Understanding and helping the person with communication difficulties

1: Conditions causing communication difficulties

Aim of this worksheet
To review the conditions that cause communication difficulties.

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- If you think any information is wrong or out of date let us know.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.
INFORMATION PAGE: Conditions causing communication difficulties

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 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.
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)

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

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?

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

CLiP 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
- 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