Leeds Centre for Neurosciences

The Leeds Teaching Hospitals NHS Trust

Non interventional management of swallow problems in Patients with Motor Neurone Disease (pwMND)

Patients with Motor Neurone Disease (MND) can develop swallowing problems. Not every patient will choose or be medically fit for interventional procedures for assisted nutrition. The Leeds MND Care Centre Team has developed guidelines for this group of patients who are cared for at the Leeds MND Care Centre. Previous guidelines developed by a regional team of MND experts across West Yorkshire including the MND Association, MND coordinators, Palliative Medicine Consultant and Specialist Nurses were also taken into consideration.

Non interventional management of swallowing problems in pwMND

Fluid management

Symptoms and signs that may indicate dehydration:

- Dry skin
- Dry nose, eyes and mouth
- Thirst (as opposed to dry mouth)
- Headaches
- Dark & strong smelling urine/reduced urine output
- Feeling light-headed or dizzy

Optimise oral intake of fluids by mouth, or moist foods if cannot manage fluids

- Consider crushed ice
- Consider mouth care (eg biotene gel / artificial saliva)
- Check oral cavity for thrush
- Maintain oral hygiene
- Support carers with strategies (consider providing written information)

If symptoms are not improving: (eg thirst, headaches)

- Consider subcutaneous fluids if available locally – availability differs across regions.
- Discuss practicalities, benefits and burdens with patient and Healthcare Team

If health care can facilitate subcutaneous fluids, and patient wishes to accept

- Refer to local guidelines for subcutaneous fluids
- Liaise with District Nurses, GP and night nursing service re prescription of s/c fluids; insertion of s/c cannula; care of site and commencement of fluids.

Minimum daily review by community nursing team. Suggest GP review in 3 days and negotiate whether to continue fluids based on benefits and burdens.

If health care cannot provide subcutaneous fluids and/or patient declines

- Offer involvement of palliative care team and review by MND team
- Continue symptomatic measures
- If prognosis likely to be days as a result of reduced oral intake, consider offering sedation to reduce discomfort that results from dehydration

Monitor for changes in condition that might suggest the person is starting to die and commence usual symptom control measures; consider offering sedation to reduce discomfort that results from dehydration.

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Secretion management

Excess thin watery saliva

GENERAL MEASURES

- Optimising posture
- Support collar
- Suction

MEDICATION options include:

- **Hyoscine hydrobromide** patch 1mg/72 hrs (Scopoderm) or S/C infusion of 1200micrograms in 24 hours max*
- **Amitriptyline** 10-50mg orally nocte*
- **1% Atropine drops** (eye drops used SUBLINGUALLY) – 1-4 drops QDS max (drop onto spoon first to avoid excess)
- **Glycopyrronium** 500micrograms to 2mg TDS orally (sometimes lower or higher doses are needed), or SC infusion up to 1200micrograms/24 hrs
- **Hyoscine butyl bromide** S/C infusion up to 120mg/24 hrs

(*may cause confusion/urinary retention, in which case consider other options)

BOTULINUM TOXIN

Have a low threshold for using this early in treatment, especially if first line medications are not effective, not tolerated or contraindicated)

NATURAL REMEDIES (limited evidence)

- Sage (tea, capsules, tincture)
- Dark grape juice

If there is a **LACK OF RESPONSE** to the above, consider radiotherapy or surgery to salivary glands

Consider early specialist palliative care advice

If choking, consider laryngospasm as a possible cause. If laryngospasm is a factor, manage thin saliva and consider breathing exercises, and medications to reduce future episodes - muscle relaxants (e.g. baclofen) and/or anxiolytics (e.g. lorazepam).

Thick tenacious saliva

GENERAL MEASURES

- Optimise hydration and oral hygiene
- Review medication that dries/thickens secretions (e.g. anti-cholinergics)
- If sucking slivers of crushed ice/eating/drinking, strong flavours will stimulate thinner saliva to flow
- Optimise hydration (caffeine and alcohol are more dehydrating that other drinks)
- Consider replacing dairy products with other highly calorific foods if possible
- Steam inhalation / room humidification
- For acid reflux – consider mucolytics and protein pump inhibitor management (eg lansoprazole)

MEDICATIONS options include:

- Carbocisteine 750mg TDS (tab/liquid) or Acetylcysteine 600mg daily (Effervescent tablet)
- Saline nebulisers (0.9%) 5ml PRN
- Propanolol or metoprolol (NB possible dizziness and other cardiac side effects, so start with minimal dose and titrate)

NATURAL REMEDIES (limited evidence)

- Papaya / fresh pineapple (or fresh juice – contains enzyme that breaks down thick saliva, and strong flavour may stimulate salivary flow)

If there is a **LACK OF RESPONSE** to the above, consider radiotherapy or surgery to salivary glands

