

# PSSRU

Personal Social Services Research Unit



Monday 24 February –  
Saturday 1 March 2014

## Reflections

LSE *space  
for  
thought*  
LITERARY  
FESTIVAL

PSSRU LSE Literary Festival discussion

## "Who is it who can tell me who I am?" Understanding Dementia through Art and Literature

### Melvyn Bragg

*Award-winning author and broadcaster. Books including Grace and Mary.*

### Professor Justine Schneider

*Professor of Mental Health and Social Care, University of Nottingham*

### Dr Andrea Capstick

*Lecturer in Dementia Studies, University of Bradford*

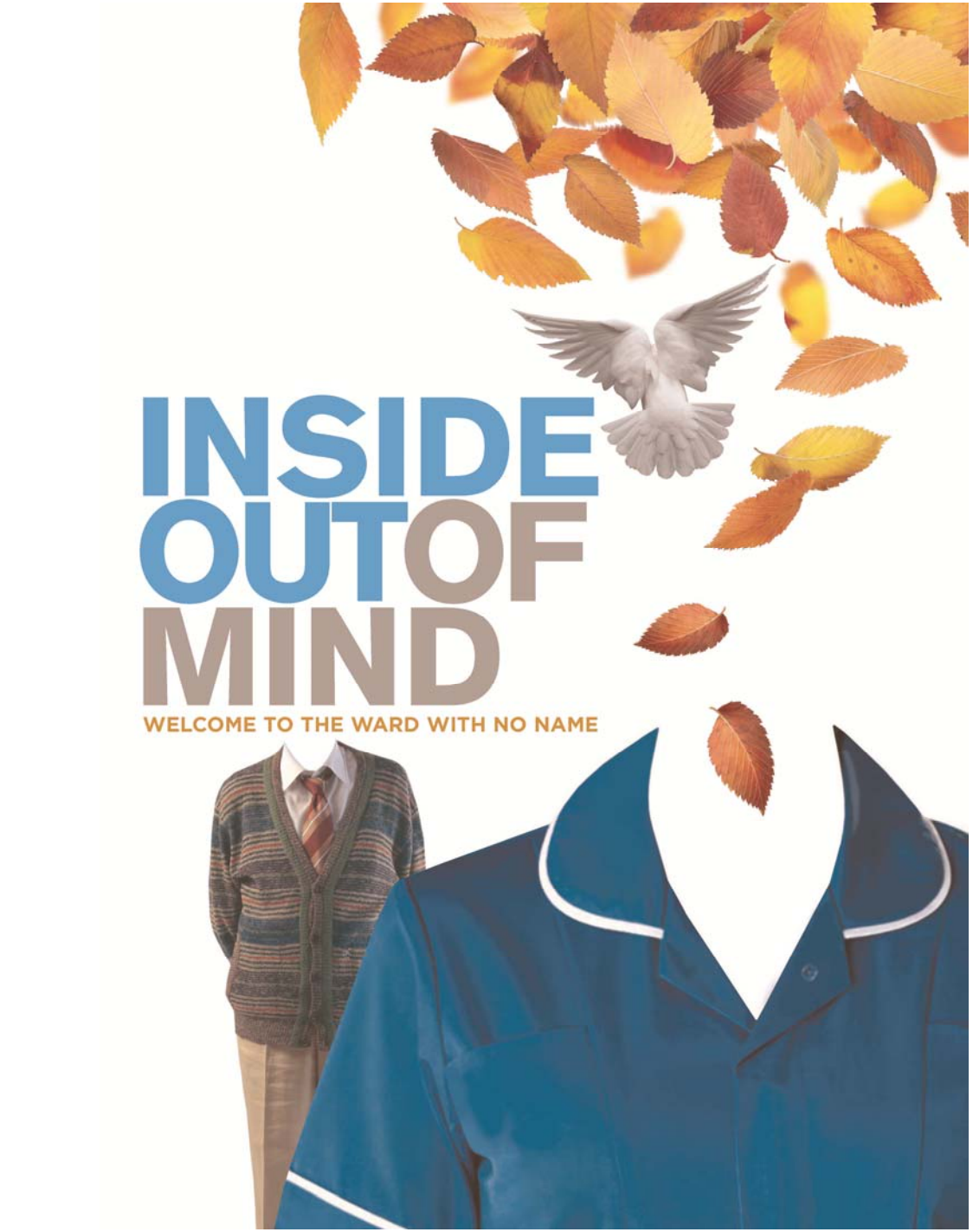
### Professor Martin Knapp

*Chair, LSE*

LSE events

Suggested hashtag for Twitter users: #LSElitfest





**INSIDE  
OUT OF  
MIND**

WELCOME TO THE WARD WITH NO NAME

Justine Schneider  
Researcher

Tanya Myers  
Writer, Director

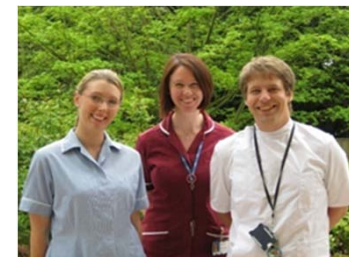
# Challenging care: role of HCAs in dementia wards

Joanne Lloyd, Kezia Scales, Simon Bailey



# Observations

Observation	Reflection	Themes
The last patient we bathed was P11, one of my favourites.	I know I shouldn't have favourites but – guiltily – I find that I do.	Attachment, loss, grief when patient dies



# Focus Groups

*Researcher: Does it take a certain kind of person to do this job?*

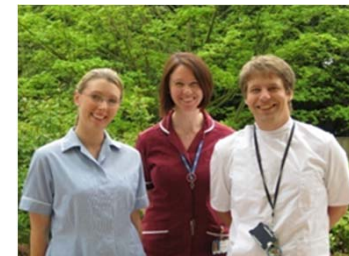
HCA: No, all you need is patience.

*Researcher: Any other personal kind of traits?*

HCA: Just got to be able to give them the love and attention what they need, and respect. It's always somebody's mother or father or grandparent. Show them the respect as though they're yours, they're no different form anybody else.

