

***Presentation:***

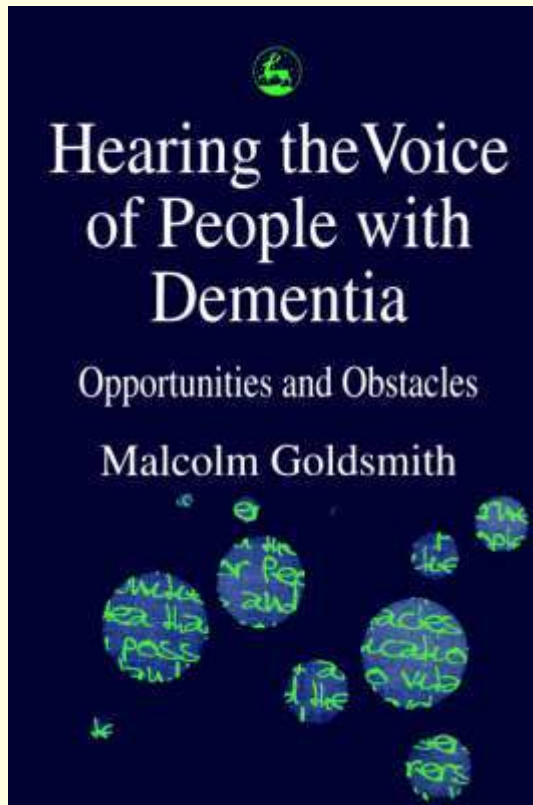
# ***Telling Dementia Stories***

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**Dementia and Ageing Research Team**  
**School of Nursing, Midwifery and**  
**Social Work**  
**The University of Manchester/**  
**Greater Manchester West (GMW)**  
**Mental Health NHS Foundation Trust**

Genio Conference  
Dublin: 5<sup>th</sup> December 2013

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Literature review  
6 interviews with people with dementia  
12 fragmented interviews  
Observation

Hearing the Voice of  
People with Dementia  
**Opportunities and  
Obstacles**  
Malcolm Goldsmith  
Preface by Mary  
Marshall: 1996

**Advisory Group**  
**The Joseph Rowntree Foundation**  
**York: 1993-1995**  
**Dr Lesley Jones; John Keady; Sue**  
**Benson; Harry Cayton; Martin**  
**Shreeve; Derek Brown**

# HEARING THE VOICE OF PEOPLE WITH DEMENTIA:

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Quote ...

‘Our knowledge about dementia is still rather basic, and understanding about the many aspects of the subject is not developing at the same speed or with the same degree of insight.’

# Dementia and Ageing Research Theme

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## Clusters

1. Biographical and narrative work
2. Psychosocial interventions
3. Lifestyle and creative arts
4. Education

## Transcending themes

- Family-centred practice
- Transitions
- Neighbourhoods

# DART Group: PhD students

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- Emma Ferguson-Coleman; Sarah Campbell; Jackie Kindell; Xia Li
- May Yeok Koo [Singapore]
- Started 2013: Lesley Jones; Rachel Plant; Sarah Hunter:

# Prime Minister's challenge on dementia: Key Points

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1. **Driving improvement in health and social care**
2. **Creating dementia friendly communities**
3. **Better research**

Emphasis: The importance of keeping people at home and in local communities

# Auguste Deter: Case Observations

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Admitted to Frankfurt am Maine insane asylum in November 1901

*Displaying signs of:*

- Weakening of the memory
- Persecution mania
- Sleeplessness
- Restlessness
- Unable to perform any physical or mental work
- Condition needs 'treatment' from the local mental institution

*Taken from the family doctor's admission note, 1901*

# Auguste Deter: Early Assessment

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Alzheimer's case note entry November 29 1901:

Writing: When she has to write Mrs Auguste D, she writes Mrs and we must repeat the other words because she forgets them. The patient is not able to progress in writing and repeats, *I have lost myself*.

Reading: She seems not to understand what she reads. She stresses the words in an unusual way. Suddenly she says *twins*. *I know Mr Twin*. She repeats the word twin during the whole interview. (p.1548)

- Auguste D died in Frankfurt am Maine on April 8 1906 aged 56 years.

