

Dementia and People with Learning Disabilities

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What is dementia?

- Dementia is when parts of the brain stop working as well as they did.
- When people get dementia they seem to get older more quickly. They need extra care.
- Dementia is different from just getting older.
- It is an illness where people have problems doing their normal jobs and activities.
- There are several different sorts of dementia. The most common is called Alzheimer's disease.

Quiz

1. How many adults are there in Surrey with Down's Syndrome?
2. At what age can someone with Down's Syndrome develop dementia?
3. What is the chance of getting dementia for someone with Down's Syndrome at the age of 60?
4. What age, on average, did people with Down's Syndrome live to in 1930?
5. What age, on average, do people with Down's Syndrome live to now?

Quiz Answers

1. 382 adults with Down's Syndrome
2. From as early as 35, but on average it starts when the person is in their late 40's.
3. 1 in 2 people with Down's Syndrome will have dementia at 60.
4. Men lived on average for 9.9 years and women for 12 years.
5. On average, people with Down's Syndrome now live to their mid 50's.

Number of adults with Down's Syndrome in Surrey

Age	Mid Surrey	East Surry	South West Surrey	North West Surrey	TOTAL
18 - 29	15	16	12	1	44
30 - 39	27	17	12	5	61
40 - 49	25	37	35	23	120
50 - 59	33	25	25	22	105
60 - 69	12	15	10	12	49
70 +	0	0	2	1	3
TOTAL	112	110	96	64	382

Number of adults with Down's Syndrome with diagnosed or suspected dementia

Age	Mid Surrey	East Surrey	South West Surrey	North West Surrey	TOTAL
18 - 29	0	0	0	0	0
30 - 39	1	0	1	3	5
40 - 49	5	4	1	6	16
50 - 59	12	10	7	8	37
60 - 69	7	6	2	1	16
70 - 79	0	0	0	0	0
TOTAL	25	20	11	18	74

Where do people with Down's Syndrome live in Surrey?

	Mid Surrey	East Surrey	SW Surrey	NW Surrey	TOTAL
Own Home	1	2	2	0	5
Family Home	26	23	14	11	74
Supported Living	5	4	12	0	21
Residential home	70	67	59	52	248
Nursing home	0	2	1	0	3
Unknown	10	12	8	1	31
TOTAL	112	110	96	64	382

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 that 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.

Consequences of disturbed encoding

- Disorientation in an unfamiliar environment
- Disorientation in time
- The same questions are asked repeatedly
- The person quickly loses track of things
- The person is unable to learn anything new
- The person is unable to recall people that they have recently met
- Appointments are quickly forgotten
- Mood swings are frequent.

The law of roll-back memory

- Your long-term memory contains all the memories that you acquired throughout your life starting with your most recent memories working back to your childhood memories.
- When you develop dementia you will be unable to form any new memories after this time.
- At first your long term memories will remain intact, however as dementia progresses, long term memories will also begin to deteriorate and eventually disappear altogether.
- Deterioration of memory will begin with the most recent memories and will progress until only memories of early childhood remain, hence memory can be said to be 'rolling back'.

Consequences of roll-back memory

- Loss of daily skills such as using kitchen appliances
- Memory loss for events beginning with the most recent e.g. last holiday
- Decreased social skills and inappropriate behavior
- 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 that they are younger and that time has actually ‘rolled back’

Social model of dementia

- Proposes that people have an impairment, but are disabled by the way they are treated by or excluded from society

Advantages of this framework are:

- It's not the fault of the individual
- Focus on remaining skills rather than losses
- Person can be fully understood (their history, likes / dislikes etc)
- Supportive environment is essential
- Appropriate communication is essential
- The responsibility to reach out to people with dementia lies with people who do not have dementia.

What is the challenge?

