise your whole operation basically, because you can either do it to make things easy, to make the place run smoothly or you can go that extra mile and reverse that and gear the organisation to the person rather than the other way round”*

Frontline staff (service providing respite beds)



# Aspirations for short breaks



Institute of  
Health&Society

- Person-centred service with benefits for people with dementia as well as carers
  - Range of models of short breaks
  - Increased flexibility
  - Emphasis on opportunities for therapeutic input
  - Emphasis on social inclusion



# Aim



- Consider ways of closing the gap between policy & personal priorities & service provision
- Overview of types of short breaks
- What 'person-centred' means in practice
- Approaches to evaluating short breaks
  - Facilitate comparison of different models
  - Align with person-centred care



# Models of short breaks identified

	Duration	
	<24 hours	Overnight or longer
Person with dementia	Traditional day care One-to-one support Home day care Clubs/activity/interest groups	Specialist respite centres Adult placement scheme Respite beds Extended day care
Carer	Pamper days	Short stay in dedicated holiday home
Joint	Dementia cafes Outings Lunch clubs	Supported holidays (group or individual)



# One-to-one support



Institute of  
Health&Society

- Available between 7am and 9pm
- 365 days a year
- Support worker takes the person with dementia out shopping, for a trip to the country or whatever best suits their individual needs
- Sitting service will stay with the person with dementia in their own home



## Views on one-to-one support

- *“a few years ago they used to go and have a round of golf with somebody. He was very impaired in every other aspect of his life except, he had a frontal lobe dementia, he still had this ability to play a round of golf. He’d lost the social skills and he didn’t understand to wait at one golf, one bit you know for anybody else that went but he could still do that and again it gave him some enjoyment and it gave his wife a break.”*  
Social worker (specialist team for younger people with dementia)
- *“In fact I think it was a good thing that she did have a change because she was getting too attached.”* Carer

# Home day care



Institute of  
Health&Society

- Available between 10 am and 3 pm
- Five days a week
- Trained and qualified care workers open up their home on the same day of each week to the same small (4-5) group of people with dementia
- Provides a friendly and safe domestic environment
- Refreshments and a home-cooked lunch are provided



# Views on home day care



Institute of  
Health&Society

- “Throughout the whole time I was present, there was continuous banter, teasing, joke telling, serious and fun conversation, making fun of themselves, the hostess and close relatives.”

Field notes (home day care service)

- “All four people with dementia seemed to value one another (and the hostess) and were respectful of each other, for example [.....] when either of the two quieter people with dementia said anything, the two more vocal service users immediately stopped talking to listen to what they were saying and then responded in some way.”

Field notes (home day care service)



# Extended day care



Institute of  
Health&Society

- Available between 8am and 8pm
- Open 7 days a week
- Overnight care available two nights a week
- Additionally reclining chairs for overnight use in emergencies



# Views on extended day care



Institute of  
Health&Society

- *“At present we’re actually supporting a gentleman with his wife who comes on a Wednesday and stays the full 24 hours because he’s having some chemo treatment at the moment. And he’s said that he’s found that so invaluable because she comes in on a Wednesday at half past nine [in the morning] and then he picks her up after his treatment on a Thursday about half seven at night.”*

Manager (extended day care)



# Adult placement



Institute of  
Health&Society

- Offer short- or long-term care
- Trained and qualified care workers provide accommodation and care for one (or sometimes two or three) people with dementia
- Provides a friendly and safe domestic environment
- <http://sharedlivessw.org.uk/videos/>

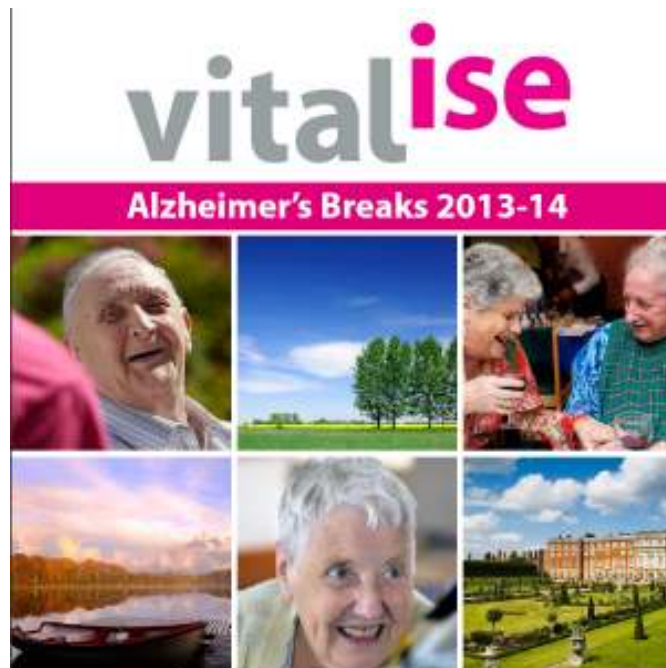


# Supported holidays



**Respite Care  
Themed Weeks**

Book now for 2014



Institute of  
Health & Society





# Supported holidays



- 24-hour care and personal support
- Programme of activities, excursions and entertainment
- Limited availability & funding
- Group and individual (couple) holidays available