# Reflections

It makes me sad to see a new patient on the ward – not just because they're **there** at all but also because there's no apparent mechanism for easing the transition – how can we expect them to instantly assimilate into this crazy context?



Ageing & Society, Page 1 of 24. © Cambridge University Press 2013  
doi:10.1017/S0144686X13000573

## The emotional labour of health-care assistants in inpatient dementia care

SIMON BAILEY\*, KEZIA SCALES†, JOANNE LLOYD‡, JUSTINE SCHNEIDER† and ROB JONES†

Journal of Interprofessional Care, 2011, 25: 345–351  
© 2011 Informa UK, Ltd.  
ISSN 1356-1820 print/1469-9567 online  
DOI: 10.3109/13561820.2011.567381

## Ingroup identity as an obstacle to effective multiprofessional and interprofessional teamwork: findings from an ethnographic study of healthcare assistants in dementia care

Joanne V. Lloyd<sup>1</sup>, Justine Schneider<sup>2</sup>, Kezia Scales<sup>2</sup>, Simon Bailey<sup>2</sup> and Rob Jones<sup>3</sup>

<sup>1</sup>Department of Clinical Psychology and Neuropsychology, Queens Medical Centre, Nottingham NG7 2UH, UK, <sup>2</sup>School of Sociology and Social Policy, University of Nottingham, Nottingham NG7 2RD, UK, <sup>3</sup>Division of Psychiatry, School of Community Health Sciences, University of Nottingham, Queens Medical Centre, Nottingham NG7 2UH, UK

SDO Network research digest June 2011 Issue 1

SDO Network

### Study two: Challenging care – the role and experience of healthcare assistants in dementia wards

Most of the direct care in dementia wards and in many other hospital and nursing home settings is provided by HCAs, who are low-paid staff with little formal training. Yet, in comparison with nurses, little is known about the role and functions of HCAs.

