

CLiP

15 minute Worksheet



Helping the patient with communication difficulties

3: Down's Syndrome

Intermediate level

Produced by
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Aim of this worksheet

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

How to use this worksheet

- You can work through this worksheet by yourself, or with a tutor. All CLiPs and assessments are available on <http://learning.helpthehospices.org.uk/>
- 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- If you think any information is wrong or out of date let us know.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 50 year old lady with Down's 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.

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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's syndrome, Trisomy 21. There are other rare forms of chromosome disorders.

The mother's age is a key risk. Although 70% of Down's people are born to women under 35, the risk of a baby with Down's 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's syndrome babies are identified before birth, but recent advances in testing before birth may increase that number. Improved care has resulted in 80% of people with Down's Syndrome being aged over 50.

How the person with Down's syndrome is affected

People with Down's 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's syndrome people alive today are over 50 years old, but the death rate is six times that of the general population.

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's 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's syndrome. Other cancers are no more common in Down's syndrome, but they now live long enough to develop the same cancers as the rest of the population.

Alzheimer's dementia: after the age of 50, there is a greater likelihood of developing a rapidly progressive type of dementia causing deteriorating intellect and mobility, mood and personality changes, hallucinations, swallowing problems, a tendency to seizures (fits) and sudden muscle jerks. Life expectancy is usually between 3-6 years following diagnosis.

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

- **Appearance**

This makes most people with Down's syndrome recognisable. They are of short stature, 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

Susan'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's people are infertile, females like Susan are fertile and can have children. Susan 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's syndrome people can suffer demands that physical causes are checked whenever behaviour changes (see CliP on *Identifying Distress*).

Choose

Ring What is the risk of having a baby with Down's 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

Choose

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

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

Write

What problems could have affected Susan?

- Communication:

- Mobility:

- Illness:

- Appearance:

Write

What are the consequences for Susan in the following areas?

1. Prejudice by others:

2. Vulnerability:

3. Identifying distress:

FURTHER READING: Down's syndrome

In Down's 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 are their physical health care needs?

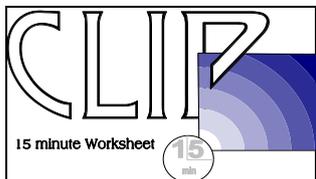
FURTHER READING: Down's syndrome

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
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- Nieuwenhuis-Mark RE. Diagnosing Alzheimer's dementia in Down syndrome: problems and possible solutions. *Research in Developmental Disabilities*. 2009; **30**(5): 827-38.
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- 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.
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- Weijerman ME, de Winter JP. Clinical practice. The care of children with Down syndrome. *European Journal of Pediatrics*. 2010; **169**(12): 1445-52.

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
- End of Life Care: A Resource pack for those caring for or supporting people with a learning disability at the end of life* <http://www.endoflifecareforadults.nhs.uk/publications/what-can-we-do-a-guide> NHS North East (2007)
- 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)
- The route to success in end of life care – achieving quality for people with learning disabilities. National end of Life Programme, (2011). www.endoflifecareforadults.nhs.uk/publications/route-to-success-people-with-learning-disabilities
- Down's 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
- Procedures in palliative care
- 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