## Reference:

Maurerer, K., Volk, S. and Gerbaldo, H. (1997). Auguste D and Alzheimer's disease. *Lancet*, **349**: 1546-1549



# John: My Father's Life

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- 'Living in a hole'
- Wrong Shoes
- Lists and memory aids
- Strength of our relationship
- Familiarity and routine
- A changed life

## **Reference:**

**Keady, J. and Keady, J. (2006). The wrong shoes; Living with memory loss. *Nursing Older People*, 17(9): 36-37**

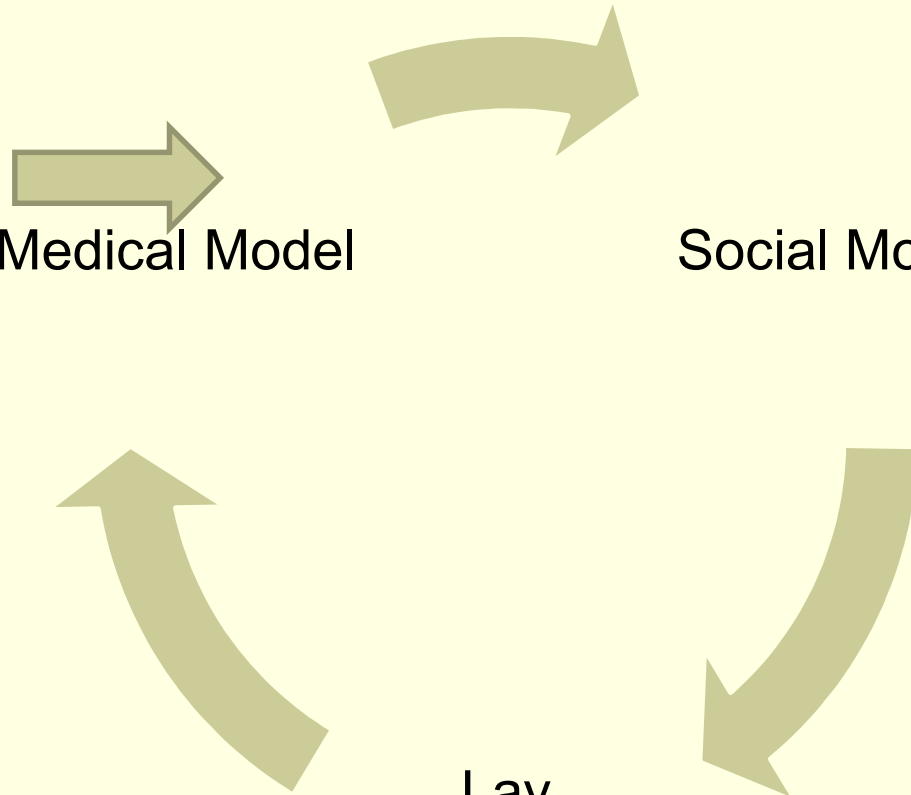
# Dementia: Different Perspectives

Community  
Public Health

Medical Model

Social Model

Lay  
Understanding  
and Experience



# Dementia: Displaced Meanings

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- **First Research Interview: 1992**

**‘Alzheimer’s disease you say? I’ve never heard of that. I just look after my husband you see’**

**and**

**‘wandering behaviour’ =  
‘his get up and go’**

# Awareness and Time

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**People can cope with this  
disease. But you need time.**

**(Sterin, 2002 p.9)**



**Reference:**

Sterin, G. (2002). Essay on a word: A lived experience of Alzheimer's disease. *Dementia: The International Journal of Social Research and Practice*, 1(1): 7-10

# Salford development: Open Doors support network

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## VALUES AND VISION

- The OPEN DOORS Support Network “opens doors” for people with dementia and carers to radically and innovatively support the delivery and development of dementia services within Salford [Mike Howorth]
- OPEN DOORS has been developed by the initial collaboration from representatives from The Salford Memory Assessment and Treatment Service, Reach Beyond, Day Hospital and inpatient dementia services at Woodlands and the University of Manchester, with funding supported by Salford PCT and the University of Manchester

# **HBRC Research Strategy**

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The Research Strategy and Values has been developed and led by people with dementia with the collaboration of families, services and other organisations, including myself

# HBRC: Our Values

*As people with dementia we want...*

- The right to run risks
- To share positive messages about living with our dementia
- To remain connected to our everyday lives, communities and the places where we live.
- The opportunity to take part in the research that is done in our name.

