

## **Geeta and Sheena** **Managing saliva and coughing**

**Geeta**

At night time.

**Sheena**

Night time.

**Geeta**

You know I have dry mouth.

**Sheena**

Yeah, yeah.

**Geeta**

Because of the drooling.

**Sheena**

So at night time, she has a dry mouth and drooling. And really, I think the dry mouth is because of your night mask from her NIV. But she also does have a lot of drooling.

We do have, well mum has had issues with thick secretions and saliva as well. And as mum's condition's progressed, we've ended up having to transition to using a cough assist.

We used to have an LVR bag (Lung Volume Recruitment). We have got medication to help keep the secretion viscosity as low as possible now. So now mum was taking carbocysteine, she's taking acetylcysteine now and that really helps with keeping the saliva quite runny.

Yeah. And it's easier for mum to sort of clear those secretions. I don't think we realised how much she would struggle with her own secretions.

So it's not necessarily a cough or being unwell. It's just her daily secretions clearing her throat and things like that. So after that medication and having the cough assist, it helps massively.

**Geeta**

It's like, really bad and dry– It can be like... I can't explain it.

**Sheena**

So I'm a dentist so I noticed that mum has a lot of halitosis associated with a dry mouth. I'm always concerned that because of she's not got as much saliva production in her mouth that she's at risk of getting some dental infection or periodontal disease.

Which worries me because obviously her immune system's not as good to fight any sort of infection. So that's something that I'm always checking and making sure that she has assistance with her brushing and trying to keep the oral hygiene as good as we can.

Because obviously the dryness due to her NIV, and I think it's not something we can bypass because she needs her, the NIV at night time.

But I do feel like they're just things that you can sort of work on. Try and encourage mum frequently throughout the day to sip on water as well, and just to help keep the mouth moisturised.

You did go through a stage of having quite sore ulcerations in her mouth as well, and I do feel like that was probably linked to the dryness of her mouth as well.

So we discussed it with mum's specialist nurses, and they recommended some sort of topical sprays. Ones without sort of analgesics in which would irritate her throat and her coughing and her swallowing which help keep her mouth lubricated and give her the comfort as well as she was having those periods.

I think you've had to sacrifice a lot of symptoms as a result of the, the equipment or the medications. That's essential, and we've just had to sort of deal with it and manage it.

But it's sort of it is a balance. What's more important, being ventilated or having a dry mouth. So yeah, it just manage the best you can.

**Geeta**

I don't sleep the full night. It (the secretions) keeps me awake.

**Sheena**

Do you feel like it pools in your mouth or

**Geeta**

It give me dry mouth. Sometimes I bite my cheek.

**Sheena**

Biting your cheek because your mouth's quite dry?

So that was again during a hospital admission when the respiratory physios came round. Mum was admitted for a chest infection, she was struggling to clear her own secretions.

So when the physios came they first started with some techniques such as breath stacking and just some other techniques to help try and produce a cough. But then that was a little bit ineffective after a short while. So then they suggested the LVR bag to help.

That wasn't helpful at all for mum. And then because she was struggling quite a lot to get those secretions up and she was getting really fatigued and exhausted, they recommended the cough assist.

So it was a piece of scary equipment for mum and for us to see mum having used the cough assist. I think it was scary for mum as well because we'd never really seen one before and the whole family had to be trained before mum could be discharged, just in case we ever needed to use it.

The ventilation team were really good so they regularly check the settings on there. We've recently had an additional setting put on when mum's really fatigued, so it's like a more powerful setting.

But yeah, you're not as upset using it anymore.

**Geeta**

Because before I used to get scared. But– now I'm used to it.

**Sheena**

So another thing as well, although mum was admitted on the respiratory ward, a lot of the nurses weren't allowed to use mum's cough assist. So a member of the family used to stay when mum was admitted.

In case she did need the cough assist, because I can't always get hold of a respiratory physio to come and do it or they're not available during the night, so it's always good for the family to be trained so if they have a hospital admission.

You can stay with them, and we were able to provide the use of it whenever we needed, and we did need a few times during this. So me and my siblings would just take turns too.

**Geeta**

Because the family learnt how to use cough assist.

**Sheena**

And it's good that the family do get trained and do learn how to use it, because I feel like even having carers sometimes, we've had to show them the correct way to use it, or we can monitor that it's been used correctly as well.

I think just acclimatise into it the frequency of us using it. So the first time when the air is pushed into mum's face and you're seeing her cheeks expand, it just seems really aggressive.

The sounds of it and the way that the patient looks, the way that mum looks as well, but we've just sort of got used to it. Even mum's grandchildren as well.

So, they, we used to try and do it when they weren't around before. But sometimes now it's difficult for us not to do when they're here and they're all used to it.

Even mum's ventilation machine as well, they're, they're all a bit scared. But now they think mum, grandma's a superhero.

Yeah. She's got this machine, she's got super powers, so.

### **Geeta**

My granddaughter she, tried to lift it up.

### **Sheena**

Yeah. She, and she tries to suck the air in so she'll sit on my mum's lap, pull it off her face and take a big inhalation of the air and then put it back on mum's face.

So yeah, I guess with any piece of equipment, whether it's the NIV or the cough assist, it's just acclimatise into it. So it's always going to be scary. It's always going to be a bit alien at the start, but you will get used to it. And then you realise, obviously, these are really important pieces of equipment that mum needs.

And we appreciate them being there and for us to use because we see the distress that mum gets into when she's sometimes struggling with those secretions or choking, and the cough assist is able to relieve those symptoms.

So sometimes mum can just feel there's something stuck. So it's not always that she's unwell or it's phlegm. It's just her daily secretions.

So we produce a lot of secretions daily anyway where a healthy person is able to just clear their throat and move our secretions around. Sometimes, especially if mum's having a tired day, it's not always just after food or drink.

She's struggling and she's not able to clear it herself and she will tell us, like I need some help. And when we're able to bring up those secretions and clear them, it makes a big difference to how she's feeling.

It's also really important if mum does catch sort of a cold or anything like that, and it's also a good, a good piece of equipment to use to check if mum has an infection or not.

Because when we're, we have used it and we brought up any secretions, we were able to look at the secretions that she's brought up, the colour, the consistency.

So if there's any changes, we can flag that straight away and contact the respiratory team or the necessary department and say, look, can you just check mum doesn't have an infection. So we can try and prevent any escalation of an infection as early as possible.

So it's happened a couple of times where we've contacted them. And just as a preventive measure, they've just prophylactically given mum a course of antibiotics which potentially prevented a hospital admission or anything where.

So yeah, sometimes it is a good diagnostic tool as well, Although it's not used for that.