

# Getting It Right for People With a Learning Disability and Dementia at End of Life

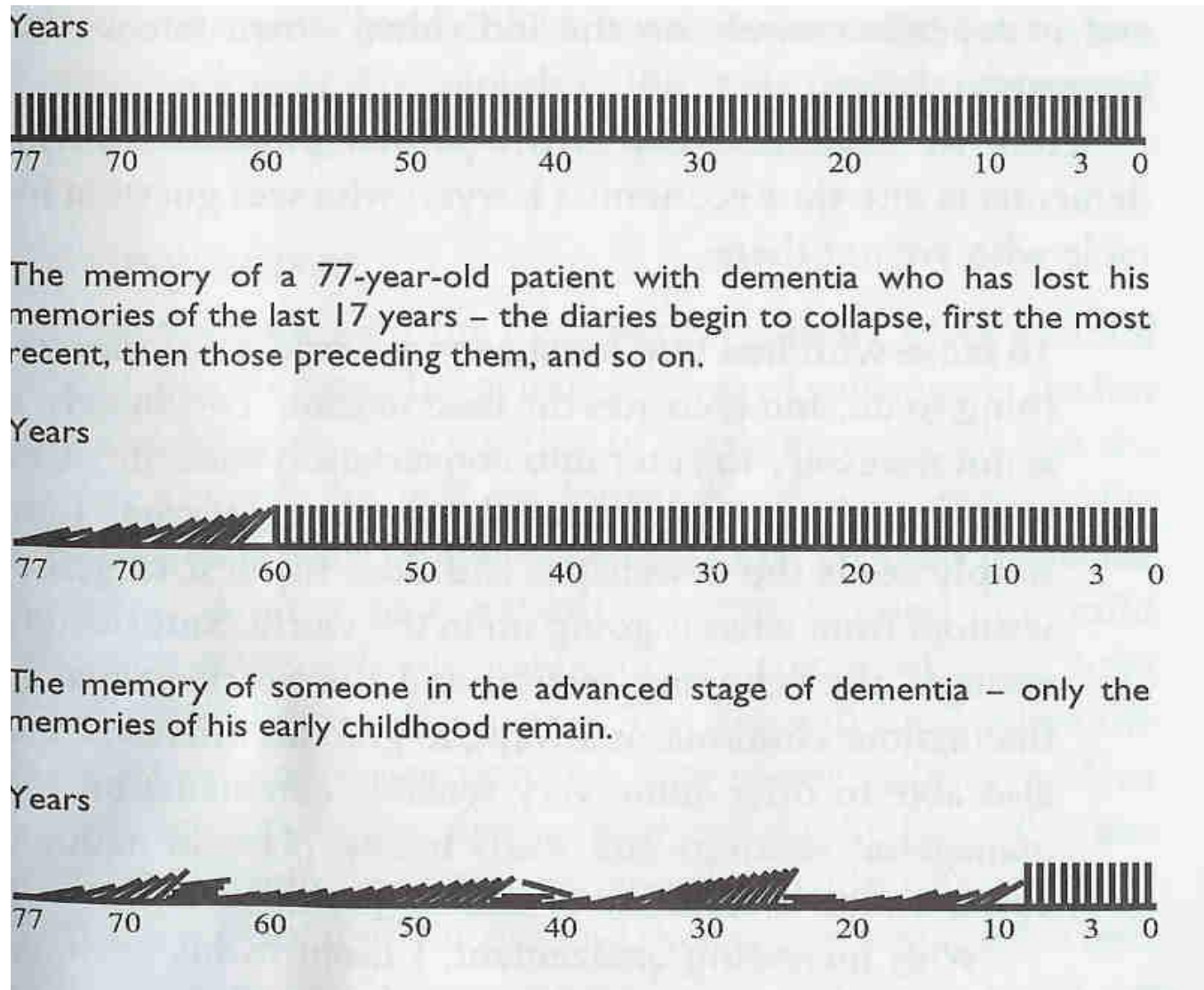
Dementia is a terminal condition

# End Stage Dementia Care: What Needs to Be Addressed?

- The experience of the person with dementia.
- The needs of staff.
- Models of provision.

How Might the Experience Be  
Different for a Person With  
Dementia?

The memory of a 77-year-old without dementia-the shelf on which the diaries containing the memories of his entire life are stacked is still intact



At the late stage people will generally experience the following.

They may:

Forget how to eat and drink

Be unable to sit up

Lose the ability to maintain balance

Find walking increasingly difficult

Lose bowel and bladder control

Become significantly less active

Experience changes in their metabolism

Have substantial weight loss

Experience the loss of short and long term memories

Lose their ability to recognise most previously familiar people and environments

May experience seizure activity

Become bedridden

Be at greater risk of choking and becoming dehydrated

Develop pressure sores

Be at great risk of infection

- May develop aspiration pneumonia
- Develop hypertonia
- Experience complete loss of self care



But the Person Is Still There

- Provide sensual experiences , touch, smells and music.

- The person will be aware of the familiar , sounds , smells etc

- Provide physical displays of affection, kisses , holding hands and face.

- They will need companionship. Don't leave them alone
- Familiar staff , friends and relatives

- Great attention needs to be paid to facial expressions and any speech that occurs.
- This brings me to PAIN

# Communication Difficulties Associated With Dementia

- Loss of previous level of verbal skills
- Can no longer find the word ‘tooth ache’
- Loss of sense of geography of the body
- Can no longer locate the toothache
- Use generalised words ‘head hurts’
- Use substitute phrases: ‘oh dear oh dear’
- Well remembered words ‘tummy ache’

# Implications for Staff

- Spend time with the person even if there is only silence as response.
- Need to provide 24 hour cover, people need to be turned every two hours.
- Need to have night waking staff.
- Need to have nursing support.
- Need shorter shifts.

# Implications for Staff

- Need extra staff to support other tenants / residents.
- Staff often doing unpaid or underpaid work.

# Implications for service providers

## Which Model are you using?

- ‘Ageing in place’.
- ‘In place progression’
- ‘Referral out’



# Findings From ‘Home for Good?’ In Relation to End Stage Care

- Ad hoc funding .

*Meant people were moved in a crisis , often at late stage.*

- Inadequate use of palliative care / district nurse.

*People moved to service rather than service to them.*

- Often moved to nursing home for older people.

*Generally not a good experience.This shortened life.*

# Findings From ‘Home for Good?’ In Relation to End Stage Care

- Changing needs not regularly assessed. *This lead to staff doing unpaid or underpaid work.*
- Lack of staff training.

*Staff often not aware of the changing needs of the person in relation to end stage care*

# What Is Needed?

- Staff to be employed for short term work with the people without dementia.
- Avoid moving people unless it is of clear benefit to their well being.
- Provide block funding.

# What Is Needed?

- Provide the right physical environment.
- Deal with pain.
- Train staff.
- Inform peers.
- Use palliative care services.
- Develop ‘in place progression.’