This NIHR SDO-funded study investigated their work looking after older people with dementia in specialist hospital wards. The aim was to understand the job, what motivates HCAs, and what makes a good carer in relation to 'person-centred' care. Three researchers joined the HCA workforce as participant observers to understand the job from the inside. They kept field notes, undertook 30 individual interviews and led focus groups with hospital staff and informal carers.

Overall, the assistants studied were highly motivated and took

great satisfaction from their work. A distinctive but previously unrecognised role for HCAs is that they deliberately manage the ward environment, maintaining a consistent emotional climate. HCAs were also well placed to communicate with patients' families concerning their relative. Areas for improvement were low staffing levels, limited training and career development opportunities, lack of recognition and appreciation of the HCAs' knowledge, along with poor communication about change.

Another key finding was that belonging to and participating in 'the team' was a fundamental aspect of coping with the job for HCAs, in terms of emotional support and setting standards for effective care. 'Relationship-centred care' may be a better framework for understanding the work of HCAs than 'person-centred

'Healthcare assistants do more than care for individual patients, they also manage the emotional climate on the ward'

care', because ward staff need to relate well to each other and also to patients' families to work effectively.

#### Source


*Challenging care: the role and experience of health care assistants in dementia wards: final report.* NIHR Service Delivery and Organisation programme, September 2010.  
[www.sdo.nihr.ac.uk/project.php](http://www.sdo.nihr.ac.uk/project.php)

#### Contact

Justine Schneider, University of Nottingham  
[justine.schneider@nottingham.ac.uk](mailto:justine.schneider@nottingham.ac.uk)





- 
- A Black woman with her hair pulled back, wearing a dark uniform with a purple collar, is shown from the chest up. She is holding a black clipboard and looking off to the side with a serious, contemplative expression. The background is slightly blurred, showing vertical lines that could be window blinds or a door frame.
- **Motivations and rewards of dementia care**
  - **Stress and coping**

