

# *Younger People with Dementia: Planning Practice and Development- Revisited*

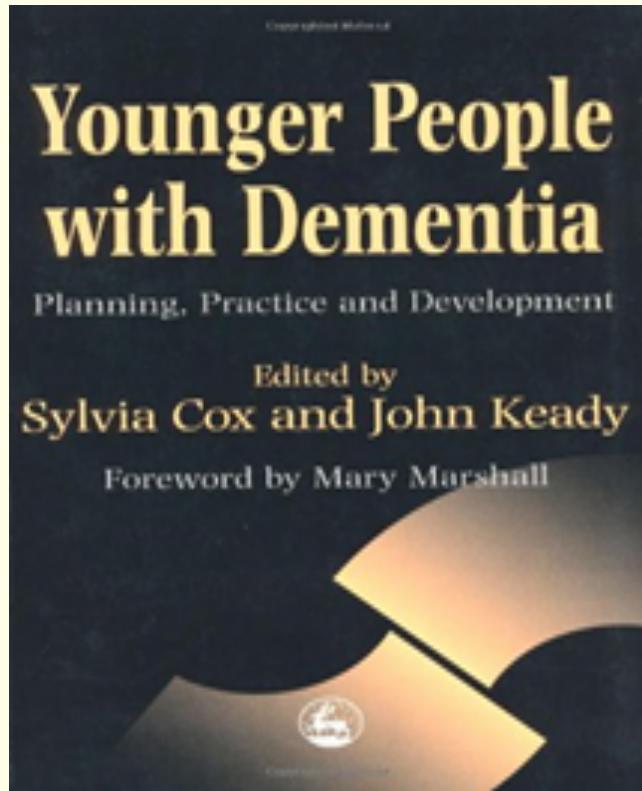
Presentation by:

**John Keady, Caroline Swarbrick,  
Jackie Kindell:** Dementia and Ageing  
Research Team, The University of  
Manchester and **Pam Roach:**  
University of Alberta, Edmonton,  
Alberta, Canada

Young Onset Dementia  
Conference  
Dublin: 20<sup>th</sup> November  
2014



This presentation is dedicated to my friend and colleague Sylvia Cox who died earlier this year. She was 66.



# Presentation Ambition

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**To outline the development of the 1999 book and to trace some recent research developments**

How? ...Through 4 channels

1. **Steps to the 1999 book**
2. **What did we say?**
3. **What is happening now?**
4. **Where do we go?**

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## 1. Steps to the 1999 book

..... Took 16 years

***The best of the best***



# Recommended reading in 1982

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**Dementia is a ‘tragic disorder’:**

**‘...sometimes it seems as if the true self dies long before the body’s death, and in the intervening years a smudged caricature disintegrates noisily and without dignity into chaos.’ (p.39)**

**Reference:**

Pitt, B. (1982). *Psychogeriatrics: an introduction to the psychiatry of old age*. Second Edition. London: Churchill Livingstone.

# Whilst there is a lot to criticise...

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- n In 1985 Warley Hospital started one of the first wards specifically dedicated to younger people with dementia
- n There was an organisational admission that the needs of younger people were somehow ‘different’ and that needs were not easily assimilated into the psychogeriatric service model of the time
- n Did not get exposure to this ward environment
- n Early evaluation of dedicated service

# Younger People Always There ...

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1980s-1990s...

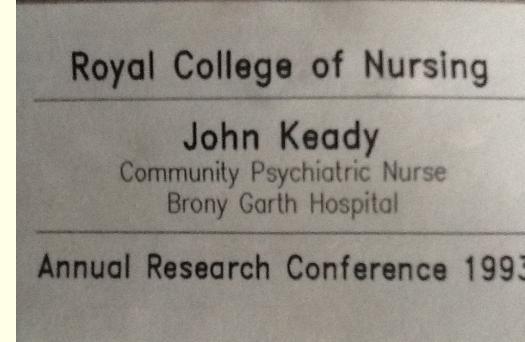
Staff Nurse, Deputy Charge Nurse, Community  
Psychiatric Nurse for the 'Elderly Mentally Infirm'

Early 1990s ... Research work on individual adjustment  
and personal meanings of dementia ...

Motivation: to understand practice better



# John: Early work



## Articles

- Keady, J. and Matthew, L. Younger People with Dementia. *Elderly Care* 1997, 9 (4): 19-23
- Keady, J. and Nolan, M. Raising the Profile of Young People with Dementia. *Mental Health Nursing* 1997, 17(2): 7-10
- Keady, J. The Experience of Dementia: A Review of the Literature and Implications for Nursing Practice. *Journal of Clinical Nursing (Review Section)* 1996, 5(5): 275-288
- Williams, O., Keady, J. and Nolan, M. Younger onset Alzheimer's disease: learning from the experience of one spouse carer. *Journal of Clinical Nursing* 1995, 4(1): 31-36
- Keady, J. and Nolan, M.R. Younger Onset Dementia: Developing a Longitudinal Model as the Basis for a Research Agenda and as a Guide to Interventions with Sufferers and Carers. *Journal of Advanced Nursing* 1993, 19: 659-669