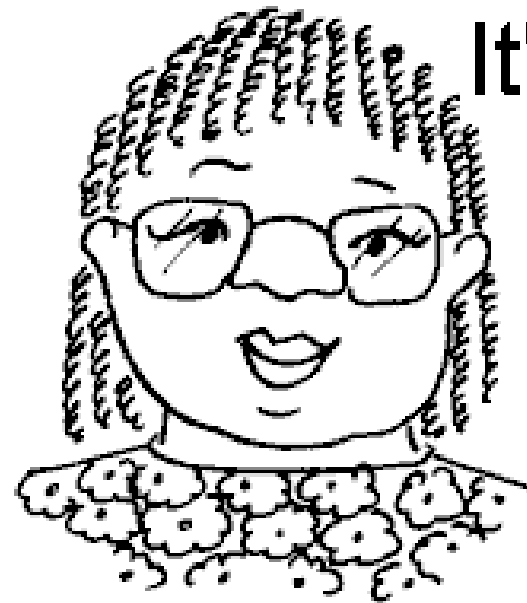
90% of Catastrophic Behaviours in people with dementia are induced by Carers and the Environment.

Bawley E (1997) Designing for Alzheimer's Disease.
Strategies for creating better care environments.

Keep The Person At The Centre

- The most important tenet in caring for a person with learning disabilities with dementia is that the needs of the person are paramount.
- People with dementia need to have / be:
 - Stress free
 - Failure free
 - Individualised care
 - Consistency but without time pressures
- Staff need to:
 - Understand and know the person
 - Understand dementia
 - Think ahead and predict 'stressors'

Establish philosophy of care

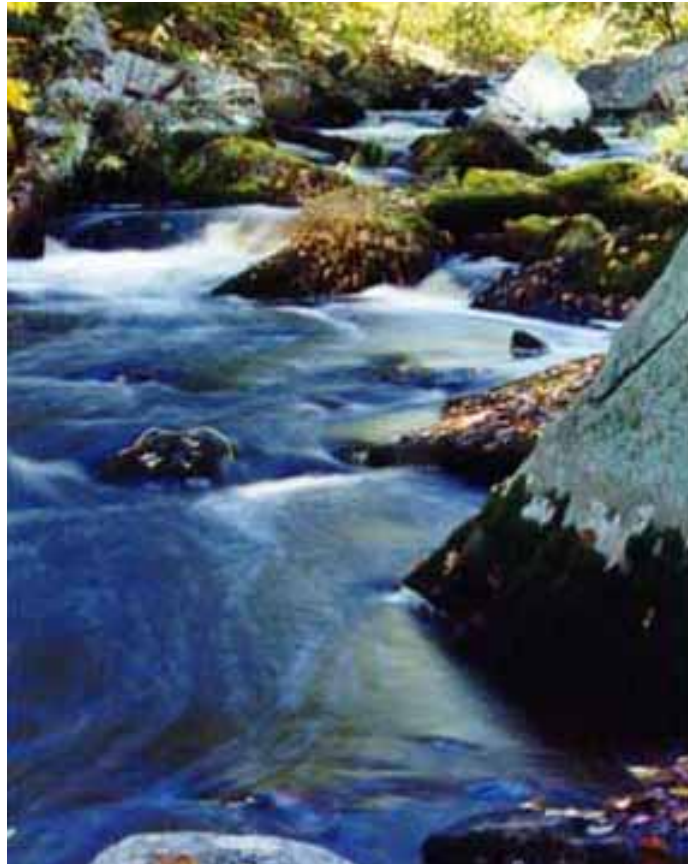


It's my life!

Philosophy of Care

- Look at the Person not the Diagnosis
- Adopt a flexible approach; Go with the flow!
- Use Regular Staff
- Promote Failure Free Activities
- Take off Time Pressures
- Communication and Memory
- Daily Living Tasks as Activities
- Remain Consistent
- Interpreting Behaviours and how to minimise them
- Planning for the Future

Go with the flow



Think about the present and future

- Be clear about what needs to be achieved.
- Consider the persons happiness, comfort, security and freedom from pain.
- Maintain relationships and family involvement.
- Change the focus of care to quality of life.
- Forget targets!
- Think about the environment, where the person lives, day activities, training for staff, baseline assessments.
- Think ahead to later stages of dementia including palliative care.