- Managing the emotional climate
- Working with families



- **Team identity**



- **Dignity**



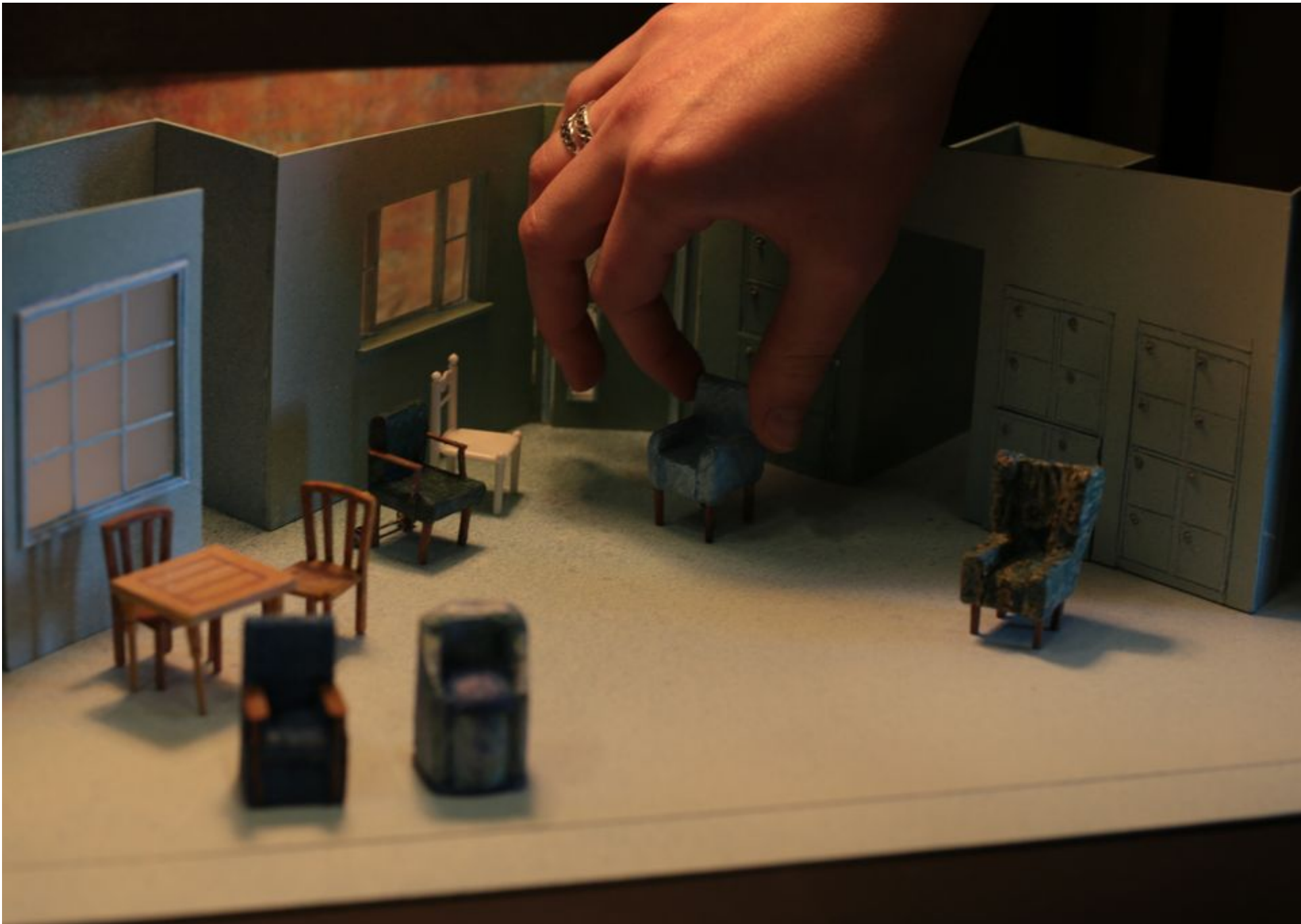
- **Death**



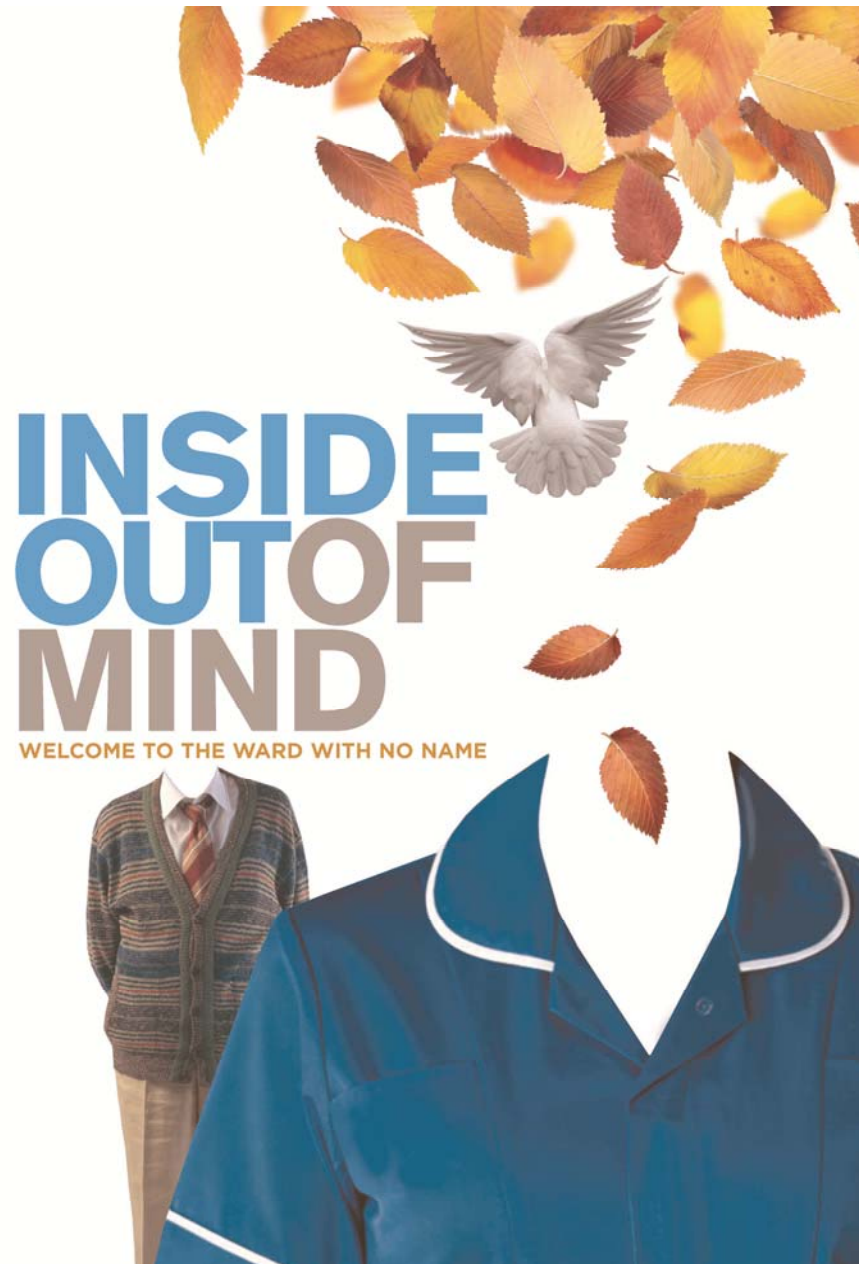
# Production Planning and Performance











## World premiere Lakeside Arts Centre Nottingham **13 – 27 June 2013**

2,200 people saw the play, more than  
half HCAs released by their employers  
to attend one of 8 day-long learning  
events

Discussions chaired by NHS managers  
workshops co-facilitated by the actors.

Local press, TV & radio coverage  
increased public awareness

There will be those who believe that nothing produced in this way can be anything but worthy and dull or—in the ultimate insult that some in the arts world reserve for what they neither value nor understand—instrumentalised art. They could not be more wrong. *Inside Out of Mind* is a memorable, clever and moving theatre performance, enjoyable even its hardest moments. What it achieves in developing understanding of dementia and dementia services it achieves because it is excellent theatre.

**Francois Matarasso,  
former chair Arts Council East Midlands**

# Acknowledgements

The research received funding from the National Institute for Health Research (SDO 08/1819/222). We are grateful to the people we observed, their managers and their employing Trust.