## Conferences

- Keady, J. 'Younger People with Dementia: Research Advances and Practice Development' to the 'Younger People with Dementia: 2nd National Conference'. March 1996, University of Stirling, Stirling

- Keady, J. and Nolan, M. 'Carers, Coping and Dementia : A Quantitative Analysis of the Carers Assessment of Managing Index (CAMI): A New Instrument to Appraise Caregiving Coping Behaviours' to 'A Decade of Change', the 10<sup>th</sup> International Conference of Alzheimer's Disease International. August 1994, Edinburgh University, Edinburgh

# Sylvia's writings at this time

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- n Cox, S. (1991) *Pre-Senile Dementia: An Issues Paper for Service Planners and Providers*. Planning Report 1. Stirling: Dementia Services Development Centre
- n Cox, S. and McLennan J.K. (1994) *A Guide to Early Onset Dementia*. Stirling: Dementia Services Development Centre
- n Cox, S. Gilhooly, M. & McLennan J. (1996) *Dying and Dementia*. Stirling: Dementia Services Development Centre

## 2. What did we say?

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- n Started discussions about content in 1996
- n Contacted people we knew and some we didn't
- n Prepared a book outline
- n Book outline turned down by publishers a number of times: '*not enough interest*'; '*too specialised*'; '*it wont sell*'
- n Jessica Kingsley agreed to publish in 1997 and issued contracts
- n Book delivered on time and published in 1999

Copyrighted Material

# Younger People with Dementia

Planning, Practice and Development

Edited by  
**Sylvia Cox and John Keady**

Foreword by Mary Marshall



Copyrighted Material

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### THE CONTRIBUTORS

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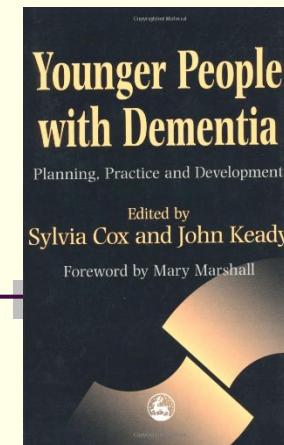
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320

326

# The 1999 Book

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## **Some of the Contents that still strike a chord**

- n Epidemiology, Employment, Young carers
- n Rare and unusual dementias
- n What is 'State of the art care?'
- n Poetry and creative approaches to understanding experience

## **What the book lacked**

- n Perspective of person with young onset dementia
- n Intergenerational experiences
- n Policy emphasis
- n Focus on 'doing' in the real/outside world

# YPWD Book: Changing the Mind-Set (Chapter 17)

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The argument is not that younger people with dementia deserve better or more carefully developed services than older people, rather that they and their support networks (which includes employers, where relevant) have different, though intertwined, needs.

(p293)

Original Conclusions/Thoughts ...

# YPWD Book: Changing the Mind-Set (Chapter 17: Final Summary pp 293-294)

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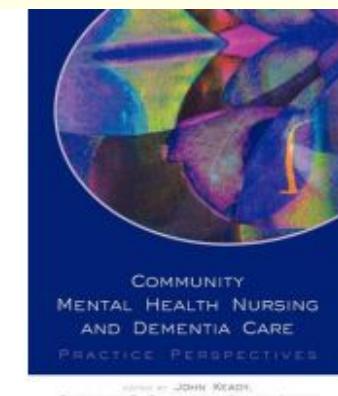
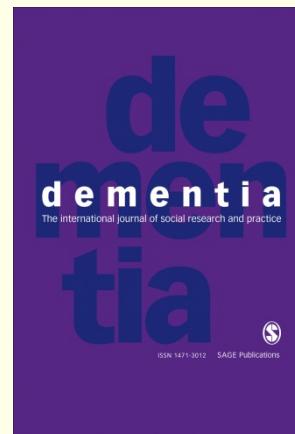
- n Points in the life stage: life stories and current roles, responsibilities and concerns
- n Identifying lifestyle changes – what people view as significant and meaningful in their lives
- n Retained mobility and physical strength
- n The presence and importance of dependent children: from infants to teenagers to grandchildren
- n Financial commitments and concerns
- n Uncertainty over genetic issues arising from a diagnosis?
- n Changing patterns of social contacts and networks
- n A changed future and everyday life, including preparation for palliative care needs

# What this meant (for me)

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To continue to seek opportunities to support and work within the field of younger people with dementia if the opportunity arose, for example through:

- n Alcohol related dementia as part of the risk and dementia study (2003-2006)
- n Manchester Camerata (orchestra) and dedicated young onset dementia service in central Manchester
- n The Dementia Journal, e.g. Kate Swaffer's editorial in the current edition: 13(6)
- n ACE Club in North Wales



### 3. What is happening now? [in our corner/s of the world]

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Three recent developments stemming from our research work:

- n Dr Pam Roach: Funding - MRC [2007-2010] then Alzheimer's Society Canada 2011-onwards
- n Jackie Kindell: Funding - Dunhill Medical Foundation [2011-ongoing]
- n Dr Caroline Swarbrick: Funding - ESRC/NIHR [2014 – ongoing]

# **A family centred study of younger people with dementia**

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**First supervised grant when starting at the University of Manchester in October 2006**

**Study aims:**

**To gain an in-depth understanding about how families experience young onset dementia by focusing on the construction of family storylines framed in the context of everyday life**



# Families and Young Onset Dementia

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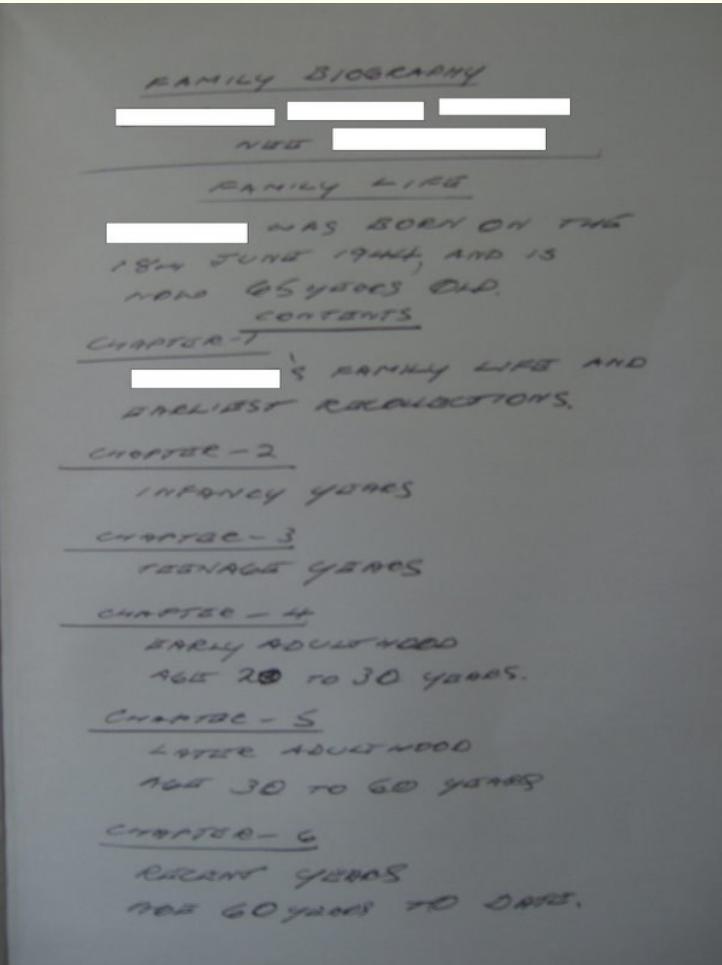
- n Supervisors: John Keady, Penny Bee (and Kevin Hope for the first year)
- n Longitudinal data collection: 12-15 months spent visiting around once a month with each family
- n Family-led co-construction of family biographies
- n Narrative Analysis (Cathy Riessman-visual artefacts)

# Participating Families

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<i>Younger person with dementia:</i>	Family 1	Family 2	Family 3	Family 4	Family 5
<i>Diagnosis:</i>	John (47)	Henry (61)	Sandra (61)	Susan (64)	Irene (60)
<i>Participating Family Members:</i>	Wife: Marjorie (55)	Wife: Mary (53)	Husband: William (72) Daughter: Diane (32)	Husband: William (73) Brother: James (47) Uncle: Andrew (76)	Husband: James (58)