# We have Four Research 'wants'

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## 1. Always Remember It's About Me

*As a person with dementia I want to be involved in research that:*

- Means something **to** me and others in my life
- Is about my everyday life
- Is about things I can understand and relate to



# Interactive Lunchtime Sessions

## **20 April What is 'Normal' in Normal Brain Ageing?**

*Facilitated by Caroline Swarbrick*

### **What to expect in normal brain ageing**

Dr Neil Pendleton (Geriatric Medicine)

### **Living with young onset Alzheimer's disease**

Mrs Ann Johnson (person living with dementia and Alzheimer's Society Ambassador)

## **29 May Diagnosis, Assessment and Dementia**

*Facilitated by John Keady*

### **The dementia assessment process**

Dr Anna Richardson (Consultant Neurologist, SRFT)

### **Support steps after the diagnosis: what helps and what it all means**

Mike Howorth (person living with dementia and facilitator of the Open Doors Network, Salford, GMW)

## **2 July Assistive Technology in Dementia**

*Facilitated by Neil Pendleton*

### **AT Dementia**

Simon Burrow (Programme Director MSc Dementia Care, UoM)

### **Our life story**

EDUCATE (Group of people living with dementia from Stockport)

## 2. To Get The Most from Life

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*As a person with dementia I want to be involved in research that:*

- Focuses on my abilities and not just on what I can't do anymore
- Helps my confidence and self-belief in what I am doing
- Says something about my physical health as well as my dementia
- Reaches out to others who may be isolated

# 3. Having a Healthy Memory

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*As a person with dementia I want to be involved in research that:*

- Makes life far more simple
- Exchanges ideas
- Finds out what works and why

## 4. Keeps Me Involved

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*As a person with dementia I want to be involved in research that:*

- Joins up my experience with that of other people
- Is done locally and with my consent
- **Listens to what I say and treats me as a person**

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# **Centre Stage Diagrams Phase-1**

**Acknowledgements to Dr Sion Williams,  
Bangor University**

**And all our PhD students ...**

# Development of Research

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- Objectivist vs. Subjectivist debates
- Biographical and narrative research methods

‘Constructivist grounded theory’ that addressed the:

**‘mutual creation of knowledge by the viewer and viewed {that} aims towards interpretive understanding of subject’s meaning’**

**(Charmaz, 2000 p.510)**

## Reference

**Charmaz, K. (2000). Grounded Theory: Objectivist and Constructivist Methods. In: N.K. Denzin and Y.S. Lincoln (Eds). *Handbook of Qualitative Research*, 2nd Edition. Thousand Oaks: Sage. Pp. 509-535**

# Sarah's Biography

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- 70 year old woman who lives(d) alone;
- Supported by her friend Laura;
- Diagnosed with AD in September 2002;
- First practitioner – co-research visit commenced in March 2004 **and is on-going.**

# Sarah's chapter headings

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The development of Sarah's Life Story Script resulted in:

- **Chapter 1 – An introduction to my life**
- **Chapter 2 – Childhood**
- **Chapter 3 – Teenage years**
- **Chapter 4 – Working life**
- **Chapter 5 – Married life**
- **Chapter 6 – Life after the death of my husband**
- **Chapter 7 – Megan and the fellowship**
- **Chapter 8 – Current life with Laura**



## Chapter 5 – Married Life: Extract

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I married when I was about 29; I had several boyfriends before. We went out for 12 months, there were no signs of any problems between us; it went very well. He did his National Service and then we got married, and it didn't last, the marriage lasted but nothing else! I had 2 children eventually. It wasn't a very good marriage *'How dare you do this, How dare you do that'*. He had a violent, explosive temper. Great long sulks, this was the way he was. I didn't expect him to be like that, there had been no signs of that before we married.

## Chapter 8 – Current life with Laura (Extract)

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Although I live alone I'm not alone. And I just love my life at the moment. I go to the day centre and I love it there. And I got on well with the older people there. Because I like older people, I always have done they fascinate me. **I know the illness will progress so I do everything now**; I live life to the full. I try not to look too far ahead. I tell people I have Alzheimer's disease, it's nothing to be ashamed of and we all know where we stand.

# Working with Sarah

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- Developing a Life Story Script and Personal Theory involved 19 researcher-practitioner visits;
- The first 7 visits were with Sarah and Laura; all subsequent visits were with Sarah alone;
- Of the 19 research contacts, two became clinical visits.

# Sarah's Storyboard

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## **(What) Lonely journey (1)**

### **Why?:**

- **Only and lonely child**
- **Respite: leader of the bleeders**
- **Marriage and addiction**
- **Worm that turned**
- **Merry widow**

## **(What) Journey of survival (2)**

### **Why?:**

- **Recovery, Anonymous and Fellowship**
- **'Beautiful spiritual messages'**
- **Chris and the dog**
- **Dad and the 'saddest day'**

## **(What) Making mistakes (3)**

### **Why?:**

- **It isn't normal**
- **Embarrassment**
- **It doesn't add up**
- **'Where do I go?'**

