

# CASE STUDIES TUBE PLACEMENT DECISIONS

Emma Sherrington D.Phil. RD

Community Dietitian

Buckinghamshire Healthcare NHS Trust

# Emma Sherrington RD Community Dietitian (BHT)

I studied Human Nutrition & Dietetics at London Metropolitan University 2009-2013. HCPC Registered Dietitian since 2013 and worked for Buckinghamshire NHS Trust since December 2014 as Community Dietitian. I work with people with MND and their loved ones across the county and am an integral member of our MND MDTs; working very closely with our Speech and Language Therapists, Nutrition Team from Gastroenterology and Nutrition Nurse and Respiratory Specialist Physiotherapist. Over the last seven years, I have been involved in many discussions around the decision whether or not to place a feeding tube for patients with MND.

I am a member of the British Dietetic Association (BDA) Neurosciences specialist group, the MND Professional Forum on Facebook and you can find me on Twitter @EmmaJaneRD





# AGENDA

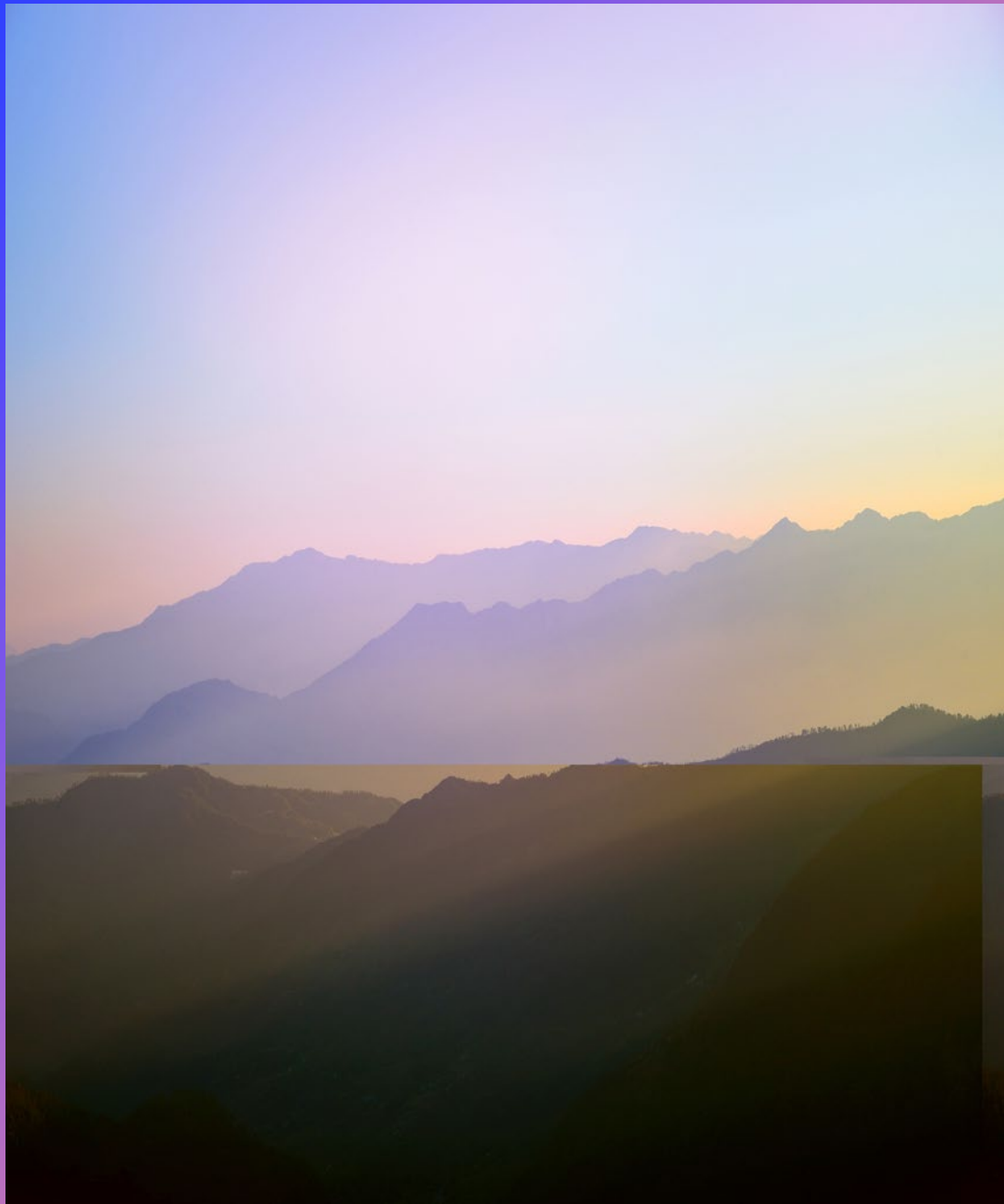
When it went well

When it could have gone better

When decision was maybe taken too early

When decision was taken too late

When deciding no was the right decision



In this presentation I will use case studies to explore the outcomes following on from decisions taken by patients regarding gastrostomy placement and tube feeding.

The patient stories will illustrate the importance of effective discussions and considered patient involvement in decision making

• + WHEN IT WENT WELL + •



# CASE 1



Female patient in her early sixties

Lives with husband and two grown-up children, third grown-up child lives close by

Diagnosed with rapidly progressing MND with bulbar symptoms

Already dysarthric, has SLT support with communication

Early involvement of Specialist Respiratory Physiotherapist with extensive Palliative Care experience

Able to have open conversations with patient and her family about pros and cons

Email I received from daughter when her mother died

*"I would also like to say thank you for support you have given us over the last few months, even in mums final days, the hospice told us you had called to see how she was.*

*I can't thank you enough, you made the last few months so memorable and comfortable for her and for us."*

# CASE 2



Male in his 70s, lives alone (widower) stepchildren live abroad

Diagnosed with MND with bulbar symptoms

Already dysarthric, has SLT support with communication

+ Was losing weight and starting to struggle with certain textures of food. Salvia management an issue.

- Experienced significant emotional lability

Found discussing future plans very difficult, was easily distressed.

