Guidelines for Health Care Professionals:

Alternative Routes of Medication Administration for Symptom Management in End of Life Care for People with Dementia

1. Preamble

Guidelines for symptom management in palliative care have been agreed across the YCN and North East Yorkshire and Humber Clinical Alliance (www.ycn.nhs.uk)
These are intended to supplement the above guidelines when considering routes of medication in End of Life Care in people with dementia. It is essential that the patient has first been assessed for capacity to consent to take medicines. If the patient does not have capacity, a best interests decision should be made in line with the Mental Capacity Act http://www.legislation.gov.uk/ukpga/2005/9/contents.

2. Assessment – Including optimisation of current treatment

A thorough, holistic assessment, including history and examination where possible, is necessary before making any changes Consider:

- These guidelines are intended for the end of life phase. A prognostic indicator tool may be helpful (http://www.leedspalliativecare.co.uk/resourcefiles/SPICT.pdf)
- Does the patient have unmanaged symptoms? Are they able to report pain or other symptoms?
- Are there any reversible causes?
- Can the patient take medicines orally? (use oral route first line wherever possible)
- Are oral medicines being absorbed?
- Is the patient compliant with taking oral medicines? Are there any factors that may aid the taking
 of oral medicines ?(e.g. switch from tablets to syrups/liquids, giving tables with jam/yoghurt, orodispersible preparations). Liaise with pharmacist.
- Optimise dosing schedule (e.g. is a once daily/slow release preparation available?)
- Some medications can be administered rectally; however this is rarely appropriate in people with dementia. As rectal administration is an intimate and invasive procedure, it is vital that valid consent is obtained prior to commencing. Where a patient lacks capacity to consent, a best interest's decision should be made in line with the Mental Capacity Act.
- Prioritise essential meds (in dying phase, symptom management is priority)
- Seek specialist advice before stopping anti-convulsants, anti-psychotics, analgesia
- Involve family members/carers in assessment and decision making

For further advice refer to:

YCN and North East Yorkshire and Humber Clinical Alliance – A Guide to Symptom Management in Palliative Care Version 5.1 (www.ycn.nhs.uk)

Leeds Health Pathways

Specialist palliative care teams at LTHT (0113 2064563), Sue Ryder Care Wheatfields (0113 2787249) or St Gemma's (0113 2185500) Hospices

Leeds Community Healthcare NHS Trust - Leeds Care Homes End of Life Care Facilitator (07950751490)

Palliative Care Website www.leedspalliativecare.co.uk

3. Alternatives to the Oral Route

3.1 Pain management

- · Identify and, where possible, treat any contributing causes eg constipation, pressure sores
- Use of a pain/behavioural assessment tool may be helpful.
- If unclear if patient has pain, consider a trial of regular analgesia oral paracetamol if possible

a. Topical preparations

Topical preparations such as non-steroidal anti-inflammatory gels can be effective in mild-moderate localised pain in acute and chronic musculoskeletal conditions such as arthritis.

Heat pads and warm baths can relax muscles, reduce joint stiffness and help relieve aches and pains. Ice packs can help relieve pain where there is inflammation and swelling. Care should always be taken to protect the skin from burns when using heat pads and ice packs. Heat shouldn't be used on body areas that are already inflamed or swollen, as it can make the swelling worse

b. Transdermal patches

These are applied to the patient's skin and analgesia is absorbed through the skin into the bloodstream. They are mainly suitable for patients with chronic pain and stable analgesic requirements. They may be useful in patients with poor compliance with oral opioids or where there are swallowing/absorption problems. A number of different continuous release preparations are available to treat moderate to severe pain including BuTrans® (buprenorphine) patches (lowest strength 5mcg/hr lasts 7 days and is equivalent to 90mg oral codeine/24hr. Conversion charts available in "A Guide to Symptom Management in Palliative Care"). All patients using continuous release preparations should also be prescribed an immediate release preparation for breakthrough pain such as codeine or morphine (dose dependent on patch strength)

Tips for using patches:

- Apply patches to an area of dry, non-irritated, hairless, intact skin. Do not apply creams/lotions
 to chosen site as may prevent patch sticking. Check information leaflet for frequency of
 changing varies with different patches.
- If the edges of the patch begin to peel up, or patient picks at patch, it can be stuck down with occlusive dressing e.g. Tegaderm or similar, or tape.
- Do not apply direct heat to the area with the patch (e.g. heat pack, hot bath water) as this may lead to higher quantities of the active drug being absorbed into bloodstream.
- Patches should be changed at the same time of day. Remove old patch, fold it in half sticky side inwards, place in empty pouch and discard in yellow sharps bin
- Apply new patch to a different skin site so that one area is not used twice in a row.
- On initiation or after a change in patch strength, continuous analgesia may take a day or more
 to reach optimal levels within the bloodstream. Monitor patients for signs of pain during this
 time and provide immediate release analgesia as needed.

c. Sub-cutaneous injections

Sub-cutaneous injections are an alternative means of administering a range of symptom management drugs. Injections may be administered regularly or on an "as required" basis. Whilst a syringe pump may be the preferred option for delivery of sub-cutaneous medication at the end of life, it is not always possible due to lack of equipment or trained staff.

d. Rectal preparations

Certain analgesics eg paracetamol and diclofenac can be administered rectally as suppositories (see section 2. Assessment).