## **(What) Walking a pathway (4)**

### **Why?:**

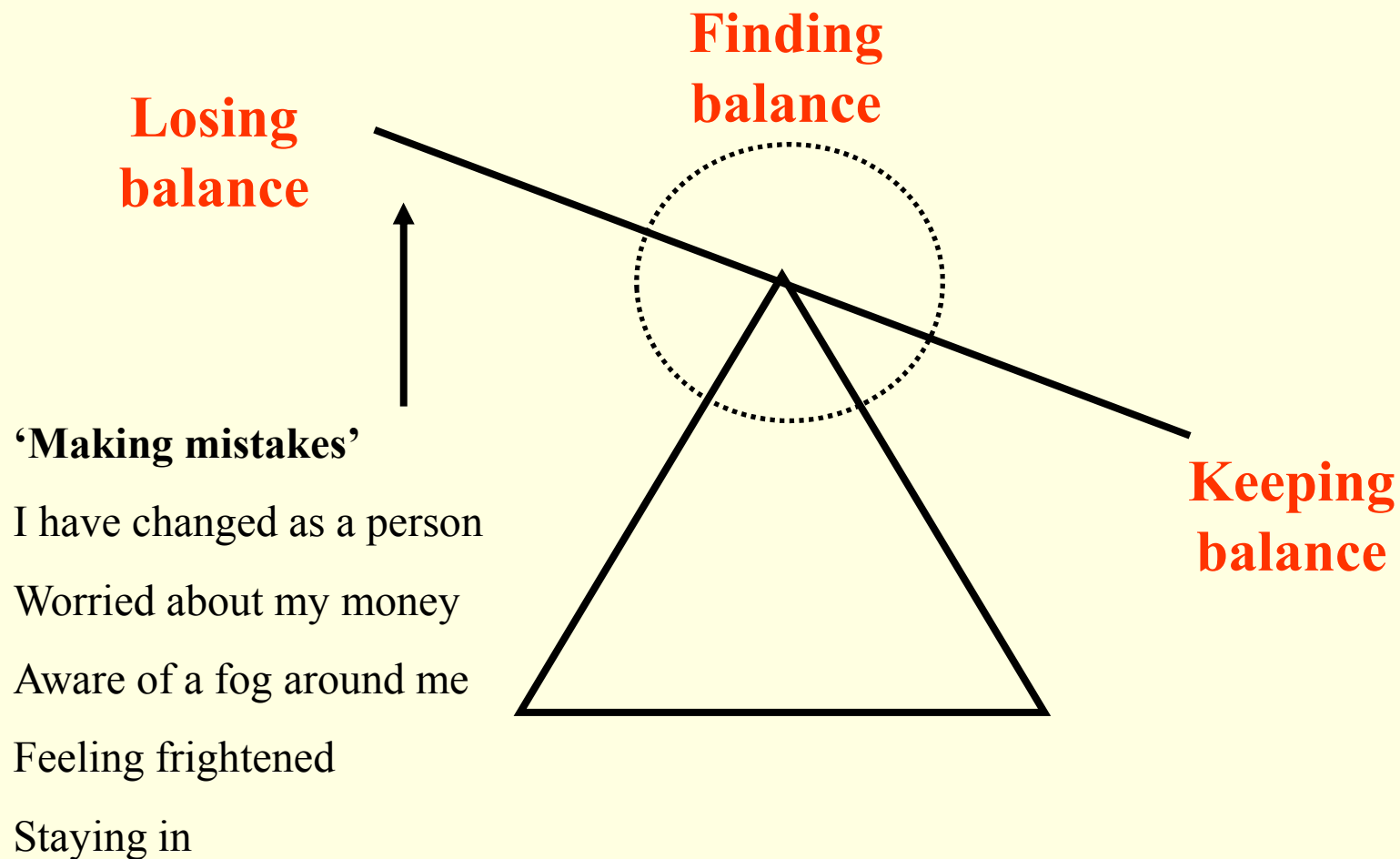
- **Journeying**
- **Worm that turned too late**
- **Contentment and later life**
- **People that matter**