However, after several discussions with dietitian, SLT and Palliative Care/Respiratory Physiotherapist decided to go ahead with PEG placement.

Initial phase after placement was challenging adjustment – needed to take on carers.

He wrote to me that he was very glad he had made this decision and it did improve his quality of life



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WHEN IT DID NOT GO WELL +  
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# CASE 3



Female in her 80s, lives alone but has grown-up daughters living close by

Diagnosed with rapidly progressing MND with bulbar symptoms.

Very reluctant to have tube placed, was worried about pain, how it would look and feel, whether it would be messy.

- However, had been told by doctor that she “needed a feeding tube”.

Assessment by respiratory physiotherapist concluded respiration was compromised. Gastroenterologist recommended a RIG rather than PEG.

Lots of discussions had with patient and daughters with dietitian, SLT, physio, tube care nurse, going through pros and cons.

Patient decided to go through with it but afterwards repeatedly said they wished they had not.

Patient experienced lots of complications – granulation at stoma site, tube fell out several times.

My belief is patient would have been happier not accepting tube but had felt under pressure to take the “expected” route.



# CASE 4



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Female in her 70s, lives with husband

Referred to dietitian after she had had her PEG tube placed.

At this point showing very minimal bulbar symptoms, main issue was saliva. Speech intelligible, no swallowing issues, constant weight.

However, already had very limited hand function so unable to look after the tube herself. Husband had tremor so also not able to use tube. Found accepting daily carers into their home very difficult.

Did not really start using tube for fluid, food or medications until nearly 3 years after it was placed.

Tube placement caused a considerable amount of anxiety for the patient and her husband. My belief is the feeding tube was placed far too early in this ladies disease progression.

# CASE 5<sup>11</sup>



Male in his early 40s, lives with his wife and little girl.

Diagnosed with MND with bulbar symptoms.

Referred to dietitian by SLT, he was already anarthric and losing weight.

+ Offered ONS and raised idea of tube placement.

Always refused to discuss the idea, he would always state he was certain he did not want a tube.

Continued to really struggle with oral intake and continued to lose weight despite all ONS efforts.

In final weeks, when clearly struggling with respiratory function, he asked if he could be considered for a feeding tube.

