

CLIP

15 minute Worksheet



Helping the patient with communication difficulties

5: Dementia

Intermediate level

Produced by
St. Oswald's Hospice
Regent Avenue
Gosforth
Newcastle-upon-Tyne
NE3 1EE

Tel: 0191 285 0063
Fax: 0191 284 8004

This version written and edited
by:

Claud Regnard Honorary
consultant in Palliative Care
Medicine, St. Oswald's Hospice

Dorothy Mathews Macmillan
Nurse for People with Learning
Disability. **Lynn Gibson**
Manager of Northumberland
Physiotherapy service (LD)
Northumberland Tyne & Wear
NHS Foundation Trust

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, and then turn to the Work page overleaf.
- Work any way you want. You can start with the exercises on the Work page using your own knowledge. The answers are on the Information page - this is not cheating since you learn as you find the information. Alternatively you may prefer to start by reading the Information page before moving to the exercises on the Work page.
- This CLiP worksheet should take about 15 minutes to complete, but will take longer if you are working with colleagues or in a group. If anything is unclear, discuss it with a colleague.
- If you think any information is wrong or out of date let us know.
- Take this learning into your workplace using the activity on the back page.

Case study

Susan 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 Susan 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 Susan getting older.

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

v13

Susan'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, eg. urine infection.

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Depression could explain her more withdrawn behaviour.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 Susan has.

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

Dementia is associated with Down syndrome and initially presents with some unaccountable change in behaviour which could be cognitive, functional (ie affecting daily living skills) or in personality. Other indicators could be confusion, apathy, fits, and problems with eating and drinking. It is usually 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**

These can include agitation, aggression, wandering, delusions, hallucinations, disturbed sleeping patterns, sexual dysinhibition 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, present at an earlier stage and some features are more common; such as epileptic seizures. 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 Susan

- *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, 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.

Choose**What could be happening to Susan?****Ring** possible cause of Susan's problems

Chest infection

Old age

Cancer

Brain tumour

Epilepsy

Depression

Recent fall

Alzheimer's

Viral infection

Write**What effects might dementia have on Susan?**

- Effects on her thinking skills:
- Effects on behaviour:
- Effects on her carers:

Reflect**What could help Susan 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

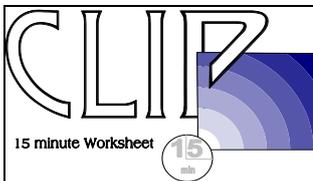
FURTHER READING: Dementia

Journal articles

- Aminoff BZ, Adunsky A. Their last 6 months: suffering and survival of end-stage dementia patients. *Age and Ageing*, 2006; **35**: 597-601.
- Butler R. The carers of people with dementia. *BMJ*. 2008; **336**: 1260-1.
- Chatterjee J. End of life care for patients with dementia. *Nursing Older People*, 2008; **20**(2): 29-34.
- Dartington T. Dying from dementia: a patient's journey. *BMJ*, 2008; **337**: 931-3.
- Eustace, A., Coen, R., Walsh, C., *et al.* A longitudinal evaluation of behavioural and psychological symptoms of probably Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 2002; **17**: 968-973.
- Grabowski DC, Aschbrenner KA, Rome VF, Bartels SJ. Quality of mental health care for nursing home residents: a literature review. *Medical Care Research & Review*. 2010; **67**(6): 627-56.
- Hanrahan P. *et al* Criteria for enrolling dementia patients in hospice: a replication. *American Journal of Hospice & Palliative Care*, 1999; **6**(1): 395-400.
- Harris D. Forget me not: palliative care for people with dementia. *Postgraduate Journal*, 2007; **83**: 362-6.
- Hertogh CPM. Advance care planning and the relevance of a palliative care approach in dementia. *Age and Ageing*, 2006; **35**: 553-5.
- Hughes J.C., Robinson L., Volicer L. Specialist palliative care in dementia. Specialised units with outreach and liaison are needed. *BMJ*, 2005; **330**: 57-8.
- Hughes J.C., *et al* Palliative care in dementia: issues and evidence. *Advances in Psychiatric Treatment*, 2007; **13**: 251-60.
- Jordan A, Lloyd-Williams M. Distress and pain in dementia. In, Hughes JC, Lloyd-Williams M, Sachs GS, eds. *Supportive Care for the Person with Dementia*. Oxford: Oxford University Press, pp 129-37, 2011.
- Isik AT. Late onset Alzheimer's disease in older people. *Clinical Interventions In Aging*. 2010; **5**: 307-11.
- Kaasalainen S. *et al* Nurses' perceptions around providing palliative care for long-term care residents with dementia. *Journal of Palliative Care*, 2007; **23**(3): 173-80.
- Lloyd-Williams M. An audit of palliative care in dementia. *European Journal of Cancer Care*, 1996; **5**: 53-5.
- Macdonald, A. and B. Cooper. Long-term care and dementia services: an impending crisis. *Age & Ageing*, 2007; **36**(1): p. 16-22.
- 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.
- Sampson E.L., *et al* A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. *Int Psychogeriatr*, 2005; **17**: 31-40.
- Seitz DP, Adunuri N, Gill SS, Gruneir A, Herrmann N, Rochon P. Antidepressants for agitation and psychosis in dementia. *Cochrane Database of Systematic Reviews*. 2011; **2**: CD008191.

Resource books and websites

- Department of Health. *Living well with dementia: A National Dementia Strategy- Putting People First*. London: Department of Health, 2009.
- Downs Syndrome Association www.downs-syndrome.org.uk



Current Learning in Palliative care
An accessible learning programme for health care professionals

15 minute worksheets are available on:

- An introduction to palliative care
- Helping the patient with pain
- Helping the patient with symptoms other than pain
- Moving the ill patient
- Psychological and spiritual needs
- Helping patients with reduced hydration and nutrition
- Planning care in advance
- Understanding and helping the person with learning disabilities
- The last hours and days
- Bereavement

Available online on
www.clip.org.uk