# Sarah's diagrams

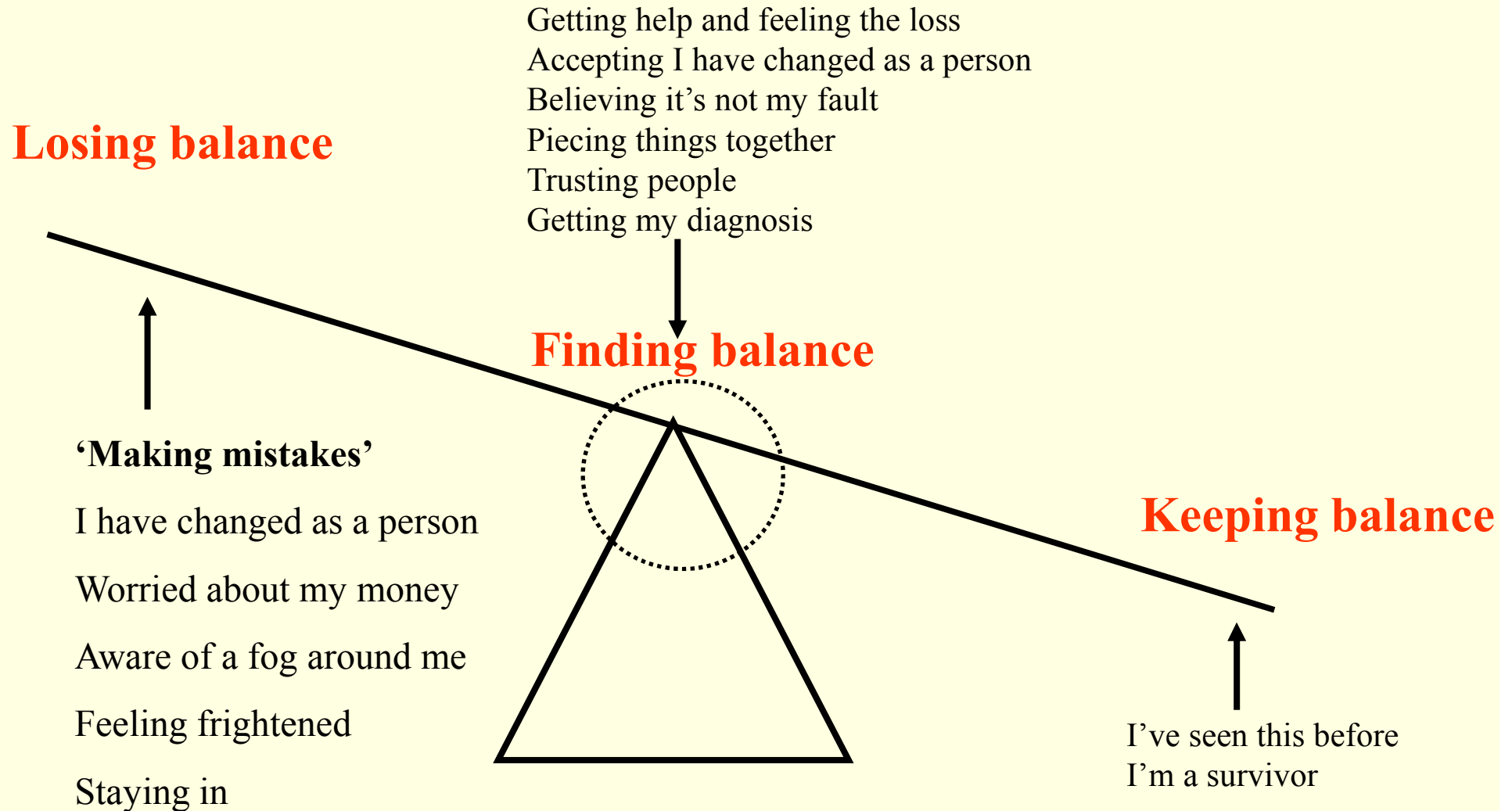
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- Visually, Sarah saw her experience as a 'see-saw'
- Movement and momentum are constantly changing and stability goes 'up and down'
- Three diagrams were eventually co-constructed as an agreed representation of her life.