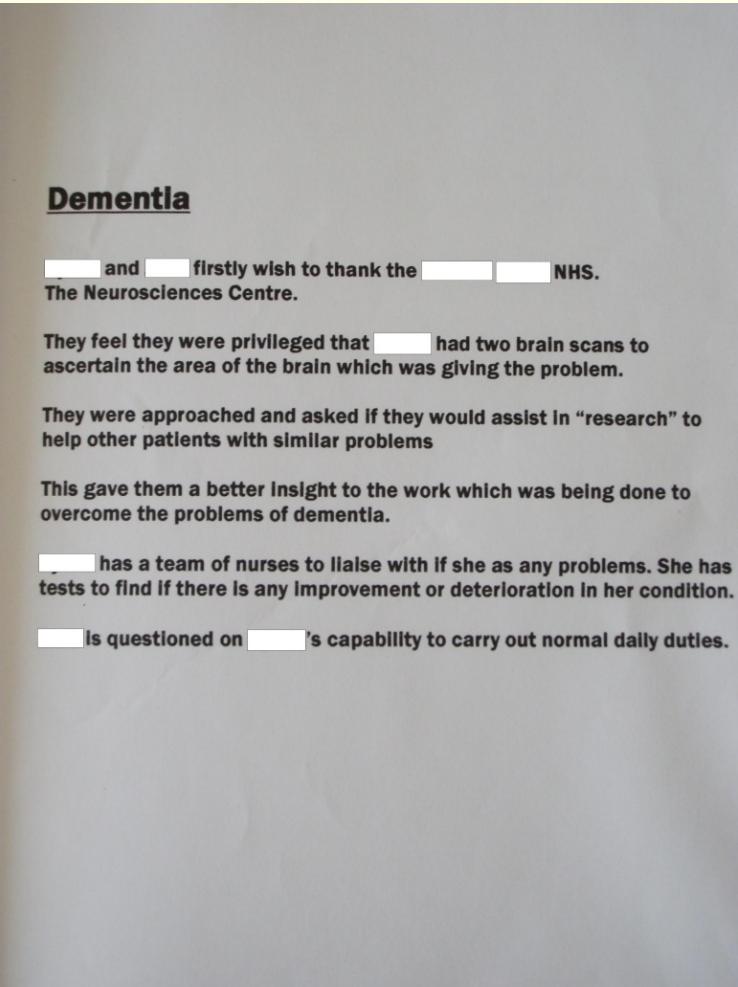
# Family Biography Examples



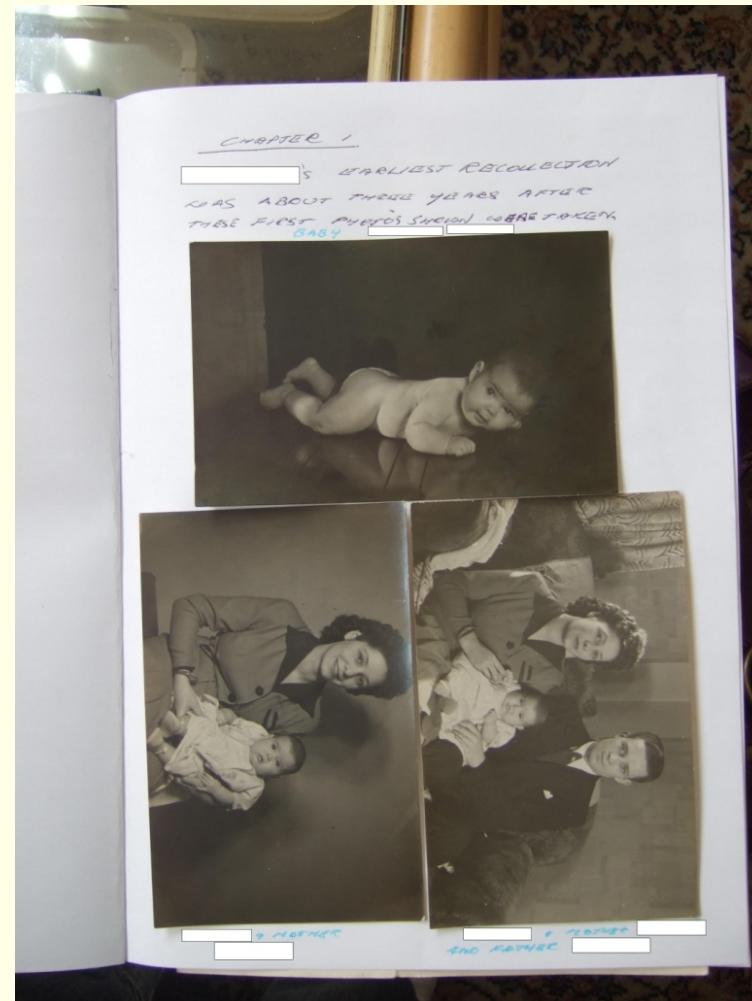
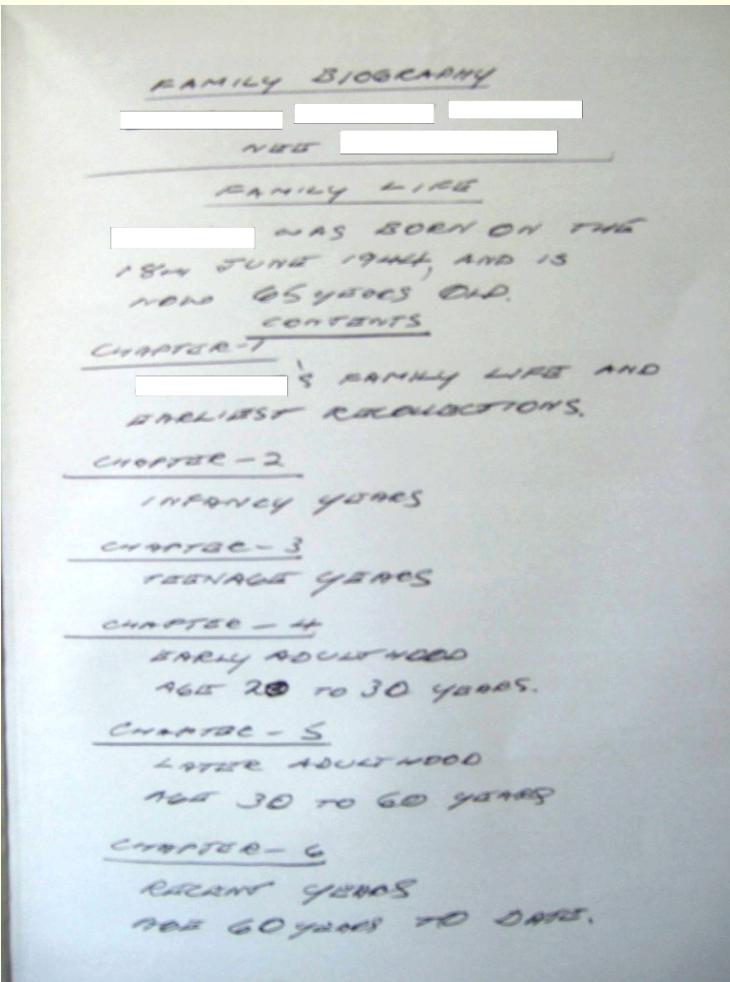
# Family Biography Examples



