Toolkit for eating and drinking with dysphagia in MND

West Yorkshire & Harrogate MND Special Interest Group (WY&H)

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Why this toolkit?

Developing PEG pathway but

- PEG not wanted / “not yet”
- deferred, now wanted, risks > benefits

Supports people affected by MND, supports staff

Discussion at WY&H MND special interest group

- fully informed decision, with capacity=> valid to decline
- what can we offer?
- difficult to find existing guidelines

Who / where?

Interested professionals from Harrogate, Leeds, Calderdale and Huddersfield, support from MND Association

Online meetings over the last 6 months

Individually reviewed **existing guidelines** for components of this toolkit

e.g. coughing and choking, saliva management

What?

It is: ✓

- Toolkit of references
- Pragmatic guidance
- Useful for non-specialists
- This presentation is an opportunity for us to gain your feedback so we can improve the toolkit

It is not: ✗

- The result of an extensive systematic literature review
- Universally applicable to all teams/areas – would need adapting to local practice

What? 1

Background notes

Specific guidelines

Secretion management

Fluid intake

Summary pathway

Patient held care plan

What? 2

Background notes

Summarise context and existing guidelines and literature:

- Impact of gastrostomy (ProGas study)
- Current studies re nutrition and outcomes in MND (HighCALS, OptiCALS)
- Feeding tube pathways
- Risk stratification tools (Middlesbrough)
- Impact of psychology on decision making and behaviour
- Psychological / physical / pharmacological / complementary therapies to manage symptoms and complications
- Suggested systems

What? 3

West Yorkshire & Harrogate MND special interest group

Background notes for Eating and drinking with dysphagia

National guidelines recommend early discussions with people with MND (pwMND) regarding gastrostomy. The ProGas study, looking at clinical outcomes following gastrostomy, found that maximum benefit was derived when the gastrostomy was inserted at 5% weight loss. However, the average time from diagnosis to elective gastrostomy for the cohort was 16.7 months. During this time, people may be coping with symptoms related to dysphagia and they may also be in a psychological process of adaptation. Multiple pwMND, carer and health service factors have been reported to complicate decision making and lead to pwMND delaying making decisions. ProGas also showed that risks from gastrostomy insertion increase once weight loss exceeds 10%, and as respiratory function deteriorates. In addition, for some people living with MND, cognitive change may challenge their ability to accept a gastrostomy; either due to a lack of insight or ability to plan ahead, or due to changes to mental capacity. Communication may also become more difficult as time progresses, and therefore there is an optimal window of time for each person to have a gastrostomy if they want one, both of in terms of safety of the procedure, and gaining maximum benefits.

What? 4

Summary Pathway

Prompt to explore nutritional status and swallowing

Professional decision –

? Offer tube (net benefit?)

Person's decision –

? Accept tube if offered

Mental capacity factors

If no feeding tube:

- optimising intake/minimising risks
- managing symptoms and complications

Need for regular review – decisions, support

Eating and drinking with dysphagia – Summary pathway

Person eating and drinking with dysphagia

Take into account

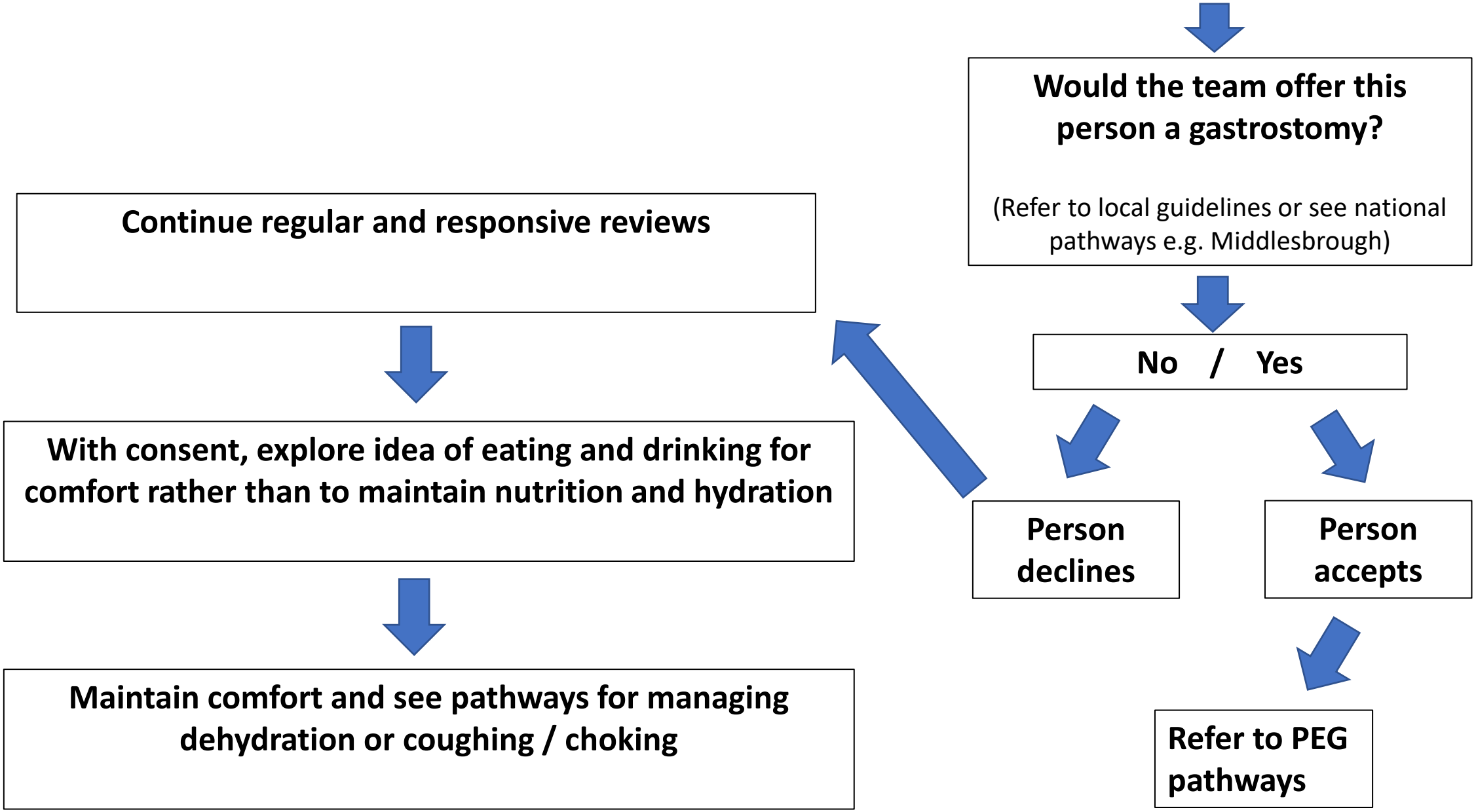
- Understanding wishes, preferences and priorities
- Fluid / food intake vs hydration and nutritional needs
- Appetite and thirst
- Gastrointestinal symptoms (e.g. nausea / constipation)
- Causes of decreased oral intake (e.g. swallow difficulty; breathlessness or NIV use; limb weakness or possibility of low mood or depression causing lack of appetite)
- Implications for swallowing medication
- Person's capacity for planned 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)
- 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

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

- Weight
- Nutrition
- Swallow

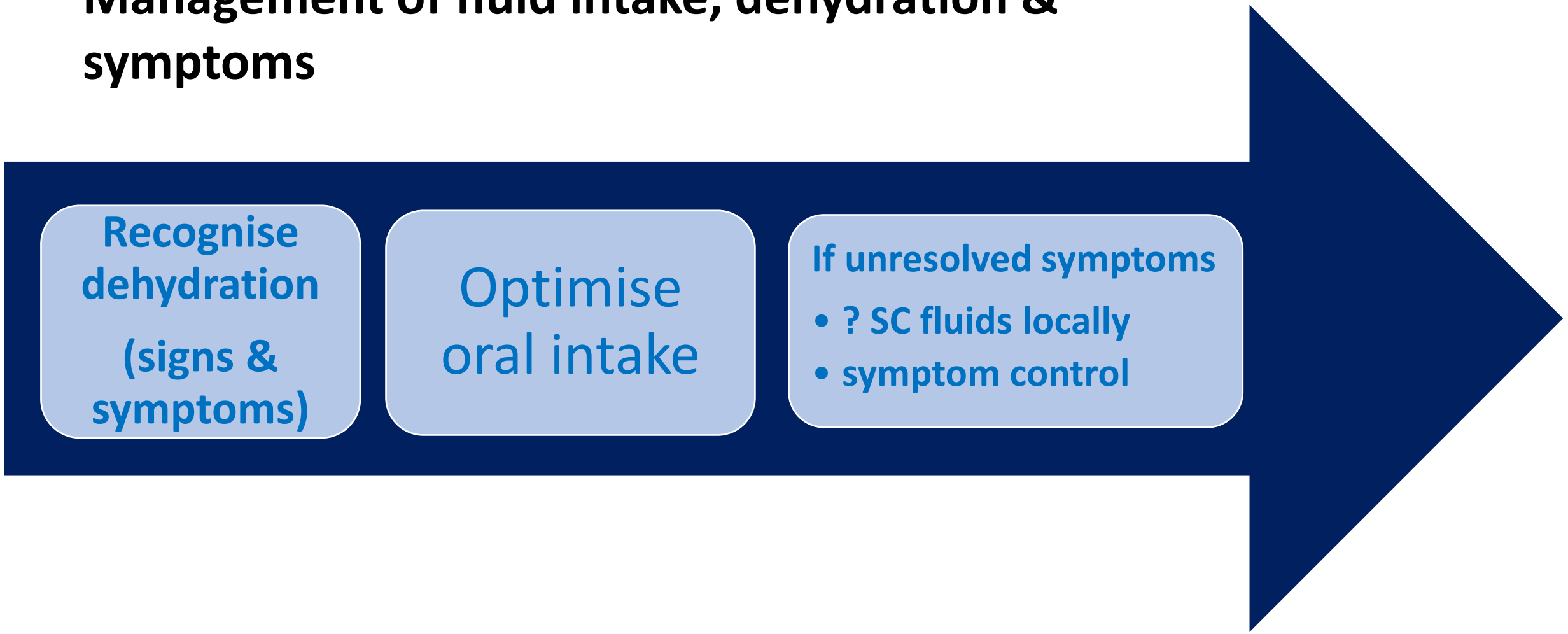
Assess weight, nutritional intake, fluid intake, hydration, oral-health, feeding, drinking and swallow