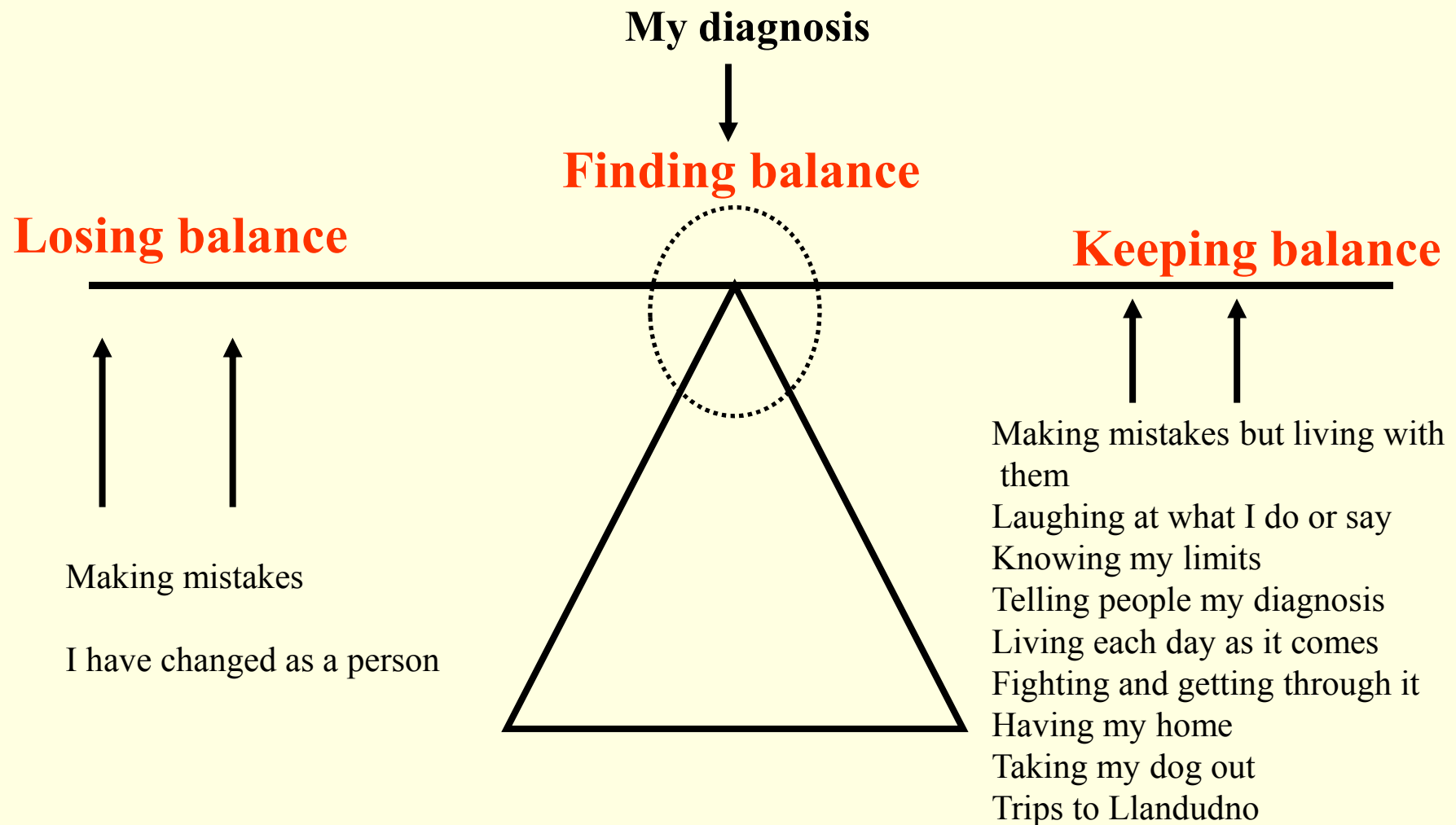
# Diagram 1- Sarah: Losing Balance



# Diagram 2 – Sarah: Finding Balance



# Diagram 3 – Sarah: Keeping Balance





# Sarah: Practice implications

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- Working from Sarah's knowledge, words and understanding of her condition
- Substituting making mistakes for dementia in dialogue
- Keeping the life story script as a living document and rehearsing new lines when recall becomes uncertain/altered
- Providing supportive counselling for an abusive marriage
- Valuing person knowledge
- Changing practice through new working procedures

# Practice Change: Reconstructing Memory Work

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- Carry out assessments in the home to introduce the concept of 'testing' in a less formal way and reduce performance anxiety.
- Control over sharing of the diagnosis is given to the client/family, where appropriate, they can choose who shares the diagnosis with them i.e. doctor, nurse, occupational therapist. The person can also choose the location of this procedure i.e. their own home.
- Facilitate an understanding that memory clinic involves a full psychosocial service, as well as offering medication.
- Joint assessments
- Less reliance on the use of objective measures of 'assessment testing'

## Reference

Keady, J., Williams, S. and Hughes-Roberts, J. (2005). Emancipatory practice development through life-story work: Changing care in a memory clinic in North Wales. *Practice Development in Health Care*, 4(4): 203-212.