# Family Biography Examples



# Family Biography Examples



## Chapter 7

### - How LIFE IS NOW -

"We're stronger now than we've ever been"

"It's the happiest time of our life now!"

#### OUR SONG

OUR LIFE HAS BEEN A BURDEN  
SOME TIMES IT'S VERY HARD BUT YOU  
LOVE ME WHEN I'M HAPPY AND YOU  
LOVE ME WHEN I'M SAD.  
WE BATTLE ON TOGETHER SOME TIMES  
I KNOW NOT WHY BUT WE HAVE  
GOT EACH OTHER AND I KNOW  
THAT WE WILL GET BY.

I'LL GET BY BECAUSE YOU LOVE ME  
I'LL GET BY BECAUSE YOU CARE  
AND WE'LL GET BY MY DARLING  
FOR OUR LOVE IS WHAT WE SHARE  
AND YOU'LL GET BY MY DARLING  
BECAUSE YOU GOT THE BIT OF  
RIGHT AND YOU ALWAYS THERE  
BESIDE ME YOU TRY TO HOLD ME  
THROUGH THE NIGHT.  
I'LL GET BY BECAUSE YOU LOVE ME

# Significant Findings



- n Clinical decision making and relational care (particularly support through transitions) through **enhanced knowledge of family biography and history**
- n Through narrative analysis, methods of family coping were identified as ‘family storylines’: **Agreeing; Colluding; Conflicting; Fabricating; Protecting** . Types of storylines employed by families are influenced by family biography and this knowledge can highlight areas of increased need and support.
- n Development of preliminary family biography tool (**Family-AiD**) to support care provision.

**Family Assessment in Dementia (Family-AiD)**

Carefully read each statement below and show if it applies to you by placing a tick in the space available. SA = Strongly Agree; A = Agree; D = Disagree; SD = Strongly Disagree

***Since the onset of dementia in our family...***

		SA	A	D	SD
1	We support each other when we experience a crisis				
2	We are able to talk to each other about our real fears and feelings				
3	We think of different ways to solve problems that consider all our points of view				
4	We have been able to continue with our day-to-day lives as normal				
5	We gain strength from one another				
6	We have been able to become closer as a family				
7	We can openly share our concerns with our extended family network				
8	Our life together as a family is still very similar to what we imagined it to be at this time in our lives				
9	Love is the tie that binds our family together				
10	The roles and responsibilities of some family members remain unchanged				
11	We have found new ways to live positively as a family				
12	Our identity as a family helps us to get through each day				

# Post Doctoral Work: Family Experience in Transitions and Health Expectations

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- n Pamela Roach, Neil Drummond
- n University of Alberta, Edmonton, Alberta, Canada
- n Postdoctoral Study funded by the Alzheimer Society of Canada
  - n Currently ongoing
  - n Developing a model of transition and health expectation for families living with young onset dementia
  - n Identifying unmet needs and service gaps

# Significant Findings to Date

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- n Themes emerging from Framework to date:
  1. Diagnosis
  2. Finances
  3. Relationships
  4. Meaningful Activity
    - n The loss of work or purposeful activity reported as a traumatic event. Impacted all other areas and often prompted help-seeking behaviour.
    - n Two subthemes:
      - § Traumatic cessation of work
      - § Need for purposeful activity

**Jackie Kindell**  
Clinical Research Fellow/  
Speech & Language Therapist

**Life story work in  
semantic dementia**

# Semantic dementia

- **Biomedical literature:**
  - Language changes on tests (e.g. Gorno-Tempini et al 2011)
  - Changes to personality and behaviour
  - Brain changes, scanning, genetics
  - All important for differential diagnosis
- **Lack of research on the ‘everyday’:**
  - Living with semantic dementia (Kindell, Sage, Wilkinson & Keady 2014)
  - Adapting to conversation (Kindell, Sage, Keady & Wilkinson 2013)



