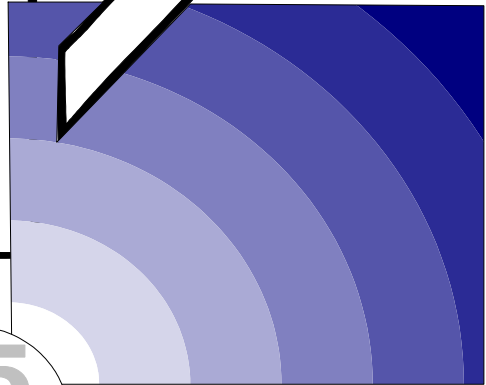
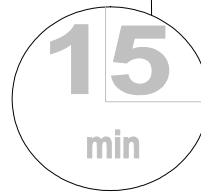


CLIP

15 minute Worksheet



Helping the patient with communication difficulties

5: Dementia

Intermediate level

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Aim of this worksheet

To introduce the health professional to the person with dementia.

How to use this worksheet

- You can work through this worksheet by yourself, or with a tutor.
- Read the case study below, then work on the questions overleaf.
- The work page is on the right side, the information page is on the left.
- Work any way you want: you can try answering from your own knowledge (in which case fold over the information page), you can use the information page (this is not cheating- you learn as you find the information), or you can use other sources of information
- It should take you about 15 minutes. If anything is unclear, discuss it with a colleague.
- If you think any information is wrong or out of date let us know
- Use the activity on the back page and take this learning into your workplace.

Case study

Margaret is a 57 year old lady with Down Syndrome who has always lived at home with her sister. About 2 years ago it was noticed that Margaret was becoming quieter, less lively, with less sparkle to her personality. At times she would be unsure where she was or what day it was. Her sister thought these changes were related to Margaret getting older.

She now has difficulty remembering the way back to her bedroom and occasionally does not recognise her sister and her carers.

Margaret's difficulties

Old age does not cause these problems by itself, but any of the others could:

Bacterial infections can cause confusion and rigors due to a high temperature.

Cancer can cause confusion by a number of mechanisms. *Brain tumours* are an uncommon cause of confusion but can cause epileptic fits (seizures)

Epilepsy can develop due to a number of reasons. In older people this can be due to brain damage caused by strokes or previous head injury.

Depression could explain her more withdrawn behaviour.

Recent fall can cause a clot to form slowly between the brain and skull (a subdural haematoma) which can cause the problems that Margaret has.

Viral infections can cause confusion and a high temperature. Some viruses can infect the brain directly.

Dementia is associated with Down syndrome and can present with fits, visual hallucinations, swallowing problems and a rapidly progressing dementia.

The nature of dementia

Dementia is a progressive reduction in cognitive abilities (the ability to think, remember, learn and reason), leading to reduced capacity for self care and self direction.

5% of people over 65 years have dementia, rising to 20% of people over the age of 80 years.

There are several types:

Alzheimer's disease accounts for 50% of cases.

Vascular dementia is due to problems in the brain's blood supply and accounts for 15%

Lewy body dementia accounts for 15% overall

Mixed and other rare types account for the remainder.

The effects of dementia

- **Cognitive difficulties**

Memory: recent memory is most affected so that people remember the name of a teacher, but not what happened yesterday.

Speech: the wrong words can be used (dysphasia) or no speech at all (aphasia)

Loss of self-help skills: there is increasing difficulty in carrying out a sequence of tasks (apraxia)

Difficulty in recognition of people and objects.

- **Behavioural difficulties**

This includes agitation, aggression, wandering, delusions, hallucinations, disturbed sleeping patterns, sexual disinhibition and mood disturbance (including anxiety and depression).

70-80% of people with dementia can suffer these problems which are distressing to both the patient and carers, and may be the cause of admission to hospital or nursing home.

Behavioural problems can be worsened by drugs (depression due to H2-blockers and NSAIDs; increased sensitivity to neuroleptics), stresses such as changes in carer or environment, or the loss of a carer.

- **Dementia associated with Down syndrome**

This can have a more rapid course and some features are more common such as epileptic seizures and visual hallucinations. Some patients are also troubled with sudden muscle jerks (myoclonic jerks). The commonest presentation is a change in behaviour.

- **The effects on carers**

The multiple changes in abilities, behaviour and personality put heavy pressure onto the carers and partners. The unpredictability of knowing how much time is left can make it difficult for carers to plan how they are going to respond and cope, for these reasons dementia has been defined as "The Long Bereavement."

