

# Quality of Life in Patients Suffering from Dementia: A UK Perspective

Peter G. Coleman  
Heidelberg, May 2008

# Caring for the carer

- Dementia a threat to personhood
- Personhood is an ethical concept = being worthy of respect
- Being a person is also social – it refers to the human being in relation to others (Kitwood, 1997)
- We do not exist in isolation: our identity depends on others
- The well-being of the person with dementia and their caregiver are closely interrelated

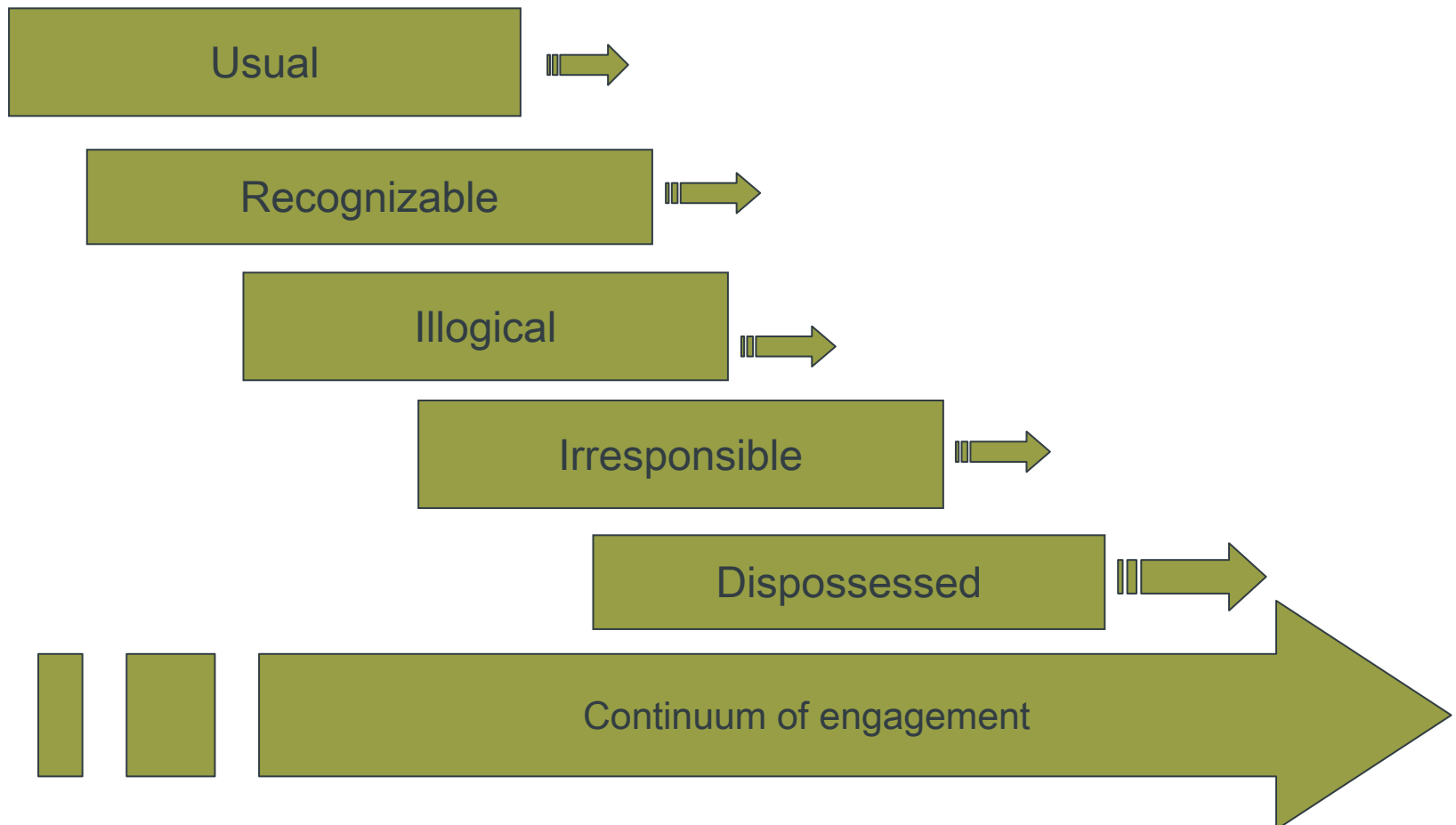
# Future Demands and Costs of Dementia Care in the UK

- Numbers suffering from dementia predicted to rise from the current 700,000 to 940,000 by 2021 and to 1,735,000 by 2051, an increase of 154% from now.
- Costs of caring for late-onset dementia estimated at £25,500 per person a year, which cost is currently mainly met by the person's family.
- Two thirds of dementia sufferers live at home

# Current dilemmas in dementia service provision

- New guidelines on dementia care (NICE/SCIE 2006) emphasise training, communication skills and early diagnosis
- This raises difficult issues especially for social workers: early diagnosis gives rise to expectations in families which cannot be met
- Respite care stressed by government, but it is of limited value in dealing with carer stress