Offer support, advice and interventions as needed


Would the team offer this person a gastrostomy?
(Refer to local guidelines or see national pathways e.g. Middlesbrough)
No / Yes
Person declines
Person accepts
Refer to PEG pathways
Continue regular and responsive reviews
With consent, explore idea of eating and drinking for comfort rather than to maintain nutrition and hydration
Maintain comfort and see pathways for managing dehydration or coughing / choking

What? 4

Management of fluid intake, dehydration & symptoms



Eating and Drinking with Dysphagia – Fluid intake

Symptoms and signs that may indicate dehydration:

- Dry skin
- Dry nose, eyes and mouth
- Thirst (as opposed to dry mouth)
- Headaches
- Dark and strong smelling urine / making less urine
- 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 (e.g. 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: (e.g. thirst, headaches)

- Consider subcutaneous fluids if available locally
- Discuss practicalities, benefits and burdens with patient and Healthcare Team

Health care team can facilitate subcutaneous fluids, and Patient wishes to pursue

- 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.
- Refer to local guidelines for more detail

Patient declines or primary health care team express concern

- 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

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

What? 5

Secretion management

Excess thin saliva	Thick / tenacious saliva	Sputum	Dry mouth

Eating & Drinking with Dysphagia – 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

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)

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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)

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- 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

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).

Excess thin watery saliva

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MEDICATIONS options include:

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- Bethanechol 10-25mg TDS-QDS oral 30 minutes before food.

NATURAL REMEDIES (limited evidence)

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Consider early specialist palliative care advice

What? 5

Patient held record

Care plan specific to eating and drinking with dysphagia

current recommendations for optimal safety and comfort

documentation of discussions with patient / family

Patient held record

Overgate HOSPICE ¶ Leeds Centre for Neurosciences Saint Michael's Hospice Calderdale and Huddersfield NHS NHS Foundation Trust

Eating·and·drinking·advice·for·Bertie

(fictitious·example·only·-·something·like·this·might·be·updated·by·the·SLT·and·dietician·and·referred·to·by·the·MDT·so·they·are·aware·of·anything·to·follow·up.)

Date·of·review¤	**Current·advice·on·eating·and·drinking·**(swallow·techniques;·positioning;·texture·modification;·food·fortification)¤
21st·March·2022¶	We·reviewed·your·swallow·today,·you·are·managing·minced·and·moist·foods·and·aiming·for·two·snacks·a·day·as·well.¶ ¶ You·are·practicing·chin·tucks·to·help·you·swallow.¶ ¶ Whilst·eating,·try·a·chair·with·arms·and·remember·to·stay·upright·for·30·minutes·after·eating.··Swap·lunch·and·dinner·so·you·have·your·main·meal·when·you·are·less·tired.¶ ¶ We·talked·about·the·PEG.··Dr·Brain·had·asked·you·about·it·at·clinic,·but·you·do·not·feel·it·is·right·for·you·at·the·moment.··You·are·happy·that·we·continue·to·weigh·you·and·ask·you·and·Brenda·how·you·are·getting·on·with·mealtimes.¶ ¶ You·can·also·talk·to·any·one·of·us·if·you·are·worried·about·your·weight,·swallowing·or·coughing·and·choking·after·meals.¤

Thanks to

- Pharmacist Helen Dove and medicines information team at CHFT
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- Jennifer Benson (Speech and Language Therapist)