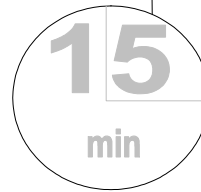


CLIP

15 minute Worksheet



Helping the patient with communication difficulties

3: Down Syndrome

Intermediate level

Produced by
Coleman Education Centre
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
 Consultant in Palliative Medicine
 St. Oswald's Hospice, Newcastle
 Hospitals NHS Trust and
 Northgate&Prudhoe NHS Trust
Margaret Kindlen, Head of Education
 St. Oswald's Hospice

Christine K Armstrong
 Clinical co-ordinator
Dorothy Mathews, Senior Nurse
Lynn Gibson, Senior Physiotherapist
 Northgate Hospital Learning Disability
 Palliative Care Team

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Aim of this worksheet

To introduce the health professional to the person with Down syndrome.

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- If you think any information is wrong or out of date let us know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 50 year old lady with Down Syndrome. She attended a 'special school' when she was young. She was always friendly and happy except for a short time when she was with foster parents. After that she moved in with her sister and manages to look after herself at home while her sister works.

The nature of Down syndrome

Documented in 1866, it was only explained in 1959.

It is a genetic abnormality caused by an extra chromosome. There are three 21st chromosomes instead of the usual two, hence the other name for Down syndrome, Trisomy 21. There are other rare forms of chromosome disorders.

The mother's age is a key risk. Although 70% of Downs people are born to women under 35, the risk of a baby with Down syndrome is 15 times higher if the mother is aged 40, compared with a mother aged 21 (1 in 100 births for mothers age 40 compared with 1 in 1500 births aged 21).

One third of Down syndrome babies are identified before birth, but recent advances in testing before birth may increase that number. Improved care has resulted in 80% being aged over 50.

How the person with Down syndrome is affected

People with Down syndrome have an affectionate, happy personality with an inherent sense of fun, but they also have a number of difficulties which make it more harder for them to interact and join with their peers:

- **Communication problems:**

Eye problems: cataracts, squints and nystagmus can cause difficulties with vision.

Speech problems: this can be due to two reasons 1) poor tongue control causing difficulty in forming words (dysarthria) and 2) hearing loss which can delay or prevent language development.

Hearing problems: frequent middle ear disease can result in up to 70% hearing loss.

Learning disability: this can be very mild, allowing a high level of involvement in society. For others, their learning disability can be severe with very delayed development.

- **Mobility problems:**

Reduced muscle tone: this delays walking. As babies they are often 'floppy'. *Poor co-ordination.*

Lax ligaments produce hypermobile joints. *Low foot arches* produce flat feet and make walking more difficult.

- **Reduced life expectancy:**

Current research shows that 80% of Down syndrome people alive today are over 50 years old.

Chest infections: nasal problems, middle ear infections and reduced muscle tone can all result in repeated respiratory infections and progressive lung damage over the years.

Congenital heart disease: a range of defects can occur in 40% of individuals which if severe, or not treated, can result in death in the first year of life.

Malignancies: Down syndrome is associated with an increased likelihood of acute lymphoblastic leukaemia. If it appears in childhood, 60-70% can be cured, but survival is much less likely in older people with Down syndrome. Other cancers are no more common in Down syndrome, but they now live long enough to develop the same cancers as the rest of the population.

Alzheimer's dementia: by the age of 50 – 60, a rapidly progressive type of dementia develops with deteriorating intellect and mobility, mood and personality changes, hallucinations, swallowing problems, a tendency to seizures (fits) and sudden muscle jerks. Most people with this form of dementia die within two years.

Thyroid problems: the thyroid can become under-active which will need treatment.

- **Appearance**

This makes most people with Down syndrome recognisable. They are short, have sloping eyes, a flat face (with a short bridged nose, low set small ears, and in some a protruding tongue), broad and flat hands (with a single crease and incurving 5th finger), and a smaller head

Margaret's vulnerability

- *Prejudice:* her appearance makes her easily recognisable. People make assumptions about her ability to comprehend, when in reality she can often understand very well what is happening. Consequently contact is avoided (through embarrassment), screening or contraception are withheld, or treatments are not given (on the assumption she cannot give consent).
- *Vulnerability:* her trusting and friendly nature makes her vulnerable to physical, psychological and sexual abuse. Although male Down people are infertile, females like Margaret are fertile and can have children. Margaret has the same rights to protection (security and contraception) as all of us.
- *Identifying distress:* although behaviour changes can become repetitive, this can be due to aggression, fear or physical problems. The number of possible physical problems Down syndrome people can suffer demands that physical causes are checked whenever behaviour changes (see CliP on *Identifying Distress*).

Reflect

Ring What is the risk of having a baby with Down syndrome?

Mother age 21	1 in 100	1 in 200	1 in 1500
Mother age 40	1 in 100	1 in 200	1 in 1500

Reflect

Ring What is the life expectancy of a person with Down syndrome?

20 years 40 years 80% die before 50 years 80% are over 50 years age

Write

What problems could have affected Margaret?

- Communication:

- Mobility:

- Illness:

- Appearance:

Write

What are the consequences for Margaret in the following areas?

1. Prejudice by others:

2. Vulnerability:

3. Identifying distress:

FURTHER READING: Down syndrome

- In Down syndrome:
 - in what ways are clients vulnerable both within and outside their usual setting?
 - observe (or ask colleagues) what the clients do to indicate they are distressed
 - what physical health care needs do they need?

FURTHER READING: Down syndrome

Journal articles

Alderson P. Down's syndrome: cost, quality and value of life. *Social Science & Medicine*, 2001; **53**(5): 627-38.

Barr O, Gilgunn J, Kane T, Moore G. Health screening for people with Learning Disabilities by a community Learning Disability nursing in Northern Ireland. *Journal of Advanced Nursing*, 1999; **29**(6):1482-1491

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.

Cosgrave MP, Tyrrell J, McCarron M, Gill M, Lawlor BA. Age at onset of dementia and age of menopause in women with Down's syndrome. *Journal of Intellectual Disability Research*, 1999; **43**:461-5.

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.

Miller B. Palliative care for people with non-malignant disease. *Nursing Times*, 1998; **94**: 52 – 53

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**(Pt 5): 432-6.

Tuffrey-Wynne, I. The palliative care needs of people with intellectual disabilities: a case study. *International Journal of Palliative Nursing*. 2002; **8**(5): 222-32.

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. *Down's Syndrome and Dementia*. Birmingham: The Venture Press, 1997.

Marler R, Cunningham C. *Down's Syndrome and Alzheimer's Disease: A Guide for carers*. London: Down's Syndrome Association (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