# Activity patterns of persons with dementia



# Emotional history of the dementia caregiver

i

*Hope*

Annoyance

Suspicion

-- >

Worry

----- >

**RESENTMENT**

----- >

ii

*Challenge*

Impatience

Hurt

Helplessness

iii

*Activity*

Exhaustion

Depression

iv

*Responsibility*

**Fear**

-----

-----

-----

# Psychosocial interventions to ease the burden of caregiving

- Limited effectiveness of programmes that provide only knowledge and understanding about dementia
- Insight into and control over one's own reactions to the demented person's behaviour are required
- Also learning problem solving skills by means of active participation

# ESRC/MHA Care Group study in Southampton

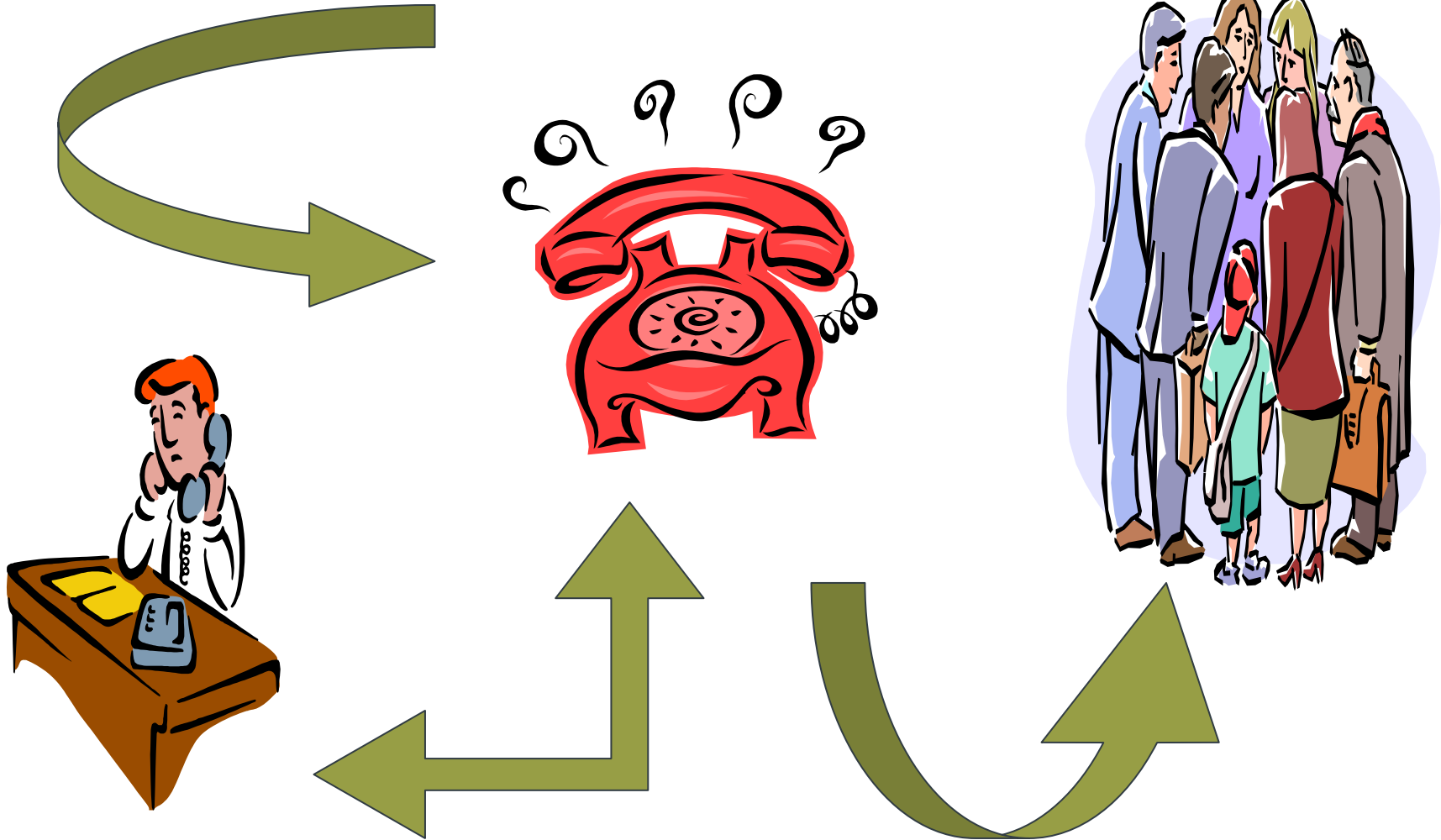
- Importance of social, psychological and spiritual perspectives on dementia
- MHA Care Group currently extending its mission to include supporting carers at home
- Relationship is a key spiritual issue: how to maintain connectedness of person with dementia; family relationships crucial to identity and well-being



# Study into sustaining caregiver relationships in dementia

- Phase 1: case studies – identifying key emotional factors in caregiver burden: a) resentment/withheld frustration; b) loss of communication/isolation; c) fear/lowering of self efficacy
- Phase 2: national survey of caregivers – confirmed the importance of these factors in determining caregiver strain and the need for facilitated mediation
- Phase 3: trial of theoretically based interventions

# THE PILOT STUDIES



➡ On-call support

➡ Daily (over 2 weeks)

➡ Caregiver in control

»»

»» Facilitated Focus Group (6 weeks)

»» Active participation, catharsis, humour