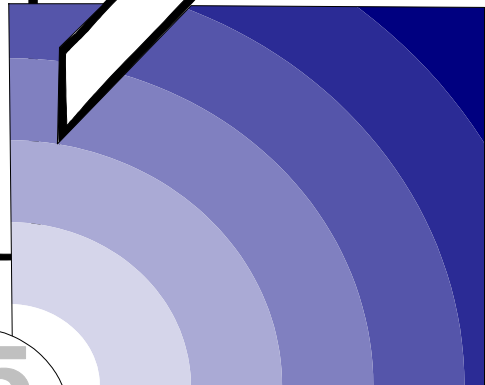
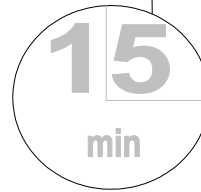


# CLIP

15 minute Worksheet



## Helping the person with communication difficulties

### 1: Conditions causing communication difficulties

Introductory level

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#### Aim of this workshop

To review the conditions that cause communication difficulties.

#### How to use this workshop

- You can work through this workshop 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- If you think any information is wrong or out of date let us know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.

## Conditions that result in people developing alternative communication

The potential list of causes is longer than you may have thought and you should have put a ring around ALL of the conditions. In children with IQs <70, Down syndrome and perinatal encephalopathies are the commonest causes. Between 3-4 per 1000 school children will have an IQ <30, and these will have to use alternative means of communication difficulties. In adults, the dementias are the commonest cause.

*Development* : eg. microcephaly, hydrocephalus.

*Bulbar palsy*: motor neurone disease

*Degeneration* eg. senile dementia, Alzheimer's, Parkinson's disease.

*Genetics* eg. trisomy 21 (Down's syndrome), Klinefelter's syndrome (XXY), cri du chat syndrome, fragile-X syndrome, Prader-Willi syndrome.

*Hypoxia*: eg. cerebral palsy.(some types affect expression only, others affect expression and comprehension).

*Infection*: eg. congenital rubella, toxoplasmosis, herpes simplex, cytomegalovirus, AIDS-related.

*Malignancy*: primary or secondary tumours of the brain, paraneoplastic dementia.

*Metabolism*: eg. galactosaemia, adrenoleucodystrophy

*Psychiatric*: conditions such as severe depression or psychosis will hinder or prevent communication, any acute confusional state will hinder communication.

*Trauma* to the brain

*Toxins*: eg. organophosphates, carbon monoxide, drugs, bacterial infections, antenatal toxins (alcohol., warfarin, opioids, organic solvents)

*Vascular system*: eg. cerebral infarction or haemorrhage, haemolytic uraemia syndrome.

Many of these causes damage comprehension such as the dementias and encephalopathies.  
(Remember that any cause of severe drowsiness or coma will make communication difficult).

In some causes comprehension is normal, but the body is affected such that speech and writing become impossible. Examples are motor neurone disease and cerebral palsy (dyskinetic and spastic diplegia types),  
A number of the causes affect comprehension and the body together, causing major communication difficulties. Examples are other types of cerebral palsy (spastic hemiplegia, bilateral hemiplegia, ataxic and tetraplegia types) and the leucodystrophies.

## Some thoughts about people with communication difficulties

1. F *Communication difficulty* implies that it is the only patient who is having difficulty communicating. In reality, patients have to *communicate in alternative ways* because of their condition, while carers often have difficulty in understanding what is being communicated. The problem lies with both the patient and the carer.
2. F In many people with alternative communication, expression (giving information) is affected differently to comprehension (receiving information). Some conditions severely affect expression, but leave comprehension intact (eg. dyskinetic and spastic types of cerebral palsy, motor neurone disease).
3. T Staff often have the skills to pick up distress but lack confidence in their ability. Much of the communication is picked up intuitively rather than by observation.
4. F It is very important we learn to pick up signs of pain or distress in a comatose patient.
5. F There is usually nothing wrong with pain receptors. However, it is true that people with alternative communication can be *indifferent* to pain. This is partly due to loss understanding of the implications of pain and reduced anticipation of the distress it causes. In practice, lack of information can lead to increased fear, and there is evidence of 11% of patients with developmental disabilities having low thresholds to pain.
6. T Close and documented observation is the key to understanding.