The production has received support to date from the Institute of Mental Health, University of Nottingham, Lakeside Arts Centre, Nottingham University Hospitals Charity, NUH Trust, Nottinghamshire Healthcare Trust, Comic Relief, CLAHRC-NDL, The Arts Council East Midlands and the RCN Foundation Trust.

# Acknowledgements – contd.

## **Cast**

Anna Mottram

Holly-Robin Harrison

Jarrood Cooke

Jim Findlay

Joanna Wells

Lily Lowe Myers

Maurice Roeves

Maxine Finch

Rebecca DeSouza

Ulrike Johansson

## **Creative team**

Barret Hodgson

Christine MacSween

David Wilson

Jo James

Keziah Serreau

Martin Hinkin

Nettie Scriven

Richard Statham

Sean Myatt

Shona Powell

Stephen Lowe

Vanessa Rawlings-Jackson

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# Participatory video in long-term social care

Dr Andrea Capstick  
Bradford Dementia Group



## Participatory video

- People who are prone to social marginalisation make films about matters of concern to them (Milne et al 2012)
- The study aims to find out whether participatory video can be adapted for use by people with dementia (Capstick 2012)



## Background

- 18-month study funded by NIHR School for Social Care Research
- 15 people with dementia living in long-term social care
- 12 women and 3 men: age range 76-99 years.
- Each participant is helped to make a short 5-10 minute film/digital story on a subject of their own choice.