# Views on supported holidays



Institute of  
Health&Society

*“Well the lasting benefits are the fact that we enjoyed it; it’s the camaraderie, the friendship and the get together in the common room and in the dining room in the evening, and in the morning, breakfast time, because we’re all the same.”*

Person with dementia

“This was their second short break at the centre. The couple did not live together, [the person with dementia] lived in a nursing home and [his wife] in sheltered accommodation. Coming to the centre for a short break allowed the couple to spend time together. They often sat in a quiet corner, holding hands and dozing together.”

Field notes, holiday service



# Short stay beds



- Care homes, continuing care facilities or hospital wards with a small number of short-stay beds
- 24 hour care and personal support
- Available 365 days
- Can offer extremely flexible support



# Views on short stay beds

- *“We had a chap who used to come for respite care, but his wife used to have terrible problems at home, and sometimes she would ring you up and say ‘I need to get him out of this house’. She said she didn’t want him away for extra respite care, she didn’t want him away permanently, she just wanted a couple of hours to herself where she didn’t have to worry about him”*

Manager (ESMI home providing respite care)

*“We had a gentleman who used to come in on a Monday and go home on a Friday. And he stayed with his wife over the weekend and she brought him back in again on the Monday, because that fitted in with her work pattern.”*

Manager (Continuing care ward)

# Choosing a model



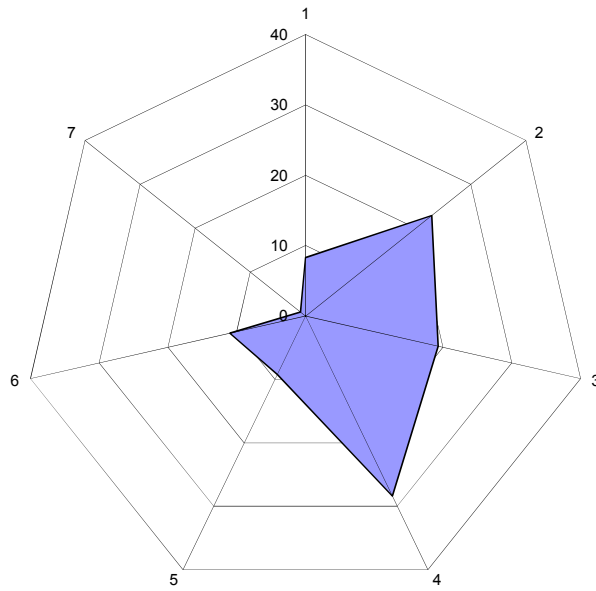
- All have advantages & disadvantages
- Providing a range of models offers maximum flexibility
- Need to match client needs to service model
  - Need a clear idea of what is most important to the person with dementia and carer



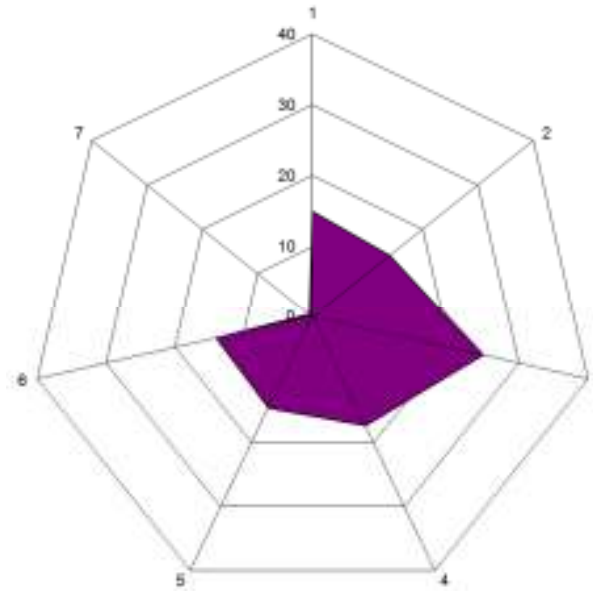
# Components of person-centred care

- Respecting individuality and values
- Promoting autonomy
- Enhancing psychological well-being
- Fostering social integration and relationships
- Meeting physical and personal needs
- Enhancing communication
- Promoting a sense of shared responsibility

# Emphasis on components of pcc



People with dementia



Carers



Professionals

- 1. Respect
- 2. Autonomy responsibility
- 3. Psychological well-being

- 4. Communication
- 5. Physical well-being

- Social integration
- 6.