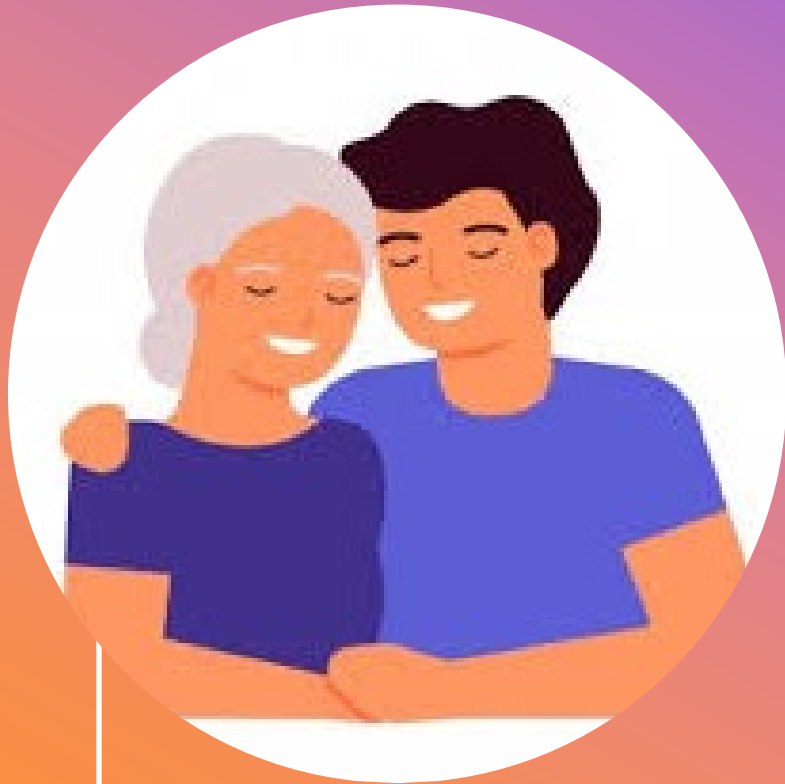
Respiratory Physiotherapist assessment was that it was now too risky.

NG placement was attempted but not tolerated.

Patient died a few days later in hospice.



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• **WHEN “NO” WENT WELL** • +  
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Female in early 60s, lives with her son

MND diagnosis, rapid onset of lower limb symptoms, poor mobility, already using motorised wheelchair. Limited bulbar symptoms, issues with saliva. Initially lost some weight due to anxiety but stabilised.

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- Always clear she did not want a tube and able to explain her reasoning.

Managed well with oral nutritional support

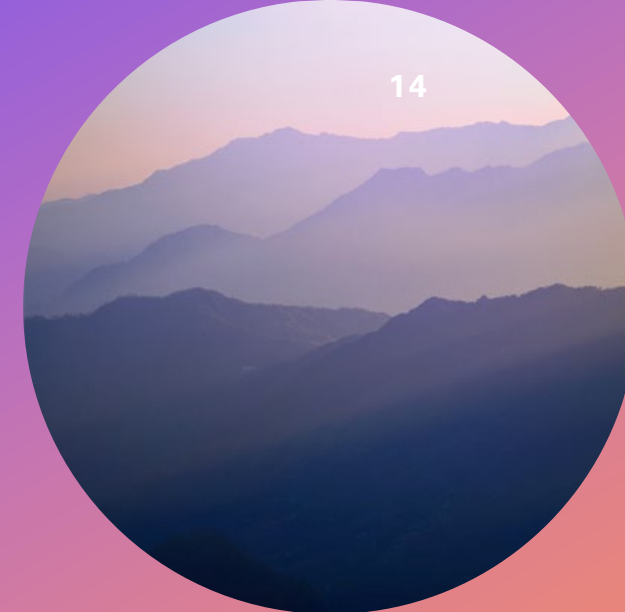
Had input throughout from dietitian and SLT.

Died peacefully at home with help from hospice at home and palliative care nurses



# SUMMARY

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- Always make it clear to the patient it is their decision, what is right for them is what matters
- Whatever their decision you will support them
- Involving wide MDT in discussions around tube placement is very important
- Need to discuss the pros and cons openly
- Raise the issue of a window of opportunity for making decision
- Involve the patient and their family but ensure patients autonomy is always maintained.







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# THANK YOU

Emma Sherrington RD

[emma.sherrington@nhs.net](mailto:emma.sherrington@nhs.net)

Twitter: @EmmaJaneRD

