

## Hydration and nutrition

The effects of dementia on food and fluid intake and hence nutritional status can be considerable. Ongoing nutritional screening and regular monitoring are important. Refer to the BCUHB Adult Nutritional Support Policy for guidance on nutritional screening and management. Consider dysphagia screening. Identify and address dental and oral care issues.

Decision making surrounding nutrition and hydration management is complex and for individual patients a multidisciplinary approach is best practice (Royal College of Physicians Report. Oral feeding difficulties and dilemmas. A guide to practical care, particularly towards the end of life, January 2010).

In the dying phase, a person's desire for food and drink lessens. Continue to offer diet and fluids unless it causes distress or burden to the patient. Good mouth care is essential and may become the more appropriate intervention rather than attempting to feed. Initiating artificial feeding is unlikely to be of overall benefit when someone is dying and therefore will not usually be appropriate. Consider the risks versus the benefits of intravenous and subcutaneous fluids. If artificial nutrition or hydration has previously been initiated, consider the appropriateness of continuing with such support.

The decision to withhold, withdraw or continue artificial nutrition and hydration requires ongoing individual assessment and clear documentation of the decision making process.

## Available support in older persons' mental health (OPMH) services:

### Conwy

- Bodnant OPMH team, Llandudno (West Conwy)  
Duty CPN 01492 868170 Consultant 01492 868180
- Bryn Hesketh OPMH team, Colwyn Bay (East Conwy)  
Duty CPN 01492 807512 Consultant 01492 807512

### Denbighshire

- Glan Traeth OPMH team, Rhyl,
- Duty CPN 01745 443194 Consultant 01745 443378

### Specialist Palliative Care Team (CENTRAL)

- TEL: 01745448720 Ext 7690
- FAX: 01745445947
- Out of Hours (Marie Curie Nursing 10 pm -7am)  
03001235566



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## Palliative Care in Advanced Dementia Leaflet for Professionals

Conwy and Denbighshire version

### Dying well with dementia includes:

- The recognition that many people with dementia will also have a co-morbidity that involves a separate life limiting condition.
- Access to community services for all those approaching the end of life so supporting people to die in their home or preferred place of death.
- Advance care planning within primary care to reduce unplanned hospital admissions in the last days. This will include entering the patient onto the palliative care register and informing out of hours services.
- Diagnosis of dying and a multidisciplinary team approach.
- Use of the All Wales Integrated Care Priorities for dying patients.
- Symptom control of physical and mental health needs.
- Psychosocial and spiritual support including carer support.
- Care in the last days of life of someone with dementia should have been planned once that person enters the severe stages of dementia through advance care planning processes.
- Frequent and open communication with the family and/or friends of the person with dementia.

### Communication

Communication is considered a vital aspect of good palliative care in advanced dementia. There must be frequent and open communication between professionals and with family and carers.

Such work is emotive and can be highly challenging. Time and planning is needed for many of the required decisions. Proper consideration is needed for all options and involving all those with an interest in the person with dementia under the Best Interests procedures of the Mental Capacity Act 2005.

The BCUHB website has links to the documents and policies described in this leaflet.

## Guidance on the use of the Do Not Attempt Resuscitation policy

Cardiac and respiratory failure is an inevitable part of dying and it is necessary to identify on a case by case basis, those for whom Cardiopulmonary Resuscitation (CPR) is likely to be unsuccessful.

There comes a time for every person when death is inevitable. It is therefore essential that patients are identified for whom cardiac arrest represents this natural event and for whom CPR is inappropriate. It is also essential to identify those patients who do not want CPR to be attempted and those who completely refuse it.

It may well be inappropriate to consider a patient for Cardiopulmonary Resuscitation if the patient is considered to be near the end of their life. This would include such patients with advanced dementia.

**A Do Not Resuscitate (DNACPR) decision applies solely to CPR. It should be made clear that all other treatment and care which is appropriate for the patient are not precluded and should not be influenced by a DNACPR decision.**

Decisions relating to CPR for those who lack capacity around the decision must involve family and carer discussions and incorporate the principles of best interests under the Mental Capacity Act 2005.

## Use of the All Wales Integrated Care Priorities for the dying patient

For the past ten years the all-Wales Integrated Care Priorities (ICP) for the last days of life, is a tool endorsed by the Welsh government and NICE to deliver high quality end of life care. The ICP is used in hospitals, hospices, community hospitals, nursing homes and community care across Wales.

The ICP is based on evidence where available or best accepted practice. The tool is structured around goals of care concerned with symptom management, comfort measures, communication with the patient, their family/caregivers and healthcare professionals, spiritual, religious and cultural requirements, bereavement planning and care after death.

## Identification of the patient who may be entering the last year of life with advanced dementia

**The following advice must be taken within the clinical context.**

**Firstly, ask yourself, would you be surprised if this patient died in the next 6-12 months?**

## Now look for two or more clinical indicators of advanced progressive illness.

- Progressive deterioration in physical and/or cognitive function despite optimal therapy.
- Speech problems with increasing difficulty communicating and/or progressive dysphagia.
- Recurrent aspiration pneumonia; breathless or respiratory failure.
- Unable to dress, walk or eat without help; unable to communicate meaningfully.
- Needing assistance with feeding/ maintaining nutrition.
- Recurrent febrile episodes or infections; aspiration pneumonia.
- Urinary and faecal incontinence.