## Nora: born 1927, Jarrow, Tyneside



- Wanted to make a film about the place where she grew up, Tynemouth: 'Heaven to me'

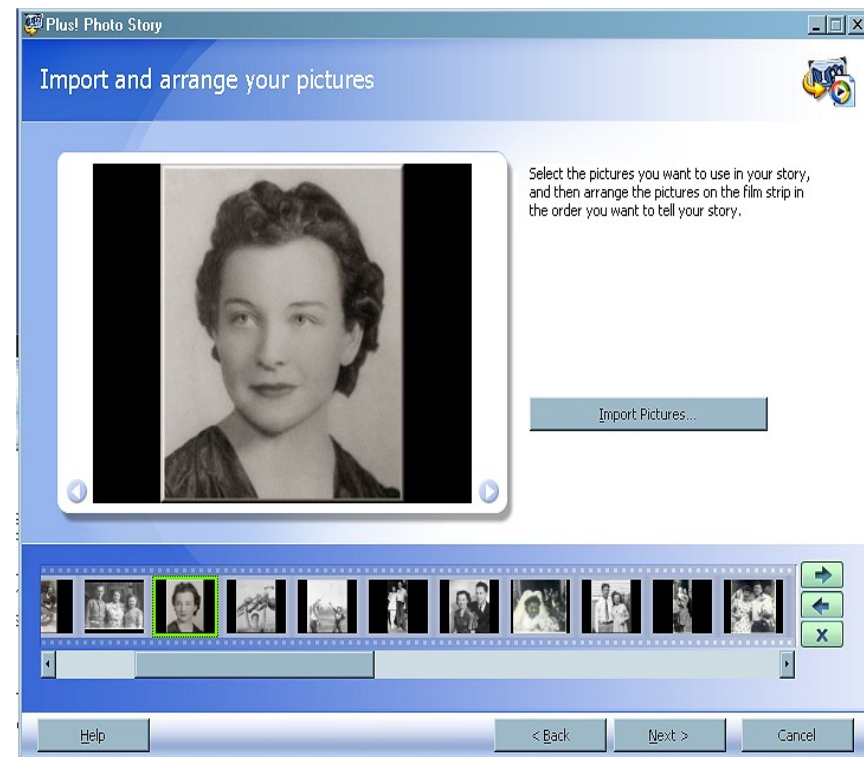
## Key themes in Nora's film

- Local history/'place memory' (Chaudhury 2008)
- Social justice/injustice
- Love of birds and animals
- Strong bond with her mother



## The process:

- Flickr/Creative Commons to search for preferred images
- Photostory 3 to import the images into a slide show
- Audacity for editing in the participant voice
- Freesound for additional sound effects.



## References and Disclaimer

- Capstick A (2012) Participatory video and situated ethics: avoiding disablism. In Milne E-J, Mitchell C and de Lange eds *A handbook of participatory video*. New York: Alta Mira.
- Chaudhury H (2008) *Remembering home: rediscovering the self in dementia*. Baltimore, MD: Johns Hopkins University Press.
- Milne E-J, Mitchell C and de Lange eds (2012) *A handbook of participatory video*. New York: Alta Mira.
- NIHR-SSCR disclaimer: This presentation presents independent research commissioned by the NIHR SSCR. The views expressed are those of the author and not necessarily those of the NIHR-SSCR or the DH, NIHR or NHS.

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