## ***Conversation Analysis***

Video at home



## ***Life story work***

Interviews, photos,  
objects, music etc



5 families



interaction in  
context



Analyse existing strategies



Refine/promote strategies  
to support interaction  
and embodied actions

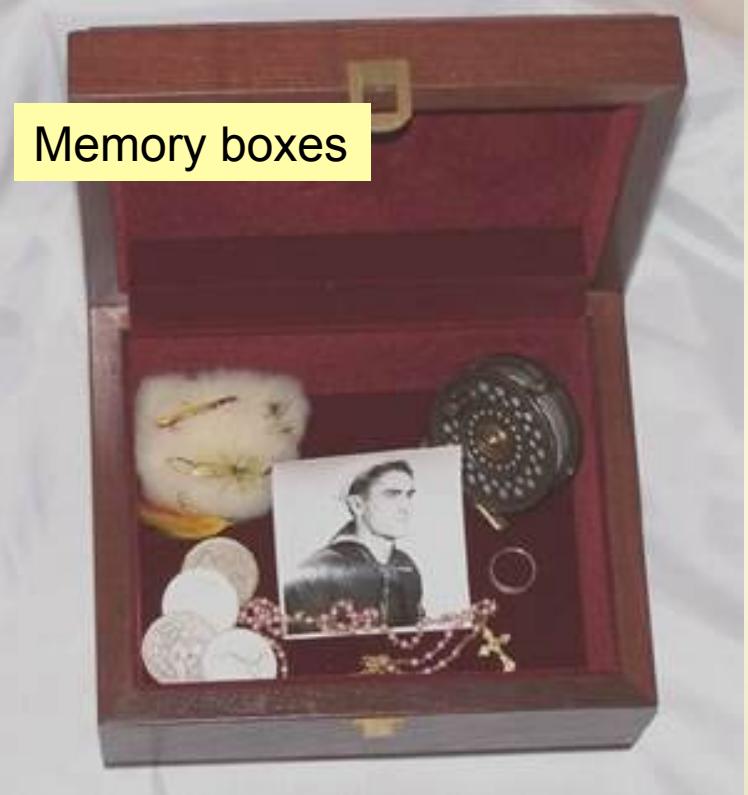


## ***Clinical reflection***

Explore, develop, refine ...  
an intervention

Ethical approval  
MCA 2005, Lack capacity  
'appropriate body'  
NHS, Trust, University  
Video

# Life story work - Products to support participation in conversation



Memory boxes



Memory books

Draw on relative preservation of long term memory  
in *dementia*  
? How would/could this work in semantic dementia?

# Creatively supporting interaction

Sarah: Life story music DVD

- Singing – interaction and identity
- Embodied - touch



# Summary

§ Individualised intervention = tailored outcomes...

  § Life story resources... (Kindell, Burrows, Wilkinson & Keady 2014)

§ Emotional connections

  § *Psychological and emotional coping*

§ Building new connections (in care)

  § *Attitudes & satisfaction with care*

§ Practical care connections

  § *Evident in personalised care plan*

§ Interactional connections

  § *In the moment effect on interaction*

  § *Video/audio exploration with life story resource*

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n Slides shared by Dr Caroline Swarbrick

# Age UK Salford – Mount Chapel Champions



Photo acknowledgement: Age UK Salford



# Established 12mths



Meet every Monday 1-3pm



Currently 25+ members



People living with dementia and families



Aim is to provide peer support and develop social networks



Group organises local social events  
(recent 70s disco)



# Joy Watson: Living Well with Dementia

**What I have accomplished in 12mths after diagnosis:**

- Turned Eccles ‘Dementia Friendly’
- Zip wired across Salford Quays (has a fear of heights!)
- Dementia Friends Champion and trainer (<https://www.youtube.com/watch?v=NlboQ5lzlwc>)
- Winner of the ‘Dementia Friends Champion’ award at the Alzheimer’s Society Dementia Friendly awards ceremony

# The Journal of **DementiaCare**

For all who work with people with dementia

Vol 22 No 6 November/December 2014



**Make a  
point about  
dementia**

**Also inside  
this issue:**

- The Forced Care Framework – guidance for staff
- DCM: building up a bigger picture ■ Intensive Interaction



# Neighbourhoods and Dementia: A Mixed Methods Study

5-Year programme grant

Part of the Prime Minister's Challenge on Dementia



# Neighbourhoods Study



## AIMS

- n To address the meanings, experiences, and structure of neighbourhoods for people living with dementia, their care partners and other in-contact-groups and individuals
- n To learn from the process and praxis of making people living with dementia and their care partners core to the research agenda
- n To encourage innovative technological advances in dementia studies and in the development of a neighbourhood model of dementia

# Neighbourhoods Study Context

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- n Commenced 1<sup>st</sup> May 2014; Ends 30<sup>th</sup> April 2019
- n Involves 10 co-investigator organisations (27 named co-investigators): Liverpool University, Lancaster University, Salford University, Stirling University, University College London, Greater Manchester West Mental Health NHS Foundation Trust, Pennine Care NHS Foundation Trust, **ACE InSight CiC**, the British Deaf Association and the Center for Dementia Research, Linköping University, Sweden:
- n Ten partner organisations, incl: Finerday; Manchester m-Health Ecosystem; North West People in Research Forum
- n The Neighbourhoods Study has four work programmes held together by the active involvement of people living with dementia and their care partners: The Member Involvement Strategy