- 7. Shared



# Evaluating pcc



- What tools already exist which could be used to evaluate short break services?
  - Need to be suitable for people with dementia
  - Can be used in a range of settings?
  - Which map onto the components of person-centred care?
  - Feasible to administer?





# Measures used in previous studies

- Admission to long-term care
- Quality of life measures
- Activities of daily living
- MMSE
- Neuropsychiatric index
- Dementia care mapping



# Development of new tools



- Conversational interview with people with dementia
- Self-completion questionnaire for carers
- Self-completion questionnaire for staff
- (Observation)



# Interview for people with dementia



Institute of  
Health&Society

- Existing research has demonstrated ability of people with dementia to provide feedback on services
- Techniques to facilitate discussion
  - Using photographs
  - Using talking mats
  - Informal discussion in pre-existing friendship groups
  - Need for familiar (but independent) person



# Sample items

Component of person-centred care	Question
Respecting individuality & values	Do you ever feel rushed here?
Enhancing psychological well-being	Do you look forward to coming here?
Promoting autonomy	Supposing you fancied a cup of tea or coffee, what would you do?

# Avoid literal interpretation



Institute of  
Health&Society

*“When I asked [name] if he had enjoyed his bath, he responded by saying ‘a mixture’, and then elaborated that there ‘seemed to be too many people there’. At this point [member of staff] commented that ‘there was only me there’. [Person with dementia] reiterated that he felt there seemed to be ‘quite a few there’. [Staff member] again focused on the fact that only they had been in the bathroom, adding ‘unless there was someone there I didn’t see; I don’t think there was.’”*

Field notes, extended day care



# Self completion questionnaire for carers



- Carers' views and experiences of the service
- Differences that using service makes to carer's life
- How service affects relative
- Open-ended questions for overall views of service and space for any other comments



# Sample items

Component of person-centred care	Question
Respecting individuality and values	Staff show little interest in my needs and wishes
Enhancing psychological well-being	Staff have a good understanding of what I am going through
Promoting a sense of shared responsibility	My views as a carer are listened to by those running the service

# Reluctance to criticise



Institute of  
Health&Society

- *“One thing I did notice. I was particularly thrilled about [service], there was no smell of urine and there was no institutional cooking smell.” Carer*





# Self-completion questionnaire for staff



- Person-centred approach to managing staff will facilitate delivery of person-centred care
  - Service organisation & delivery
  - Team working
  - Formal & informal supervision
  - Training needs
  - Views on person-centred care & service aims
  - Ideas for service improvement



# Sample items

Component of person-centred care	Questionnaire item
Promoting autonomy	There are opportunities to try out new ideas at work
Enhancing psychological well-being	My duties at work are satisfying
Shared responsibility	My colleagues are approachable if I need advice

# Observation

“You never really understand a person until you consider things from his point of view .... Until you climb inside of his skin and walk around in it.”



# Observation



Institute of  
Health&Society

- 'Hanging about'
  - Captures good practice
  - Need to avoid justifying practice, just notice what is happening
- Issues to consider
  - Where are people (particularly staff)?
  - What are people doing?
  - How are they interacting?



# Consider the physical environment



“I had noticed that there were staff toilets as well as a male and female toilet for service users. I asked [a member of staff] the reasons for having separate staff toilets. She commented that some service users were very dirty in the toilets .... and emphasised that the toilets sometimes got really mucky and had to be given a really good clean at the end of the day. She explicitly said that ‘you’ really wouldn’t want to go in them.”

Field notes



# Key messages for services



- Person-centred care is multifaceted
- Important to focus on components most relevant to the individual person with dementia
- Need a range of short breaks to meet variable needs
- Service evaluation tools need to reflect what the service is aiming to achieve
- Service development requires a willingness to question practice and be open to critical feedback



# Full report



Institute of  
Health&Society

- <http://www.nets.nihr.ac.uk/projects/hsdr/081511113>



# Acknowledgements



- The research was commissioned by the National Institute for Health Research (NIHR) Service Delivery and Organisation (SDO) Programme. The NIHR SDO programme is funded by the Department of Health. The views expressed in this presentation are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health

- Research team:

John Bond

Marie Poole

Catherine Kirkley

Julian Hughes

Lynne Corner

Hilary Arksey