Environments and people with dementia

- In planning for future care, it is usually in the person's best interests to remain in their familiar setting with familiar people and routines.
- Environments may need to be altered to be:
- **Calm** – noise (internal and external), colour
 - **Predictable and making sense** – cues, signposting, no surprises
 - **Familiar** – homely, long term memory
 - **Suitably stimulating** – noise, views
 - **Safe** – access, stairs, hazards

Furnishings and Fittings:



Life Story Work

- Promotes positive interactions and feelings.
- Engages the person, friends, carers and families in its preparation.
- Gives the person and their carers a clear individualised picture of the person.
- May take the form of a book or photo album, box with objects of significance
- Material needs to be well captioned with date, what the event/significance is, who is in the picture etc.
- Material should be used frequently and consistently

Different realities

- Vital that you do not cause additional stress in the way you respond
- Telling the person 'the truth' may be very damaging and cause stress and grief
- Remember that the person has a short term memory problem and won't retain what has been said.
- Do not believe people who tell you that it is wrong to collude with people with dementia.
- Accept that the person may not know who you are and may become confused and distressed when you are doing things with them.
- Think about what the person wanted from telling you about the reality.

Functions of behaviours

Behaviours can have a variety of functions:

- I am confused
- It's too noisy
- I want to go somewhere else
- Something hurts
- I want a drink
- I don't understand what is required of me
- I'm scared
- No – I don't want to do what you want me to do
- I'm too hot or cold

Dealing with behaviours

- Look at the situation through the eyes of the person with dementia
- View the behaviour as an attempt by the person to communicate, so interpret using all possible information
- Is this an exacerbation or return of previous behaviours?
- Is the behaviour caused by a return to a long term memory that is now inappropriate?
- Use the simplest solution available to you
- Decide if the behaviour really needs intervention.
- Environmental alterations can alter behaviours
- Decide whose reality you are dealing with.

Reading List

- Buijssen, H. (2005) *The Simplicity of Dementia*. London: Jessica Kingsley
- Dodd, K., Kerr, D. & Fern, S. (2006) *Down's Syndrome and Dementia Workbook for Carers*. Teddington: Down's Syndrome Association
- Dodd, K., Turk, V., & Christmas, M. (2003) *Resource Pack for carers of adults with Down's Syndrome and dementia*. Kidderminster: BILD Publications
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- Dodd, K., Turk, V. & Christmas, M. (2005) *Understanding Dementia - information for people with learning disabilities*. Kidderminster: BILD Publications

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People with learning disabilities are now enjoying a longer life expectancy than ever before as a result of enhanced medical and social interventions and improved quality of life. Some, particularly individuals with Down's syndrome, are susceptible to dementia at a significantly younger age than the average age of onset in the rest of the population. Currently, there is limited guidance on how to talk to people with learning disabilities about dementia and, until such information is shared, individuals cannot be positioned as an authority on their own condition. The new model presented here for Learning Disabilities (DLD) is an English translation of this instrument. Formally known as the Dementia Questionnaire for Mentally Retarded Persons (DMR). After many years of distribution through De Bruggen, its publication has now been taken over by Harcourt Test Publishers [2]. In this chapter, we review the development of the DMR (DLD) along with its clinical applications. Evenhuis HM, Kengen MMF, Eurlings HAL. Dementia questionnaire for people with intellectual disabilities (DMR). Amsterdam: Harcourt Test Publishers; 2006 (orders through info@harcourt.nl or www.harcourt-uk.com).

3. People with a learning disability are living longer and are more likely to develop illnesses associated with older age. In addition to this, they are at a greater risk of developing dementia as they get older compared with the general population (Cooper, 1997). To improve the care environment ensure that it makes sense and is calm, familiar, predictable and suitably stimulating. For people with Down's syndrome, the risk of developing dementia is significant and increases with age: Lai and Williams (1989) report a 55 per cent prevalence rate among 50- to 59-year-olds, while Prasher (1995) puts this at 36.1 per cent. Both studies report a 75 per cent prevalence rate for those aged 60 years and older. Start by marking "About Dementia: For People With Learning Disabilities" as Want to Read: Want to Read saving | Want to Read. We'd love your help. Let us know what's wrong with this preview of About Dementia by Karen Dodd. Problem: It's the wrong book It's the wrong edition Other. Details (if other): Cancel. Thanks for telling us about the problem. Return to Book Page. Not the book you're looking for? Preview "About Dementia by Karen Dodd. About Dementia: For People With Learning Disabilities. by. Karen Dodd