# Neighbourhoods Study



- n **Work Programme 1: Generating Neighbourhood Profiles of Cognitive Ageing and Service Use Using Nationally Representative Population Data**
- n **Work Programme 2: Development of a dementia core outcome set for health and social care interventions**
- n **Work Programme 3: The Dementia-friendly neighbourhood: Understanding the changing relationships of people – practices – places**
- n **Work Programme 4: Work Stream 1: Developing the evidence base for evaluating dementia training in NHS hospitals: a mixed methods design**
- n **Work Programme 4: Work Stream 2: Living Life and Doing Things Together': A pilot trial of self-management for couples living with dementia in the neighbourhood.**
- n **Work Programme 4: Work Stream 3: Personal digitised life story tools for Deaf people living with dementia**

# Neighbourhoods Study

## Member Involvement Strategy

- n Dr Caroline Swarbrick (Member Involvement Lead)

## Scottish Dementia Working Group

- National campaigning group which is run by people living with dementia.

## Open Doors (Salford)

- Facilitated by Mike Howorth who has Alzheimer's disease, 'Open Doors' supports people who have recently received a diagnosis of dementia.

## ACE InSight : Alzheimer's Collaborative Enterprise CiC (Rhyl)

- Collaborative of younger people living with the experience of a diagnosis of a dementia in North Wales. They are empowered by ACE CiC facilitators to engage in activities of their choice currently, raising awareness, and contributing to community and professional education through, consultancy, talks and presentations as well as Active Community Engagement projects.

## EDUCATE (Early Dementia Users Co-operative Aiming to Educate) (Stockport)

- Group of people living with dementia, (supported by 'buddies') who raise awareness of living with dementia through talks and presentations.