## An alternative language

Whenever we communicate face-to-face we don't just use words or writing.

*Our face* tells a great deal about us. The whole face reveals emotions such as joy, contentment, fear, anger and sadness. Parts of our face also give clues such as dilated pupils (fear or attraction), pallor (fear or pain), frown (puzzlement or distress) or biting our lower lip (anxiety, fear).

*Our voice* can provide clues through it's tone and quality. Moaning, grunting, crying and screaming all have different meanings.

*Hands* are used extensively to emphasise, illustrate or hide our feelings.

*Posture* shows our feelings and can indicate whether we are being defensive, trusting or frightened.

## Principles

- Many conditions can force children and adults to use alternative communication.
- Expression and comprehension of information can be affected differently .
- These patients are not insensitive to pain

Reflect

Ring any of these that you think *could* cause people to communication difficulties.

Underline the commonest causes.

organophosphates	trisomy 21	acute hypercalcaemia	motor neurone disease
AIDS	dementia	cerebral infarction	rubella encephalitis
Parkinson's disease	psychosis	tetraplegic cerebral palsy	head injury
adrenoleucodystrophy	coma	cerebral tumour	stroke (CVA)

MCQ

1. The problem in communication difficulties is with the patient True False
2. A severe communication difficulty is usually accompanied by poor comprehension. True False
3. Carers have the skills to understand people with communication difficulties True False
4. Communication is not relevant in a dying, comatose patient True False
5. Pain insensitivity is common in people with communication difficulties True False
6. The most important part of communication is recognising usual behaviour True False

Write

Imagine that you have lost the ability to speak or write. How could others realise that you are in pain?

Could you use any of these to show you have pain? Yes ✓ No ✗ How?

-face?

-voice?

-hands?

-posture?

Reflect

Think about the principles you have learnt from this worksheet

## FURTHER ACTIVITY: Conditions causing communication difficulties

Find a colleague with whom there is mutual trust and identify a patient with any communication difficulty

- feedback to one another your observations on the patient
- discuss your individual feelings
- identify what you learnt from the experience and plan how you will learn more.

## FURTHER READING: Conditions causing communication difficulties

### Journal articles

- Astor R. Detecting pain in people with profound learning disabilities. *Nursing Times*, 2001; **97**: 38-39.
- Fray MT. *Caring for Kathleen: A Sisters Story About Down's Syndrome and Dementia*. 2000 B.I.L.D. Publications E-mail: bild.demon.co.uk
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- Hatton C. Intellectual disabilities: epidemiology and causes. In, Emerson E *et al* eds. *Clinical Psychology and People with Intellectual Disabilities*. Chichester: John Wiley and Sons, 1998.
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- Lloyd-Williams M. An audit of palliative care in dementia. *European Journal of Cancer Care*, 1996; **5**: 53-5.
- Manfredi PL, Breurer B, Meier D, Libow L. Pain assessment in elderly patients with severe dementia. *Journal of Pain and Symptom Management*, 2003; **25**: 48-52.
- 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)
- Porter J, Ouvry C, Morgan M, Downs C. Interpreting the communication of people with profound multiple learning difficulties. *British Journal of Learning Disabilities*, 2001; **29**: 12 – 16.
- Regnard C, Matthews D, Gibson L, Clarke C, Watson B. Difficulties in identifying distress and its causes in people with severe communication problems. *International Journal of Palliative Nursing*, 2003, **9**(3): 173-6.
- Ware J. Creating a responsive environment for people with profound multiple learning difficulties. London: Fulton, 1996

### Other resources

Downs Syndrome Association  
[www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

Down's Syndrome Educational Trust  
[www.downset.org/DownsEd](http://www.downset.org/DownsEd)

## CLIP

**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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