

Speech & Language Therapy and Dietetics in an MND Care Centre

Supporting Eating and Drinking in MND

Agenda

- Our role within King's MIND Care & Research Centre
- Structure and benefits of a joint SLT/dietetics assessment
- Gastrostomy discussions – when is the right time?
- Weight loss in MND
- Practical tips for living with modified diet and fluids
- When to refer to SLT/Dietetics
- Useful resources

Who are we?



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SLT & Dietetics at Kings' MIND Care & Research Centre

Regional service

Covering SE London, Kent, Sussex and beyond

A weekly clinic

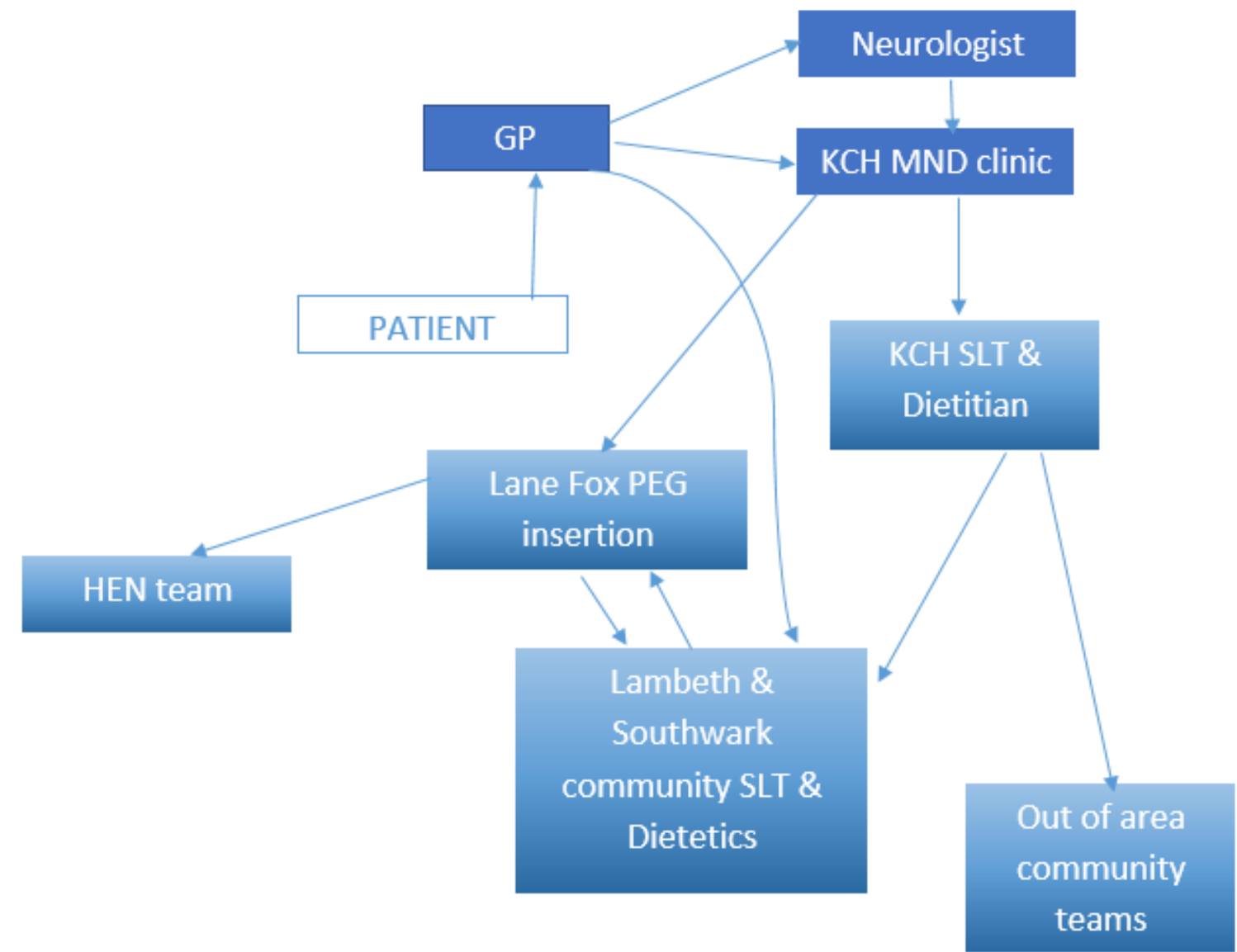
With pre-clinic MDT meeting

Face to face and video
appointments

Sometimes pre-booked,
otherwise ad-hoc

Based on issues identified in Consultant or CNS
appointment

Local Pathways for Dietetic/SLT input



Common areas we support patients with

Early advice and education

Dietary advice and reassurance

Prioritising nutritional aims

Support for unintentional weight
loss

Troubleshooting with enteral fed
patients

Comprehensive swallow
assessment

Gastrostomy

Information and support with decision making

Dietitian

- Weight/ BMI
- Weight history
- Appetite
- Fluid and food intake vs nutrition and hydration needs
- Gastrointestinal symptoms e.g. constipation/ nausea
- Assessing need for nutritional supplements

SLT

- Cranial nerve exam
- Clinical swallow assessment
- Consideration of any supportive strategies
- Texture and fluid modification trials
- Communication assessment and support

- Thorough E&D case history
- Factors impacting oral intake
- Ability to prepare and eat food
- Time taken and effort for mealtimes
- Eating in social situations
- Discussing gastrostomy
- Practical tips

Gastrostomy

When is the right time?