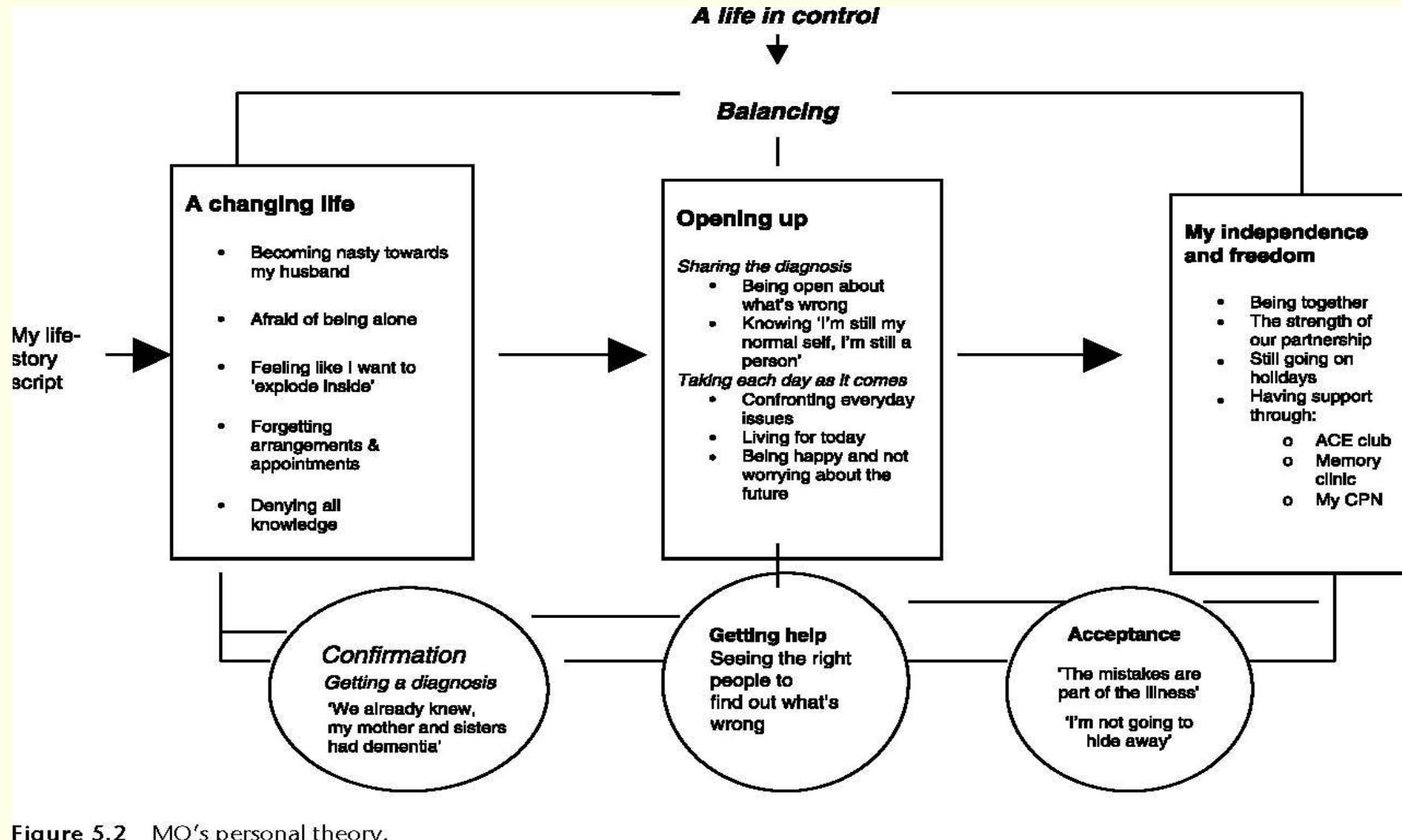
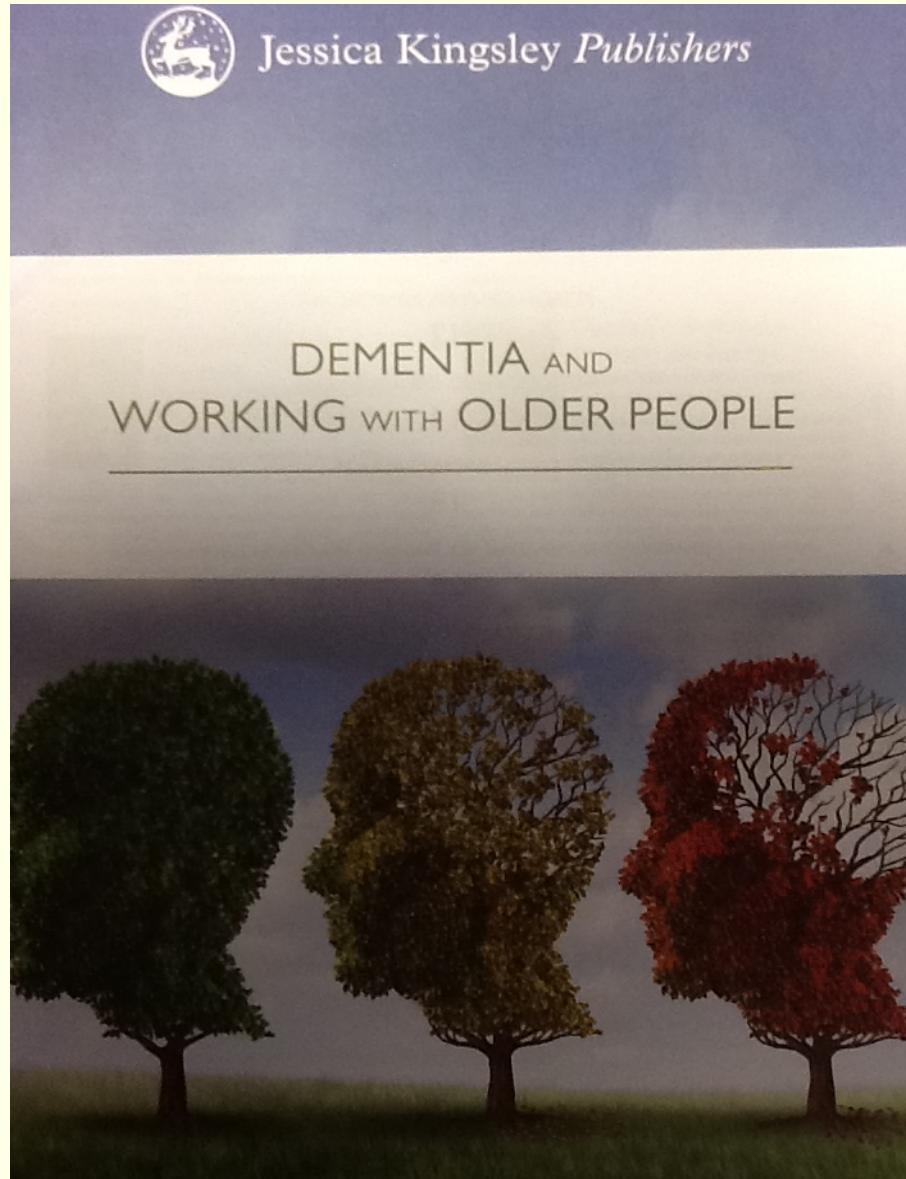


Figure 5.2 MQ's personal theory.

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Finally ...  
2014  
Nov 12<sup>th</sup>



# Where do we go?

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We ended the 1999 book with these words:

It is to ourselves that we must turn to create the most meaningful change. We must encourage others and ourselves not to be fearful, to encourage inclusion and participation, to create community-based resources and to be creative and energetic in our search for positive solutions, especially by engaging with, and involving, younger people with dementia as well as their families and support networks. Only then, in our opinion, will the mind-set begin to change for the better.

Chapter: Changing the Mind-Set (Chapter 17) pp. 303-304

**Thank You  
and Thank You Sylvia**

***“The best of the best”***



# Some References

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