Caring for Margaret

- *Safety:* she will be more vulnerable to accidents and may need more monitoring, however this needs to be balanced against the need to maintain as much of her independence as possible. Reminders (calendars, pictures indicating her bedroom, verbal clues about time, people and place) can help her cope with some of her memory loss. Sudden changes in behaviour may be due to an unrelated physical cause which needs treatment.
- *Relationships:* good quality care is provided through the preservation of relationships.
- *Interest:* stimulation is important, although she may find more complex activities (eg. going to a concert) more difficult to cope with. When caring for people with Alzheimer's, the concept that everyone has an identity, a history, a life before dementia must also be acknowledged.
- *Environment:* this may need some changes to provide reminders, improve safety and provide stimulation. However, the care and environment need to balance stimulation with safety and preventing sensory overload.

Reflect

What could be happening to Margaret?

Ring possible cause of Margaret's problems

Chest infection

Old age

Cancer

Brain tumour

Epilepsy

Depression

Recent fall

Alzheimer's

Viral infection

Write

What effects might dementia have on Margaret?

- Effects on her thinking skills:

- Effects on behaviour:

- Effects on her carers:

Write

What could help Margaret and her sister cope?

- Maintaining safety

- Maintaining relationships

- Maintaining interest

- Maintaining her environment

FURTHER ACTIVITY: Dementia

For clients with dementia:

- how do their problems make communication difficult with carers?
- note how the client communicates when they are content
- note how the client communicates distress

FURTHER READING: Dementia

Journal articles

Bonner LT. Peskind ER. Pharmacologic treatments of dementia. *Medical Clinics of North America*. 2002; **86**(3): 657-74.

Clifford DB. AIDS dementia. *Medical Clinics of North America*. 2002; **86**(3): 537-50.

Cosgrave MP. McCarron M. Anderson M. Tyrrell J. Gill M. Lawlor BA. Cognitive decline in Down syndrome: a validity/reliability study of the test for severe impairment. *American Journal of Mental Retardation*, 1998; **103**(2):193-7.

Kertesz A. Munoz DG. Frontotemporal dementia. *Medical Clinics of North America*. 2002; **86**(3): 501-18.

Kukul WA. Bowen JD. Dementia epidemiology. *Medical Clinics of North America*. 2002; **86**(3): 573-90.

Leverenz JB. McKeith IG. Dementia with Lewy bodies. *Medical Clinics of North America*. 2002; **86**(3): 519-35.

McCarron M. Some issues in caring for people with dual disability of Down's Syndrome and Alzheimer dementia. *Journal of Learning Disabilities for Nursing and Health Care*, 1999; **3B**: 123-129.

Prasher VP. End stage dementia in adults with Down syndrome. *International Journal of Geriatric Psychiatry*, 1995; **10**: 1067 – 1069.

Prasher VP. Filer A. Behavioural disturbance in people with Down's syndrome and dementia. *Journal of Intellectual Disability Research*. 1995; **39**(5): 432-6.

Roman GC. Vascular dementia revisited: diagnosis, pathogenesis, treatment, and prevention. *Medical Clinics of North America*. 2002; **86**(3): 477-99.

Ross GW. Bowen JD. The diagnosis and differential diagnosis of dementia. *Medical Clinics of North America*. 2002; **86**(3): 455-76.

Teri L. Logsdon RG. McCurry SM. Nonpharmacologic treatment of behavioral disturbance in dementia. *Medical Clinics of North America*. 2002; **86**(3): 641-56.

Tsuang DW. Bird TD. Genetics of dementia. *Medical Clinics of North America*. 2002; **86**(3): 591-614.

Resource books and websites

M.T Fray. *Caring for Kathleen: A Sisters Story About Down's Syndrome and Dementia*. 2000 B.I.L.D. Publications, 2000. www.bild.org.uk

Kerr D. (1997) *Down's Syndrome and Dementia – The Venture press Birmingham*.

Marler R, Cunningham C. *Down's Syndrome and Alzheimer's Disease: A Guide for carers*. London: Down's Syndrome Association, 1995 (155, Mitcham Road, London, SW17 9PG. Tel; 0181 6824001)

Downs Syndrome Association www.downs-syndrome.org.uk

Down's Syndrome Educational Trust www.downset.org/DownsEd

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Current Learning In

Palliative care

An accessible learning programme for health care professionals

Fifty seven 15 minute worksheets are available on:

- An introduction to palliative care (3 worksheets)
- Helping the patient with pain (9 worksheets)
- Helping the patient with symptoms other than pain (11 worksheets)
- Moving the ill patient (2 worksheets)
- Psychological needs (8 worksheets)
- Helping patients with reduced hydration and nutrition (8 worksheets)
- Procedures in palliative care (4 worksheets)
- Understanding and helping the person with alternative communication (learning disabilities) (5 worksheets)
- The last hours and days (4 worksheets)
- Bereavement (3 worksheets)

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Helping the Patient with Advanced Disease: a Workbook. Regnard C. ed.

Oxford: Radcliffe Medical Press www.radcliffe-oxford.com