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3.2 Nausea and Vomiting

Considerations:

- Treat reversible causes where appropriate (e.g. infection, review current medications)
- Are environmental factors contributing? Can they be minimised? (e.g. reduce noxious odours, strong food smells etc., reduce overwhelming food portion sizes)
- Non-pharmacological interventions may be useful (e.g. sea bands)
- Consider longer acting anti-emetics to reduce tablet burden e.g. levomepromazine

Alternatives to oral route

a. **Sub-cutaneous injection-** most anti-emetics are available in injectable preparations and can be used as sub-cutaneous injections or via syringe pump as continuous infusion.

b. Patches

Hyoscine hydrobromide is available as Scopoderm TTS patch and can be useful for motion sickness (1mg patch applied to hairless area behind ear every 72hours). Side effects include: dry mouth or skin, urinary retention and confusion.

c. Suppositories

Domperidone is available as a 30mg suppository (Daily dose-60mg bd; see section 2. Assessment)

3.3 Constipation

Considerations:

- Increase fluid intake and review diet to include fibre if possible
- · Review medication which may be causing constipation
- Non-pharmacological measures may help: abdominal massage and use of heat pack, assist
 patient to adopt correct posture for defecation, ensure privacy
- Combination of stool softener and stimulant laxative is usually required
- A number of liquid preparations are available as well as tablets and capsules
- Preparations containing dantron can cause contact dermatitis; avoid in incontinent patients
- In the dying phase it may be un-necessary to intervene unless constipation is causing distress

Rectal laxatives- may be necessary for treating faecal impaction. Digital rectal examination should be performed prior to administration (see section 2. Assessment).

3.4 Delirium

Delirium is extremely common in patients with advanced disease, especially in those with dementia. It is often unrecognised or misdiagnosed as worsening dementia, depression, anxiety or psychosis.

Clinical features

- Disturbance of consciousness (i.e. reduced clarity of awareness of the environment) with reduced ability to focus, sustain, or shift attention.
- B. A change in cognition or the development of a perceptual disturbance that is not better accounted for by a pre-existing, established, or evolving dementia.
- C. The disturbance develops over a short period of time (usually hours to days) and tends to fluctuate during the course of the day.

Assessment

Obtain a thorough history to determine the patient's pre-morbid level of functioning, the onset of the changes in their mental state and any potential cause e.g. infection, medication.

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3.4 Delirium Continued

Management

- Non-pharmacological measures are the mainstay and include:
 - Assessing thoroughly for reversible causes and treating where possible
 - Managing the patient's environment to reduce confusion and distress e.g.
 - Visible clock to aid orientation, good lighting during daytime
 - Encourage family to visit and provide them with a full explanation
 - Consistent nursing
- Pharmacological interventions:
 - Consider using haloperidol if patient is distressed
 - Olanzapine velotabs can be useful if patient can't swallow tablet or liquid
 - If oral route not possible consider haloperidol 500 micrograms 1.5mg subcut, observe for 30-60 minutes and repeat if necessary. Titrate cautiously according to symptoms, usual maximum dose 5mg over 24hrs. Review every 24 hours, monitor for adverse effects & seek further advice if not working
 - lorazepam (sublingual or IM) or midazolam (SC) may be useful, particularly in Lewy Body Dementia (LBD), and where the prime therapeutic aim is to sedate and/ or reduce agitation.

NB Use with caution. All psychotropics (including Benzodiazepines) can increase confusion. Seek advice if concerns

4. Syringe Pumps

A syringe pump is a portable battery operated device which delivers medication subcutaneously over a continuous 24 hour period. Syringe pumps allow a minimally invasive route of drug administration which provides relatively constant levels of medication. Patients at the end of life may present with multiple symptoms that necessitate the need to use several drugs. A syringe pump enables a combination of drugs to be administered in one infusion.

If the patient is likely to move about and forget to take the syringe pump or to pull at the infusion line, a syringe pump may be inappropriate.

Typical uses:

- End of life care for patients unable to take oral medication
- Pain and symptom control
- Intractable nausea and vomiting
- Intestinal obstruction
- Head and neck lesions
- Malabsorption
- Patient compliance issues

Across Leeds, the McKinley T34 syringe pump is used in palliative care. All staff using a syringe pump must have received training and be personally competent in the use and operation of such devices. Syringe pumps must be regularly serviced according to a defined schedule. For further information regarding syringe pump training within Leeds contact: End of Life Care Home Facilitator or local SPCT. On-line training is available via CME McKinley; the website is www.Mckinleymed.co.uk/training/T34

5. Last Hours or Days of Life

When it is recognised that a patient is entering the dying phase, it is recommended that a clear care plan for End of Life care is in place is used that includes guidance on symptom management for patients unable to take oral medication including pain, breathlessness, terminal restlessness and retained secretions. (Contact Specialist Palliative Care Team or End of Life Care Facilitators for further advice).