# Centre stage diagrams

## Phase-2 [2009 onwards]

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- Reached by the researcher and participant mutually engaged and interacting with two inter-related questions:
  - i) **who** is centre stage in that lived experience?
  - ii) **what** is the centre stage storyline in the lived representation of the phenomenon under study?
  - iii) **where** is centre stage in that lived experience?
- Presents 'storied meaning' and 'diagramming' into a method of data collection, analysis and theory development/presentation
- Positioning Theory underpins the diagrams

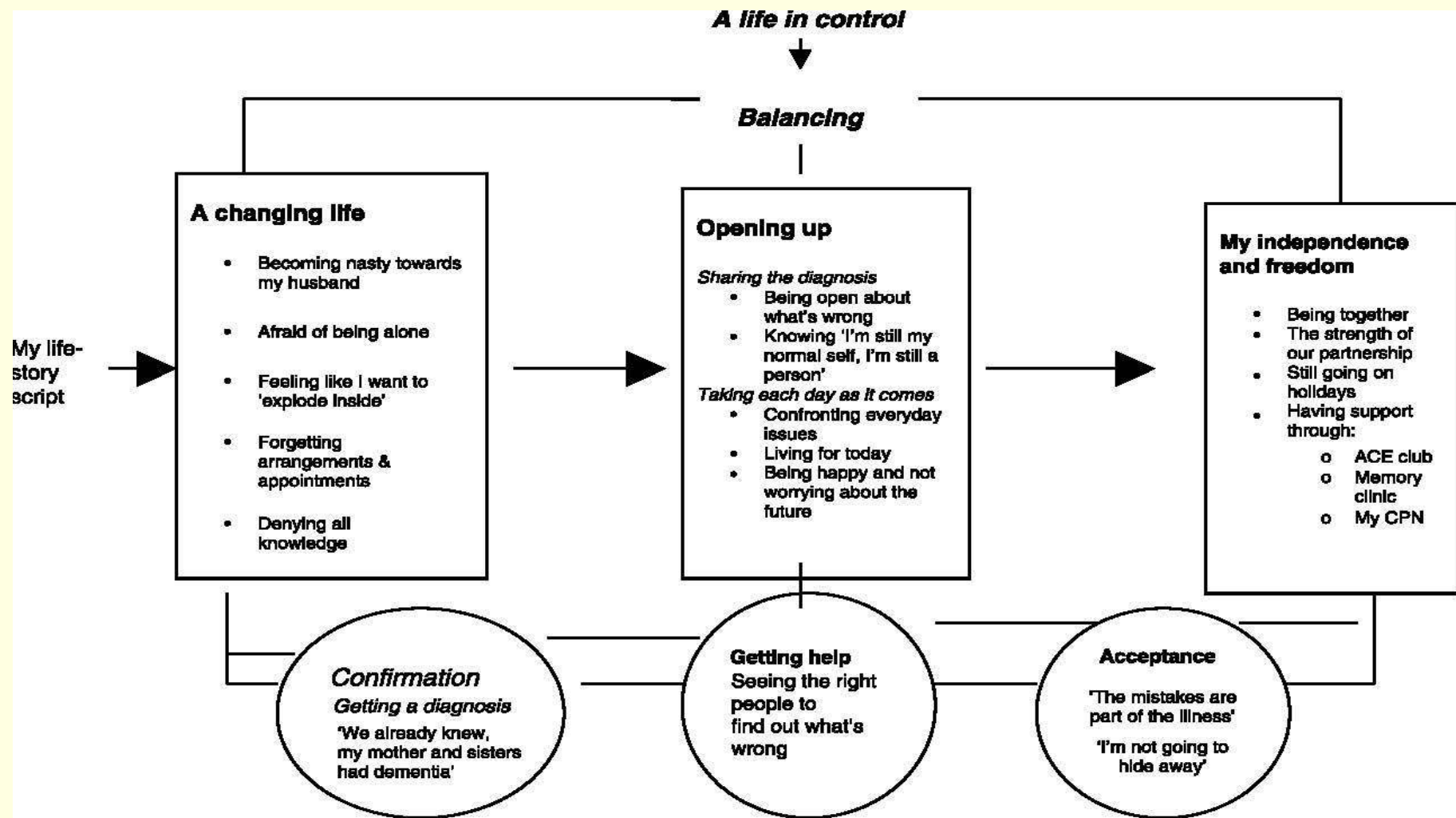


Figure 5.2 MQ's personal theory.

**Reference:**

Keady, J., Williams, S., Hughes-Roberts, J, Quinn, P. and Quinn, M. (2007). 'A Changing Life': Co-constructing a personal theory of awareness and adjustment to the onset of Alzheimer's disease. In: M. Nolan, E. Hanson, G. Grant and J. Keady (Eds). *User Participation Research in Health and Social Care: voices, values and evaluation*. Maidenhead: Open University Press/McGraw Hill. Pp. 69-88

MANCHESTER  
1824

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Mental Health NHS Foundation Trust



Royal Bolton Hospital  
NHS Foundation Trust



# “Getting To Know Me”: A Greater Manchester training resource for supporting people with dementia in general hospitals

**Ruth Elvish, Simon Burrow, John Keady, Kathryn Harney**



University of Manchester/Royal Bolton Hospital NHS Foundation Trust/  
Greater Manchester West Mental Health NHS Foundation Trust/Dementia and  
Ageing Research Team

