

Understanding and Caring for People with Learning Disabilities and Dementia

Introduction

Dementia is often described in terms of symptoms and behaviours and many people view dementia as a negative condition for which little can be achieved. The impact of caring for people with dementia is often described as burdensome and includes the physical, psychological or emotional, social, and financial impact of care.

Current thinking suggests that professionals and services should address positive outcomes such as understanding how the person is feeling, and wellbeing and life satisfaction, whilst acknowledging that the burden remains unchanged.

To achieve this, staff and family carers need to have a good understanding of what is happening to people who develop dementia and the consequences to the person of these changes within the brain.

Developing a shared vision

It is important everyone involved with the person develops a shared vision on which to build practice. Without this solid foundation, values, expectations and approaches are likely to differ greatly, which will ultimately generate conflict and frustration. This, in turn, will place unnecessary demands on an already confused person.

One model for achieving this has been put forward by Buijssen (2005). He proposes two laws of dementia and asserts that by understanding them, and their consequences, this gives a framework to understand and respond to people appropriately.

The 2 Laws of dementia (Buijssen 2005)

Law 1 - The law of disturbed encoding

The person is no longer able to successfully transfer information from their short term memory and store it in their long term memory. This basically means the person is unlikely to remember things that have just happened to them. The main consequence of disturbed encoding is that the person is unable to form any new memories for the things they experience or for things they are told.

The consequences of this are:

- Disorientation in an unfamiliar environment
- Disorientation in time
- The same questions are asked repeatedly
- The person quickly loses track of conversation
- The person is less able to learn anything new
- The person easily loses things
- The person is unable to recall people that they have recently met
- Appointments are quickly forgotten
- People experience anxiety and stress

Law 2 - The law of roll back memory

The long-term memory contains all the memories that have been acquired from most recent memories working back towards childhood memories. When you develop dementia you will be less able to form any new memories after this time. At first, long term memories will remain intact, however, as the dementia progresses, long term memories will also begin to deteriorate and eventually disappear altogether. Deterioration begins with the most recent memories and progresses until only memories of early childhood remain, hence memory can be said to be 'rolling back'.

The consequences of this are:

- Loss of daily skills such as using modern appliances
- Memory loss for events beginning with the most recent, e.g. last holiday
- Decreased social skills and inappropriate behaviour
- Decreased vocabulary and inability to find words
- Disorientation towards people: inability to recognise family and relatives
- The person may begin to have 'flashbacks' and see people from their past
- Self-care skills will begin to deteriorate
- Changes in personality
- Person believes they are younger and that time has actually 'rolled back'.

Philosophy of care

In thinking about the philosophy of care for people with learning disabilities and dementia, it is important that everyone involved in the planning and delivery of care understand the following principles:

1. Dementia is not the fault of the individual - nothing that they have done has made them get dementia and there is nothing that they personally can do to change the progression of the disease
2. The focus of care should be on the remaining skills that the person has, rather than concentrating on what the person used to be able to do. This can be difficult for family carers and for staff who have known the person for a long time
3. Knowing the person's history, their likes and dislikes can help the person to be fully understood
4. An enabling or supportive environment is vital
5. Appropriate communication is essential
6. People with dementia need opportunities for stress-free and failure-free activities.

This means that the responsibility to continue to reach out to people with dementia lies with people who do not have dementia. Family carers and staff need to change their approach to 'go with' the person and their continuing changes.

Excellence in dementia care requires staff and family carers to:

- understand and know the person through having a thorough knowledge and understanding of the person and their history
- understand dementia and its consequences for the person
- and to consequently be able to think ahead and predict 'stressors'.

Everyone involved in the lives of people with dementia needs to adapt their approach to ensure the person with dementia has a life that is:

- stress free
- failure free
- focused on individualised care
- consistent
- without time pressures.

This philosophy needs to be incorporated into the person's person centred plan. It is important that everyone involved with the person embraces this different way of working.

For a better life

Putting it into practice

In caring for the person with learning disabilities and dementia, it is important to celebrate what the person can do, rather than focussing on what the person now cannot do. This means allowing the person to carry out tasks even if they are not doing things 'properly'. Continuing to make choices for themselves is important but the number of choices may need to be reduced or the person helped to make choices through the use of pictures and objects.

People with dementia will rely more on visual cues rather than verbal cues to understand what is required of them. Simple changes can make huge differences, e.g. putting your own coat on before asking the person if they want to go out.

Good dementia care means thinking about what you are trying to achieve for the person. One way of challenging existing practice is to ask yourself, 'Does it matter?' For example, it is important the person has good nutrition and hydration over each 24 hour period not that they had 3 specific meals per day.

As the dementia progresses, the person will experience more instances of remembering things from the past because of the roll back memory. It is important everyone accepts the roll back memory and validates the person's experiences to reduce anxiety - they should be with them in their world. Arguing or contradicting the person will only make the person more anxious or stressed.

Be clear about what needs to be achieved

- this is not the time for learning new skills, achieving goals or facing change.
- consider the person's happiness, comfort, and security.
- the focus of care should move away from targets to quality of life.
- people compensate for their deterioration in functioning by making greater use of remaining abilities, e.g. earlier memories.
- there needs to be an increasing awareness of the physical consequences of getting older and additionally having dementia.
- pain recognition and management is often extremely inadequate and needs careful monitoring

Often the difficulties that staff and family experience when caring for a person with dementia can be easily resolved by seeing the situation through the eyes of the person with dementia, i.e. their current reality. Continual correction by staff/carers of a different reality, e.g. person with dementia asking when a member of staff (who is no longer employed) is working and being told that they don't work there will not reduce their immediate confusion and distress. Alternative strategies need to be considered and used by everyone consistently.

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