

# CLIP

15 minute Worksheet



## Understanding and helping the person with communication difficulties

# 1: Conditions causing communication difficulties

Introductory level

<p>Produced by <b>St. Oswald's Hospice</b> Regent Avenue Gosforth Newcastle-upon-Tyne NE3 1EE</p> <p>Tel: 0191 285 0063 Fax: 0191 284 8004</p> <p>This version written and edited by: <b>Claud Regnard</b> Honorary consultant in Palliative Care Medicine, St. Oswald's Hospice</p> <p><b>Dorothy Mathews</b> Macmillan Nurse for People with Learning Disability.</p> <p><b>Lynn Gibson</b> Manager of Northumberland Physiotherapy service (LD) Northumberland Tyne &amp; Wear NHS Foundation Trust</p>	<p><b>Aim of this worksheet</b> To review the conditions that cause communication difficulties.</p> <p><b>How to use this worksheet</b></p> <ul style="list-style-type: none"><li>• You can work through this worksheet by yourself, or with a tutor.</li><li>• Read the case study below, and then turn to the Work page overleaf.</li><li>• 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.</li><li>• 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.</li><li>• If you think any information is wrong or out of date let us know.</li><li>• Take this learning into your workplace using the activity on the back page.</li></ul>
--	---

v18

## 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. In adults, the dementias are the commonest cause.

*Development* : eg. microcephaly, hydrocephalus.

*Bulbar palsy*: motor neurone disease.

*Degeneration* eg. Alzheimer's dementia, 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 (such as the dementias and encephalopathies) damage comprehension.

(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 the leucodystrophies, Parkinson's with dementia.

## Some thoughts about people with communication difficulties

1. F *Communication difficulty* implies that it is only the 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 of 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 its 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

**Choose**

**Ring** any of these that you think *could* cause people to have 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)

**True or false?**

- |  |      |       |
|--|------|-------|
| 1. The problem with 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

Astor R. Detecting pain in people with profound learning disabilities. *Nursing Times*, 2001; **97**: 38-39.

Banat D, Summers S, Pring T. An investigation into carer's perceptions of the verbal comprehension ability of adults with severe learning disabilities. *British Journal of Developmental Disabilities*, 2002; **30**: 78-81.

Davies D, Evans L. Assessing pain in people with profound learning disabilities. *British Journal of Nursing*, 2001; **10**: 513 – 516.

Foley DC, McCutcheon H. Detecting Pain in people with intellectual disability *Accident and Emergency Medicine* 2004; **12**:196-200.

Fullerton A. Examining the comfort of the unconscious patient. *European Journal of Palliative Care*, 2002; **9**: 232-3.

Gibson L, Matthews D, Regnard C. Message received? *Learning Disability Today*. 2010; **10**(8): 24-25.

Hadjistavropoulos T, LaChapelle DL, MacLeod FK, Snider B, Craig KD. Measuring movement-exacerbated pain in cognitively impaired frail elders. *The Clinical Journal of Pain*, 2000; **16**: 54-63.

Hunt A. Towards an understanding of pain in the child with severe neurological impairment. Development of a behaviour rating scale for assessing pain. PhD thesis. Manchester: University of Manchester, 2001.

Hurley AC, Volicer BJ, Hanrahan PA, Houde S, Volicer L. Assessment of discomfort in advanced Alzheimer patients. *Research in Nursing and Health*, 1992; **15**: 369-77.

Jordan AI, Regnard C, Hughes JC. (2007) Hidden pain or hidden evidence? *Journal of Pain and Symptom Management*. **33**(6): 658–60.

Kaasalainen S. Pain assessment in older adults with dementia: using behavioral observation methods in clinical practice. *Journal of Gerontological Nursing*. 2007; **33**(6): 6–10.

Kovach CR, Weissman DE, Griffe J, Matson S, Muchka S. Assessment and treatment of discomfort for people with late-stage dementia. *Journal of Pain and Symptom Management*, 1999; **18**: 412-9.

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.

Matthews D, Gibson L, Regnard C. One size fits all? Palliative care for people with learning disabilities. *British Journal of Hospital Medicine*. 2010; **71** (1): 40-43.

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.

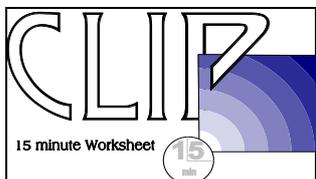
Purcell M, Morris I, McConkey R Staff perceptions of the communicative competence of adult persons with intellectual disabilities. *British Journal of Developmental Disabilities* 1999; **45**: 16-25.

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.

Regnard C, Reynolds J, Watson B, Matthews D, Gibson L, Clarke C. (2007) Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). *Journal of Intellectual Disability Research*. **51**(4): 277–92.

Regnard C. (2007) A pain tool for people with communication difficulties is no closer. *Clinical Medicine*. **7**(1): 89–90. Simons W, Malabar R. Assessing pain in elderly patients who cannot respond verbally. *Journal of Advanced Nursing*, 1995; **22**:663-9.

Whitehouse R, Chamberlain P, Tunna K. (2000) Dementia in people with learning disability: a preliminary study into care staff knowledge and attributions. *British Journal of Learning Disabilities* **28**: 148-153.



**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](http://www.clip.org.uk)