A Health Innovation and Education (HIEC) Cluster Study

# People involved

- University of Manchester: Ruth Elvish, Simon Burrow, John Keady, Rosanne Cawley, Kati Edwards, Jenna King, Abi Tarran-Jones, Pamela Roach
- People with dementia and carers: Brian Briggs, Ann Johnson, Mike Howorth (GMW)
- Greater Manchester West Mental Health NHS Foundation Trust: Kathryn Harney, Rilwan Adebisi, Harry Johnson
- Royal Bolton Hospital NHS Foundation Trust: Andrew Powell, Pat Graham, Julie Gregory, Gwen Ainsworth, Stephanie Jolly, Gillian Zajac-Roles, Rebecca Wild, Emily Feilding, Nicola Rafter
- Salford Royal NHS Foundation Trust: Janice McGrory
- Central Manchester University Hospitals NHS Foundation Trust: Nicola Johnson, Danielle Beswick

This card is for you to complete (or it may be completed by a relative or friend on your behalf). It is designed to help us to get to know you better.

Being in hospital can be an unsettling time. We hope the information you can share about yourself will help us to get to know you. It will give us ideas on how to talk to you, how to help you pass the time and how to help you feel at ease.

This card is designed to be viewed by the bedside. It is not a medical document and you do not have to complete it. If you do (or the person if you are completing it on behalf of someone else) please be mindful not to include information you would want to be kept confidential.

**Information for relatives and friends:**

- We really value the information you are able to share with us that will help us improve our care.
- Please don't hesitate to speak to the nursing team if you have any further information, ideas or tips on how we can best meet the needs of your relative/friend.
- If you would like to be more involved in the care of your relative/friend whilst they are in hospital please let us know.
- If you have any questions about sources of support/information/advice for either yourself (as a carer) or for your relative/friend, please ask.



Funded by Greater Manchester Health, Innovation and Education Cluster

And developed by a partnership between:



Bolton  
NHS Foundation Trust



Greater Manchester West  
Mental Health NHS Foundation Trust



# “Getting to Know Me”

My name is:

I like to be known as:

**Events from my past/places I have lived that are important to me:**

**Important aspects of my daily routine:**

**People or pets that are closest to me:**

**What helps me when I am feeling worried or upset:**

**How I like to spend my time:**

**My likes and dislikes:**

**Any other useful information:**



## “Getting to Know Me” - Key Messages

Focus on feelings and try  
put yourself in the  
person’s shoes

Try to help create a sense  
of security and familiarity

See all behaviour as  
having “meaning”

Provide opportunities for  
meaningful activity

Think about how best to  
support and involve  
relatives

See the person not the  
dementia

# Final messages

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- Life stories are about us
- The right for life privacy vs public knowledge
- Acting on the life story is the next step
- Life story is person-centred care
- How do we know what we do is helpful?

# Thank You

[John.Keady@manchester.ac.uk](mailto:John.Keady@manchester.ac.uk)



# A selection of publications

Roach, P., Keady, J. and Bee, P. 'It's easier just to separate them': Practice constructions in the mental health care and support of younger people with dementia and their families. **Journal of Psychiatric and Mental Health Nursing**, 2012. Available early view: doi: 10.1111/j.1365-2850.2011.01836.x

Brown Wilson, C., Swarbrick, C., Pilling, M. and Keady, J. The Senses in Practice: Enhancing the quality of care for residents with dementia in care homes. **Journal of Advanced Nursing**, 2012. Available early view: doi: 10.1111/j.1365-2648.2012.05992.x

Williams, S. and Keady, J. Centre stage diagrams: a new method to develop constructivist grounded theory - late-stage Parkinson's disease as a case exemplar. **Qualitative Research Journal**, 2012, 12(2): 218-238: doi: 10.1177/1468794111422034

Williams, S. and Keady, J. Centre Stage Diagramming: Late-stage Parkinson's disease and Alzheimer's disease. **Journal of Aging Studies**, 2012, 26: 204-213

Keady, J., Campbell, S., Barnes, H., Ward, R., Li, X., Swarbrick, C., Burrow, S. and Elvish, R. Neighbourhoods and Dementia in the Health and Social Care Context: a realist review of the literature and implications for UK policy development. **Reviews in Clinical Gerontology**, 2012, 22: 150-163.

Ward, R., Howorth, M., Wilkinson, H., Campbell, S. and Keady, J. Supporting the friendships of people with dementia. **Dementia: the international journal of social research and practice** 2012, 11, 3, 287-303