### Assess and plan:

- Review treatment / care plan and medication.
- Discuss and agree care goals with patient and family.
- Produce care plan, agreed levels of intervention, CPR status.
- Enter patient onto both the palliative care and national dementia registers (if not already).

## Common physical and mental health symptom control

### 1. Pain control

Patients with advanced dementia may not be able to directly express their pain. Pain may be expressed by behavioural change only. Utilise a recognised tool for assessing pain in dementia such as the Abbey pain scale.

Follow the WHO ladder to prescribe analgesics if required. Have a low threshold for using regular low dose mild analgesics.

#### STEP 1: MILD PAIN – NON-OPIOIDS

eg. Regular Paracetamol (max. 1g qds) or NSAID (Ibuprofen 200-400mg tds, consider gastric protection with high risk patients).

#### STEP 2: MODERATE PAIN – WEAK OPIOIDS

eg. Codeine phosphate (15, 30, 60mg qds) or Cocodamol 30/500 (up to 2 tablets qds).

#### STEP 3: SEVERE PAIN – STRONG OPIOIDS

Most pain in dementia care is not likely to require strong opioids. Doses must be carefully titrated to avoid over-sedation and falls. Transdermal patches should be used with caution and where necessary seek specialist advice.

If the pain remains uncontrolled, seek specialist advice from palliative care.

### 2. Constipation

- Anticipate this common problem
- Enquire about bowel function regularly
- Always prescribe a regular laxative when starting opioids
- Lactulose 5-15ml bd is the recommended first line laxative, if the patient is able to drink
- Titrate laxative to achieve optimum stool frequency and consistency, try to use **lowest regular** dose

### 3. Agitation, aggression and hallucinations

Most episodes of agitation and aggression in severe dementia can be managed through clear communication between the care staff, family and patient. Communication difficulties can be challenging to resolve if someone has lost verbal communication. However meaningful interactions are often possible through the use of pictures, textures and touch. Non-pharmacological methods such as aromatherapy, multisensory stimulation, music, animal assisted therapy and massage ought to be considered first.

If a patient is prescribed a memory medication, consideration ought to be given to the appropriateness of continuing that medication. This must be done through secondary care and is made on a case by case basis.

Physical causes must be actively sought and resolved. Pain, constipation, urinary tract infections and even relatively small changes in the environment can result in agitation.

Carefully consider the need for blood investigations balancing the distress to the patient against risk of injury if restraint is required. Ask yourself, will an abnormal result change my management plan?

Consider the timing of agitation and alter times and dose of medications around those times to pre-empt such behaviour.

Common medications include trazodone 25mg nocte. Slowly titrate but be careful of falls as it is highly sedating. Citalopram up to 20mg daily can be helpful. In acute delirium, a short course of lorazepam 0.5mg-1mg max. qds can be useful.

If these fail then refer to older persons' mental health services (OPMHS). It is no longer advisable for antipsychotics to be commenced by primary care for agitation.

It is appropriate for patients with hallucinations to be referred to OPMHS. If the problem is solely about hallucinations then atypical antipsychotics are generally preferred. Avoid any antipsychotics in a patient with Lewy Body dementia.

### 4. Low mood and lability of mood

Problems with low mood and lability are common in advanced dementia. This may lead to behavioural problems too. Have a low threshold for considering an SSRI medication. If there are communication issues ask the carers about biological symptoms such as newly disturbed sleep and change in appetite. Weight loss is not a useful indicator as that frequently occurs in

severe dementia, irrespective of depression. Sexual disinhibition can respond well to SSRIs.

Common medications include sertraline up to 150mg daily or fluoxetine 20mg. Mirtazapine 15-30mg can be useful for its sedative properties if there is sleep disturbance and for its appetite stimulation.

Consider other factors that may affect mood such as constipation, pain, poor mobility and falls and a lack of meaningful communication. Treatment failure, severe risks and elation of mood warrant a referral to OPMHS.

## Access to support services

Services exist to assist in preventing inappropriate hospital admissions. All areas have access to the district nurses seven days a week but there is no overnight service and each area has slightly differing working hours. Fast-track continuing healthcare funding (CHC) can also be requested for those in terminal stages. Urgent social service assessments can be arranged through First Contact. Each area also has out of hours GP provision.

## Use of the Mental Capacity Act

Use of the Mental Capacity Act is required for those with any disability of the mind and brain and who are unable to complete at least one of any of the four conditions with regards to making a decision-unable to understand information, unable to use or weigh up that information, unable to communicate at all that information and/or unable to retain the information long enough to make an effective decision.

Decisions needed around terminal care in dementia will likely require such an assessment of capacity. All major decisions for individuals who lack capacity must involve a Best Interests assessment, usually with a meeting involving relevant professionals and family. You must consider any previous wishes, any advance decisions or statements and try to involve the patient in the decision. Such decisions must be contextual upon the action required.

It is required in statute law that either a family member or an independent mental capacity advocate (IMCA) is involved in this decision. You must always establish whether the patient has Lasting Power of Attorney (Health and Well Being) since the Appointee(s) will have particular authority under the Act to direct the outcome of these major decisions.

## Use of covert medications

Covert administration involves administering medication in food or drink without the patient's awareness in those who lack capacity about the treatment. A fully documented Best Interests decision will be needed after discussions with the family and others involved, weighing up pros and cons. The pharmacist should be contacted for advice on suitable formulations.