

Towards the End of Life - Maintaining Identity

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Respond



Identity

- Is what makes us unique
- Develops through our relationships with others
- Grows out of our personal history
- Is expressed in our relationships with others through our likes and dislikes and in our skills and talents

An Exercise

- Reflect on this thought – “If I was to develop dementia what would I want from my friends and relatives as I became more confused?”
- Turn to the person next to you and share your thoughts on this

The fragility of Identity

For many people with learning disabilities:

- maintaining personal history can be difficult
- This is often dependent on relationships with others which can be difficult to sustain
- For people who develop dementia this can become even harder

Friendship

- We are not good at acknowledging or supporting the friendships of pwld
- Often friends are not told when someone develops dementia
- We are not good at recording significant relationships and keeping contact details accessible

The GOLD Group



- Stands for growing older with a learning disability
- Originally part of the GOLD research programme
- Been together for ten years
- 2 of the group developed dementia (one died and one in terminal phase)

Forget Me Not



- A play devised in response to making sense of what was happening to friends

Edna



- moved 5 times because of getting older
- She had a fall
- She got dementia
- She had a stroke
- She lost nearly all of her possessions in the moves

Edna



- The GOLD group visit Edna
- Made her room more personal
- Make sure she has baths and gets up
- Make sure she wears clothes she likes
- Make sure staff know she likes tea not coffee
- Make sure she goes out

Maintaining identity in end of life care

- Quality of care is enhanced when staff have a sense of the person they are caring for
- The confusion and distress caused to friends and family can be helped by enabling the active continuation of relationships
- This in turn can support the nursing care as the person is seen in the context of these relationships

Practical barriers

- Knowledge of a persons history
- Information about how to find this out
- Money to support connections
- Willingness to think this is important

What needs to happen?

Strategies for:

- Finding out and documenting important information
- Centralised confidential storage
- Training staff
- Flexibility and creativity with funding

But most importantly

- It's the small things that can make a difference
- If you are supporting someone, think about the manageable things that you can do that will make a difference

For more information or to buy the
training pack **Dementia and People
with Learning Disabilities –
Valuing Relationships**

- E-mail admin@respond.org.uk
- Or phone 020 7383 0700

Dementia & People with Learning Disabilities

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