Sussex MND Care & Research Network

brighton and sussex medical school

Feeding dilemmas Network day 2023

Overall question: How should the MDT manage this situation?

1. **Ruth**
   Ruth is a 52 year old lady diagnosed with MND in October 2022, following a 9 month history of upper limb weakness. Presented with upper limb onset but the disease has spread to her lower limbs and bulbar area quite quickly. Ruth has always been quite open to conversations but from the beginning has said she doesn't want to know too much at one time and will deal with issues as they arise. Hasn't wanted to discuss advance planning or life prolonging interventions.
   October 2023 - Speech only just intelligible and swallow deteriorating. Weight currently stable. Now is the time to have a PEG inserted if this is what she chooses. A delay in making a decision about this procedure has already lead to one admission for dehydration, as well as anxiety around swallow / eating and drinking.

   Prompts:
   - **What are the risks for this lady at present?**
   - Choking- hosp admission
   - Dehydration, UTOS
   - Anxiety round eating
   - Hosp admission more challenging if pt has comm difficulties
   - Low energy levels
   - Building to a more urgent decision
   - Carer burden
   - Explain risk so of not making a decision, or too late (e.g. loss of control, disempowering, wait times, NG tube if urgent, more care)

   - **What actions should be taken now and by whom?**
   - MDT approach- discuss benefits, empower the pw MND with info
   - Avoid admission.
   - What does she already know/understand? Any cognitive difficulties?
   - What can be put in place to support her if she opts not to have?
   - Considerations:
   - Emotional/social element of eating
   - Concerns re choking
   - What are her values? Explore why she doesn't want to engage on ACP
   - Be led by pw MND and family
   - EOL care- use of gastrostomy Ensure clear ACP. Which HCP best placed to do, build on previous conversations
   - Give correct factual info

2. **Audrey**
   80 year old woman diagnosed with MND in Dec 2022 during a hospital admission while living in another area.
   Moved approximately 3 months ago to be with daughter locally but has had no contact with local services, including GP. Admitted to hospital in respiratory failure, now on an acute respiratory ward. Now trialling NIV again after not using it at home. Appears to have cognitive impairment, doesn't accept diagnosis of MND. Eating and drinking small amounts, no obvious dysphagia. Frail. Wants to go home to daughter's home. Daughter works full time and no POC in place as yet.
   Discussions about possible PEG insertion amongst inpatient team.

   Prompts:
   - **What factors to take into account when making PEG decision?**
   - Cognitive assessment and capacity assessment
   - Family meeting/best interest meeting?
   - Liaise with previous services
   - What education already given?
   - Risks: resp failure, frailty
   - Explore reasons for reduced eating and drinking

3. **Mr J. 72yr man.**
   Diagnosed with limb onset MND in Jan 22. Lives with his wife. Weight is stable with no eating or drinking difficulties. He has a history of T2DM for which he takes metformin. Mr J will not engage with any ACP and only will only consider any interventions if they have immediate perceived practical benefit.

   Agreed to dietetic referral in Sep 2022 following some weight loss. Would not engage in conversations re gastrostomy. Given supplements.
   Oct 23: concerns about respiratory failure and continued weight loss. Poor appetite and getting weaker.

   Prompts:
   - **What are the risks for this man at present?**
   - Weight loss, falls, injury, infection, malnutrition, fatigue, concentration, cognition, skin
   - Crisis A&E, resp failure, chest infection

   - **What actions should be taken now and by whom?**
   - Signpost to decision tool- Diamond
   - Suggest referral to counselling, psych support.
   - Speak to wife- is she supportive? POA?- are symptoms being accurately reported?
   - Dietitian may be best placed given he has agreed to the referral.
   - Any cognitive concerns, capacity?
   - Provide written info.
   - MDT meeting

- Respiratory referral
- Establish the HCP/AHP with the best rapport to facilitate conversations.
- Don’t assume he won’t engage just because he hasn’t previously done so
- Ask patient: “what matters to you now?”
- Discuss what options may have become unavailable
- Explore other ways to have ACP discussions
- Influence of others
- Practicality of a tube