

CoP: Information and Knowledge Exchange event chat transcript March 2024

Shauna Sheridan presentation: Secretion Management in MND

Question: Would you say it is wise, based on lots of these studies and your own experience for patients to use cough assist prior to secretion problems as a maintenance therapy? to possibly delay onset of additional difficulties with secretions.

Attendee answered in chat.

- I think that the evidence has shown that if people have a good peak cough flow, MI:E will not change maximal inspiratory capacity therefore as Shauna said the burden would hugely outweigh the benefit.
- Shauna answered in Q&A – No, because there is no evidence to support.

Question: Also with cough assist, what team within the MDT would be providing and support patients with this? I work in Kent, and it is a huge gap in our service that our patients don't really have access to.

- A: This will vary in different regions/areas – whatever team issues that equipment they should be responsible for training in it and providing consumables (non-invasive).

Jan Clarke presentation: Secretion Management in MND

Question: OT asking is there any specific guidance on positioning/ideal angle for saliva management when sitting?

- Jan answered in Q&A

Question: Is anyone having resistance to prescribing Hyoscine patches by GPs, in preference for providing liquid Buscopan in patients who can still swallow?

Answers:

- 1: There has been a limited supply of Hyoscine patches.
- 2: Reason given has not been limited supply as I believe that's better now - it has been cost... Apparently much less absorption so less effective.
- 1: Ah I see - interesting to hear others' experience.
- 3: patch supply is variable and is prioritised for hospital pharmacies.
- Jan answered in Q&A – Buscopan is cheaper, oral tablets not useful if you cannot swallow.

Question: Do you still need to check with the pharmacy dispenser if a hyoscine patch is suitable for cutting?

- A: It might be an "Off label use" by cutting it.
- Jan answered in the Q&A

Question: We've had difficulty obtaining suction toothbrushes in the past. Does anyone have advice about procurement pathways and funding?

- Jan answered in Q&A

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Jan Clarke presentation Secretion Management in MND

Question: Can atropine drops be used PRN in addition to another regular anticholinergic?

- A: We've used atropine alongside glycol.

Question: Can any of the complementary meds be administered via PEG?

- Jan answered in Q&A – only one drug has a licence to be administered by PEG.

Question: Do you have any experience of propantheline?

- A: there are a couple of case reports about its use in MND- I can share. but not used it - we were considering for one patient, but she had cardiac contraindications.
- Jan answered in Q&A

We had an instance where a PD patient had an acute onset of severe pharyngeal dysphagia after botox injection to submandibular and parotid salivary glands.

- Attendee response: needs expert person doing the procedure or US guided to ensure it targets the glands and not elsewhere causing bad side effects like this.

Question: Is there a study on increasing saliva production with biozoon? I've only read things so far that say no significant increase.

Answers:

- I've not read anything, but we are starting to find some of our patients having increased chest infections and antibiotic use... suspected due to increased saliva production and aspiration (not mobile patients). **after starting biozoon. Patients that were otherwise NBM and non-oral feeding
- With this I would always consider how much the biozoon is improving the QoL of the person and weighing this up

Question: Are you aware of any practitioners that offer botox in the community?

- Jan answered in the Q&A, other attendees commented:
 - Our rehab med consultant does botox in the community
 - Our Botox team can in Lancashire
 - We have a specialist doctor at our hospice who administers Botox

Question: Any contraindications complementary therapies?

- A: About Herbs App | Memorial Sloan Kettering Cancer Centre ([mskcc.org](https://www.mskcc.org)). Free app.
- Jan discussed in Q&A

Question: What would your first line advice be for people with feeding tubes who are struggling with excess saliva production?

- Jan answered in the Q&A – drug of choice would be glycopyrronium bromide.

Question: Can you use glycol with patients with seizures / epilepsy?

- Jan answered in Q&A – best to check with team prescriber.

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Dorinda presentation: Choking - is no joking matter.

Question: Nightmare for patients with no upper limb / speech living at home, we've had real difficulty working out a plan with WAST, have you any pathways re this in England?

- A: if you find it hard to hear or speak you can send a text message to 999 to get help from these people in an emergency. Don't wait for an emergency to happen before you do this. It is a good idea to do this now and get set up.

Question: Would love to hear more about management strategies/positioning/exercises you mentioned for laryngospasm- for my other caseloads as well as MND- is there somewhere we can read about these?

- A: Dorinda answered this in the Q&A

Question: Where can families access training to assist someone with choking? I have only flagged to St Johns training in the past - any other ideas?

- A: Dorinda answered this in the Q&A – St Johns Ambulance or Resuscitation Council are the main two we should refer too.

The choking pathway is not available online to enquire more about this – contact Dorinda directly.

Question: What factors would prompt you to initiate a choking pathway

- A: Dorinda answered this in the Q&A – start early as soon as someone start to have a bit of a cough / a wet voice / early signs of dysphagia