What are your thoughts?

NICE Guidelines (NICE 2016)

"Discuss gastrostomy at an **early stage**, and at **regular intervals** as MND progresses, taking into account the person's preferences and issues"

"Explain the **benefits of early placement** of a gastrostomy, and the possible **risks of a late gastrostomy**"

"If a person is referred for a gastrostomy, it should take place **without unnecessary delay**"

"Pay particular attention to the nutritional and hydration needs of people with MND who have **frontotemporal dementia** and **who lack mental capacity.**"

ProGas Study

(ProGas Study Group, 2015)

Three methods of gastrostomy tested and found no difference in survival by type of insertion

Identified two factors that affected survival: age at onset of MND and percentage of weight loss at time of gastrostomy since diagnosis.

Those that had less than 10% weight loss since diagnosis and before gastrostomy benefited most from the procedure and had an increase in survival compared to those who had 10% or greater weight loss

This led to the recommendation that people living with MND should undergo early gastrostomy (ie before a marked weight loss of 10%).

Other Considerations

Will be driven by the individual

Respiratory function

Bulbar symptoms

Eating and drinking for pleasure,
rather than purpose

Familiarisation to support timely
decision making

Unbiased counselling on all options



Being
responsive to
weight loss

- People with MIND are susceptible to weight loss
 - Impact of disease symptoms on ability to eat
 - Hypermetabolism, increased resting energy expenditure
- Higher weight at diagnosis has been associated with prolonged survival, including those with a mildly obese BMI (Ning et al 2019)
- Weight loss >5-10% is detrimental to survival (ESPEN 2018)
- Slowing weight loss post diagnosis has shown improved survival (Shimizu et al 2019)
- Weight gain should be recommended in patients with a baseline BMI <25.0 kg/m² (ESPEN 2018)

OptiCALS

- A Randomised Controlled Trial to evaluate a nutritional management intervention for patients with ALS
- 20 ALS centres across the United Kingdom involved including KCH MND research team
- If receiving active intervention, participants are provided individualised MND specific calorie target and supported to meet this
- Assessing whether the OptiCALS intervention slows disease progression

Case Study

Andy*

PLS variant of MND

With bulbar symptoms

Anarthric

Uses text to speech app on his phone

Weight stable with BMI of 25

Intentional weight loss pre diagnosis

Lives alone, independently mobile

Managing 3 x balanced full meals per day

Preparing his own, difficult with upper limb weakness

On Level 2 mildly thickened fluids and normal diet

Needing to 'grind up' food with sauce. Lost to SLT follow up in the community

*Pseudonym

Intervention provided

Recommended IDDSI Level 5 / Minced and Moist diet

Discussed meal prep and recipes

Food first advice

Revisited gastrostomy

Referred to community dietetics

Linked in with community SLT and referred to Bowley Close for AAC

Benefits of joint input

More efficient communication

Trouble shooting issues

Joint professional discussions
regarding gastrostomy

And option to eat and drink with acknowledged risk

Holistic care

Considering swallow safety, nutritional management
and quality of life

Practical Tips

Pre-thicken fluids or make naturally thick smoothies and take this out and about

Meal delivery services such as Wiltshire Farm Foods and Oakhouse can make life easier, but can be pricy

Eat something before going out to a restaurant, so you can enjoy something small instead of it being a chore

Take a small tupperware or sachets of thickener out with you for on-th-go modification

Consider contacting the restaurant before visiting to request a meal to be cooked with more sauce, blended or cut into small pieces

When to refer

- Initial consultation at diagnosis
- At onset of bulbar symptoms e.g. saliva management difficulties, speech or swallowing changes
- If choking or coughing when eating/drinking reported
- Unintentional weight loss – consider subjective signs if difficult to measure
- Low body weight
- Recent chest infections
- To support gastrostomy decision making
- If your patient has been seen by us in the King's clinic, we're always happy to be contacted

Useful Resources

For Patients:

MyTube MIND: <https://mytube.mymnd.org.uk/>

Eating and Drinking with MIND:
<https://www.mndassociation.org/app/uploads/2017/05/Eating-and-drinking-with-MIND-final-web-PDF-2017.pdf>

Patient Gastrostomy decision aid:
gastrostomychoice.co.uk

Eating with Dignity:
<https://www.eatingwithdignity.org/recipes>

For HCPs:

Dietetics and Nutrition assessment prompt:
https://www.mndassociation.org/app/uploads/2021/09/77401_MNDA_Infographic_Dietetics_And_Nutrition_v5_HR.pdf

MIND Association Oral Nutrition Webinar Jan 2023:
<https://www.youtube.com/watch?v=jDRC8a-FdrY>

References

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Thank you for
listening!

Any thoughts or questions
welcome