Current Learning in Palliative care

Helping the patient with reduced hydration and nutrition 4: Decisions in hydration and nutrition

Intermediate level

Produced by St. Oswald's Hospice Regent Avenue Gosforth Newcastle-upon-Tyne NE3 1EE	Aim of this worksheet To consider the causes and approaches to reduced hydration and nutrition in advanced disease. How to use this worksheet
Tel: 0191 285 0063 Fax: 0191 284 8004	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.
This version written and edited by: Dorothy Mathews Macmillan Nurse for People with Learning Disability. Lynn Gibson Manager of Northumberland Physiotherapy service (LD) Northumberland Tyne & Wear	• 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.
NHS Foundation Trust	 If you think any information is wrong or out of date let us know.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.
Claud Regnard Honorary consultant in Palliative Care Medicine, St. Oswald's Hospice	Case study Ben is a 33 year old man who has a moderate learning disability together with hydrocephalus, spastic diplegia, visual impairment and epilepsy. He enjoys life, but his plans to resettle in a small group community hospital are halted when he is diagnosed as having a carcinoma of the kidney with lung metastases.
	He is normally well nourished, but in the three months since being told the diagnosis, he has lost 11kg in weight. Today he is listless and thirsty.
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Causes of reduced hydration and nutrition

Physical disability: paralysis, weakness or any difficulty with coordination will make it difficult or impossible for Ben to feed or drink. Breathlessness can make it difficult to eat or drink if it is severe enough. Swallowing problems have many causes (see CLiP Worksheet on Thinking About Swallowing Problems).

Physical illness: constipation, infection, nausea or vomiting are common causes. Cancer can reduce appetite as well as increasing the loss of fat and muscle, a syndrome known as cachexia (see CLiP worksheet on *Cachexia*). Many illnesses can result in loss of fluid eg. raised temperature, diarrhoea, vomiting, high levels of glucose or calcium.

Psychological: anxiety, low mood or depression can reduce the interest in food. Remember also that a person with capacity can choose to leave their intake unchanged.

Behavioural: food-related behaviours can occur for many reasons, and may be worsened by the stress of physical illness.

Current treatment: recent radiotherapy, chemotherapy or surgery will all reduce appetite, Some drugs can have the same effect directly (eg. phenytoin) or indirectly by causing constipation or nausea.

Environmental: some odours can reduce appetite (eg. smells from frying food, bowels or wounds). Poorly presented food is a common cause in hospital, while a lack of privacy can be a problem for someone who has difficulty eating.

Reasons for and against hydration and nutrition

For hydration: this is <u>simple</u> to administer by mouth if Ben is given help. If swallowing is difficult, a <u>subcutaneous</u> (<u>SC</u>) infusion can be used in the short term. Hydration ensures <u>good oral health</u>, helps to <u>prevent pressure sores</u>, and <u>prevents thirst</u>.

For feeding: adequate nutrition <u>prevents pressure sores</u>, <u>prevents hunger</u>, and <u>prevents the symptoms of nutritional</u> <u>deficiency</u>. If swallowing problems are present a <u>PEG can be used</u>, but this is unlikely to help Ben.

Against hydration: refusal by an individual to have a SC line placed must be accepted if the person is competent for that decision. In very ill patients, hydration can cause problems with <u>bronchial secretions</u>, <u>vomiting</u> or <u>incontinence</u>. Experience also demonstrates that <u>many patients in their last days are comfortable</u> without hydration.

Against feeding: this can be more difficult, especially if swallowing problems are present. <u>Refusal</u> by an individual to have a intravenous line or PEG placed must be accepted if the person is competent for that decision. In an ill patient the <u>prognosis may be too short for feeding to be of help</u>. Many ill patients <u>are not hungry</u> and have no desire for food. <u>Feeding does not prevent the death of a terminal patient</u>. It <u>does not prolong survival in a patient with advanced</u> <u>disease</u>, and if cachexia is present it will not increase weight (see CLiP worksheet on *The Cachexia syndrome*).

Clinical decisions for Ben

- Is the prognosis short (ie. day by day deterioration)? Hydration and nutrition are often unnecessary in a terminal patient who is comfortable and settled.
- Is there a request to withdraw nutrition or hydration? If Ben is making this request and he has capacity for this decision, then this must be followed. However, if Ben does not have capacity for this decision then see the CLiP worksheets on *Difficult Decisions* especially *Issues around Capacity* and *Best interests*.
- Are physical problems present? Exclude dysphagia, nausea, vomiting, pain, infection, odour, weakness, breathlessness and physical disability. See the relevant CLiP worksheets.
- Could drugs be a cause? For example, drugs that cause nausea, constipation, diarrhoea or gastric irritation.
- Is the food presentation or environment still a problem? Recheck these as above.
- Is anorexia persisting? Exclude altered taste due to a dry mouth or other problems. Consider using appetite stimulants such as dexamethasone. In cachexia, see CLiP worksheet on *The Cachexia syndrome*.
- Is thirst still present? Moisten the mouth frequently. Consider subcutaneous hydration.

Making the decision

This depends on Ben's capacity to make this decision. If he has capacity for this decision his view is paramount. If he does not have capacity the decision must be made in his best interests. In England and Wales this is a minimum 9 point checklist required by the 2005 Mental Capacity Act. See the CLiP module on *Planning Care in Advance*.

Advising and treating Ben

The overriding need is for comfort. Hydrating and feeding Ben will not prevent him dying from his cancer, but it will help him to feel as well as possible so that he can cope with his problems.

Hydration: He is having symptoms from a lack of fluid and replacing fluid will help him feel better. He may be able to drink enough, otherwise the subcutaneous route can be used easily in many settings.

Nutrition: The value of nutrition depends on his choice and prognosis. If he wants food, he should have this regardless of the prognosis. If his deterioration is slow (week by week, or month by month deterioration) extra nutrition in the form of supplements may help prevent symptoms due to nutritional deficiencies. His appetite can be stimulated using low dose steroids eg. dexamethasone 4mg once in the morning (see CliP worksheet on The Cachexia Syndrome)

Think of possible causes for Ben's weight and fluid loss in each of the following categories

Physical disability:

Physical illness:

Psychological :

Behavioural:

Current treatment:

Environmental:



Write down reasons for and against giving Ben fluid and food

For	Against
	For

How should you go about making the right decision for Ben?



MORE D

His listlessness and dry mouth suggest he is short of fluids. Think about what you would advise Ben to do

FURTHER ACTIVITY: Decisions in reduced hydration and nutrition

Taste a selection of commercially available supplements:

- reflect on whether you would prefer these preparations or high energy, natural, foods.

FURTHER READING : Decisions in reduced hydration and nutrition

Journal articles

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	15 minute worksheets are available on:
	An introduction to palliative care
	Helping the patient with pain
	 Helping the patient with symptoms other than pain
15 minute Worksheet	Moving the ill patient
	Psychological and spiritual needs
Current	Helping patients with reduced hydration and nutrition
Learning	Procedures in palliative care
in	Planning care in advance
	Understanding and helping the person with learning disabilities
Palliative care	The last hours and days
An accessible learning	Bereavement
programme for health	
care professionals	

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