Consider early specialist palliative care advice

Sputum & Phlegm

GENERAL MEASURES

As for thick tenacious saliva as well as:

- Postural drainage
- Breathing exercises
- Chest physiotherapy
- Suctioning – oral pharyngeal
- Prophylactic use of cough assist
- Mucus plugs are difficult to manage, prevention with regular use of above measures is preferable (in severe distress, consider cautious use of benzodiazepines to relieve severe distress)

MEDICATIONS options include:

- Carbocisteine 750mg TDS (tab/liquid) or Acetylcysteine 600mg daily (Effervescent tablet)
- Saline nebulisers (0.9%) 5ml PRN
- Propanolol or metoprolol (if no contraindications start with minimal dose and titrate)
- Acetylcysteine nebuliser TDS-QDS, using solution for injection
  3-5ml of 20% solution OR
  6-10ml of 10% solution

NATURAL REMEDIES (limited evidence)

Eucalyptus and menthol inhalations

Consider early specialist palliative care advice

Dry Mouth

Good mouth care…Moist oral mucosa improves comfort, reduces bacteria that cause bad breath and helps manage the risk of aspiration pneumonia.

GENERAL MEASURES

- Optimise hydration and oral hygiene
- Smoking & alcohol (including mouthwash that contains alcohol) can increase mouth dryness
- Review medication that may be causing dryness (anti-cholinergics, diuretics etc)
- Consider posture at night, as mouth-breathing is very drying.
- If sucking slivers of crushed ice/eating/drinking, strong flavours can stimulate salivation
- Very useful website: http://mouthcarematters.hee.nhs.uk/index.html

MEDICATIONS options include:

- Biotene gel (alternative to artificial saliva)
- Pilocarpine 4% eye drops used SUBLINGUALLY – up to 5 drops QDS to stimulate salivary flow
- Bethanechol 10-25mg TDS-QDS oral 30 minutes before food.

NATURAL REMEDIES (limited evidence)

- Ginger (capsules, tea etc)
- Swabbing mouth with ghee, groundnut oil, rapeseed oil etc at bedtime

Consider early specialist palliative care advice

Non interventional management of swallowing problems in pwMND

Eating and drinking with dysphagia pathway

Person eating and drinking with dysphagia

At diagnosis; MDT assessments and review or if there are any concerns about:

- Weight
- Nutrition
- Swallow

Assess weight, nutritional intake, fluid intake, hydration, oral health, feeding, drinking and swallow

Offer support, advice and interventions as needed

Would the team offer this person a gastrostomy (PEG)?
(Refer to the Leeds MND PEG pathway. Seek advice from MND MDT)

No/Yes

Person declines PEG

Person accepts PEG

Refer as per Leeds MND PEG pathway (Available via trust intranet)

Take into account:

- Understanding wishes, preferences and priorities
- Fluid / food intake vs hydration and nutritional needs
- Appetite and thirst
- Gastrointestinal symptoms (eg nausea / constipation)
- Causes of decreased oral intake (eg swallow difficulty; breathlessness or NIV use; limb weakness or possibility of low mood or depression causing lack of appetite)
- Implications for swallowing medication
- Consider care agency input if support is required with eating and drinking and/or PEG cares
- Person's capacity for making decisions – whilst considering that the person may eat and drink in a different way to their planned decision either due to quality of life factors *in the moment* or due to behavioural / cognitive change (consider ECAS)
- A person may eat or drink with acknowledged risk of aspiration/penetration and/or choking. This informed decision can be made from information provided during a swallowing assessment where specific recommendations are given by SLT
- If concerns re mental capacity, liaise with consultants and GP and consider if the following are in place / appropriate:
  - Mental capacity assessment
  - Best interest assessment
  - Advance Care Planning, Advance Directive to Refuse Treatment, Lasting Power of Attorney, IMCA etc
  - Court appointed Welfare Deputy

Continue regular and responsive reviews

With consent, explore idea of eating and drinking for comfort rather than to maintain nutrition and hydration. Complete EDAR. Consider tasters for comfort if they wish following a swallowing assessment by SLT and discussion of risk.

Maintain comfort. Seek advice from MDT in managing dehydration or coughing / choking

Further information can be sought from the Leeds MND Care Centre Team:

For general enquiries contact:
Claire Lang
MND CNS & Leeds MND Care Centre Coordinator
claire.lang2@nhs.net
0113 392 6755
07789174327

For speech and language advice and support contact:
Brenda Thompson
Leeds MND Speech and Language Therapist
Brenda.thompson
brenda.thompson4@nhs.net
07917284546

For dietetic support contact:
Christine Bailey-Scott
Leeds MND Dietitian
christine.bailey-scott@nhs.net
07912485212