

Dysphagia Pathways Program: Goals of care discussions

How to conduct a goals of care (GOC) discussion for dysphagia management: a resource for speech-language pathologists

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1) Prepare for the GOC discussion

- Thoroughly review the patient's medical record
- Thoroughly review previous SLP (speech-language pathology) documentation
- Consider the acuity of the patient's dysphagia
- Consider the suspected prognosis of the patient's dysphagia
- Review the plans of care that will be presented and be prepared to clearly outline the similarities, differences, risks, and benefits
- Provide notice to patient and caregivers as applicable about the GOC discussion
- Set a time for the meeting as applicable ensuring all who wish to be included can be present

2) Introduce the purpose of the discussion

- The discussion begins with introduction of all individuals present and their relationship to the patient or role in care for the patient
- The SLP should clearly convey the purpose of the meeting
 - E.g., *"We are meeting today to talk about management options for Mr. Smith's difficulty swallowing."*

3) Assess patient/caregiver understanding of the problem

- Assess patient/caregiver understanding of the patient's dysphagia
 - E.g., *"What have you heard from the medical team about your swallowing?"*
 - E.g., *"Do you know the results from your swallow study?"*
 - E.g., *"What is your understanding of why you had a swallow study?"*
- Keep in mind patients and caregivers often will have an overly optimistic or unrealistic sense of illness trajectory

4) Deliver information about the patient's dysphagia and suspected prognosis

- First, verbally teach-back what the patient/caregivers have expressed so far
 - E.g., *"So, what I am hearing is that you all are aware that Mr. Smith has been diagnosed with dysphagia, which means he is unable to swallow safely. You all feel disappointed by this news and were hoping for better results from his swallow study."*
- Share swallow study results (e.g. MBS/FEES), limiting information based on how much or how little the patient/caregivers already knew
- If the results were poor, you may want to use a supportive statement to prepare the patient/caregiver for bad news
 - E.g., *"Unfortunately, I do not have good news regarding Mr. Smith's swallow test results."*

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- E.g., *“I am afraid the results are not what you were hoping for.”*
- Share suspected etiology of dysphagia and prognosis as able
 - E.g., Dysphagia due to a neurodegenerative disease: *“We suspect that Mr. Smith’s dysphagia is due to his ALS. Given ALS is a degenerative disease that affects nerves and muscles used for swallowing, unfortunately we do not anticipate that his swallowing will improve.”*
 - E.g., Dysphagia due to an acute CVA: *“We suspect that Mr. Smith’s dysphagia is due to his stroke affecting his nerves and muscles for swallowing. Recovery through time and therapy is common, and we think his swallowing will improve.”*
- General tips for delivering information:
 - Avoid medical jargon
 - Deliver information succinctly
 - Utilize supportive but direct statements
 - E.g., *“I hope your swallowing will improve with time, but I worry that it will not.”*

5) Expect and respond to patient and caregiver emotion

- Most often a strong emotional reaction from a patient or caregiver, is a positive sign that the information that needed to be conveyed was appropriately received
- Therapeutic silence or compassionate statements can be beneficial
 - E.g., *“I wish I had different news for you.”*
 - E.g., *“I can see this news is difficult for you and your family.”*
 - E.g., *“I can tell you weren’t expecting to hear this.”*
 - E.g., *“I am so sorry to have to tell you this.”*
- When emotional responses from patients/caregivers appear stable, ask the patient/caregiver to teach-back the information you presented to assess for comprehension
 - E.g., *“Can you please summarize the information I just provided about your swallowing, that way I know we are all understanding each other?”*

6) Present dysphagia management options (the dysphagia pathways) and assess patient goals and preferences

- Present the dysphagia pathways, individually tailored to the patient as appropriate
- Explain common and palliative dysphagia management, similarities and differences, risks and benefits, and any alternative treatment options if applicable
 - (E.g., PEG with comfort feeds, Frazier Free Water Protocol, etc.)
- Questions to ask to assess goals and preferences:
 - E.g., *“Have you ever known anyone who had trouble swallowing, how did that affect them? How would that affect you?”*
 - E.g., *“Have you or anyone you know ever needed a special diet or a feeding tube?”*

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- *E.g., "Would quality of life be acceptable with a feeding tube? With a special diet?"*
- If patient/caregiver do not come to a decision at the end of the discussion, re-validate emotions and suggest further discussion at another time
- If patient/caregiver do come to a decision, everyone should leave the discussion with a clear understanding of which dysphagia management option (pathway) has been chosen and why
- Ask again for the patient/caregiver to teach-back their chosen pathway, to describe the risks and benefits, and their goals to assess for comprehension

7) Follow-up after the discussion with other medical team members

- Communicate outcomes of the discussion to all pertinent medical team members
- Document outcomes of the goals of care discussion in the medical record, and update treatment plan and orders as indicated

References

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