

# Managing Not Mending -

What's it like helping someone to swallow when they are near the end of life?

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## Speech & Language Therapy Experiences of End of life Dysphagia care for people with Head and Neck Cancer - Preliminary Findings

### Abstract

This poster depicts the preliminary findings of an exploration into the experiences of Speech and Language Therapists in providing end of life dysphagia (swallowing) care to people with Head and Neck Cancer. Whilst previous researchers have explored what the role entails (Pollens 2012; 2004, Newman 2009, Roe 2007), to date the reported experiences of those providing this care has not been fully examined. The study adopts a qualitative, phenomenological approach and has a multi-centre design.

The research question asks 'What is the experience of Speech & Language Therapist in providing end of life care to people with head and neck cancer'.

Preliminary findings indicate that \*SLTs described a lack of preparation and guidance, differing experiences across settings, successes and challenges with multi-disciplinary team working, a view that swallowing management is different with this caseload, some lack of awareness and clarity around the SLT role, a considerable emotional impact and a concern with effective risk management and patient led decision making.

### Methods

Two pilot and six main participants took part in the study along with an additional focus group of three participants. All were practicing SLTs with representation from four Scottish Health Boards. Interviews were semi-structured using an interview schedule. This was developed from an initial literature search from which key topics were identified as being of interest with respect to the research question.

All data was analysed (including pilot data) using thematic analysis consisting of detailed transcription of interview data and member checking followed by initial coding of key topics and later grouping into key themes and sub-themes.

### Findings

The study resulted in a wealth of rich data which highlights key issues reported by SLTs working in this field. This is summarised in the diagram below.

### Conclusions

The preliminary results suggest that the profession of Speech and Language Therapy needs to address the issue of adequate preparation and guidance for clinicians. Participants report different experiences according to the environment in which the care is provided. Multi-disciplinary working is shown to be variable in its effectiveness with the SLT not always fully integrated into the team. Clinicians report that this client group requires a different approach to swallowing management than other clinical groups with many commenting on the longstanding and unpredictable nature of cases. A lack of awareness of the role by SLTs, multi-disciplinary colleagues and carers is reported. Participants describe the considerable emotional impact predominantly related to multi-disciplinary patient led decision making and managing risk and also in response to the nature of the caseload.

### What Next?

The next phase of this research will be to return to the data to explore relationships within it in order to identify any additional patterns or overarching themes.

### Dissemination

The preliminary findings of this research will be shared initially at the Scottish Partnership for Palliative Care Conference and on completion, the findings will be shared with participants and relevant stakeholders. It is hoped that this research will ultimately contribute to professional development and more effective patient centred care.

*"... if they are swallowing they're aspirating to the extent that they're unwell .... its tipped them over into that high risk, unsafe category .... and that leads into difficult ground"*

*"... but as a net result of that it can be quite hard to watch them going downhill and to see them passing away sometimes with you know clear distress and well you would hope not in pain... so it can be quite upsetting ..."*

*"The only barrier would be ... a recognition that maybe we could offer something at end of life and that's again down to the awareness of the other people involved with the pt ... doctors/nurses recognising that maybe there is an issue... a patient who ... wants to eat ... might be able to eat ... more easily/safely if we were involved with them ..."*



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### References

Newman, K. 2009. Speech and Language Therapy techniques in end-of-life care. End of Life Care Journal, 3 (1). pp. 8.  
Pollens, R. D. 2012. Integrating Speech-Language Pathology services in palliative end-of-life care. Topics in Language Disorders. 32 (2). pp. 137-148.  
Pollens, R., 2004. Role of the Speech-Language Pathologist in palliative hospice care. Journal of palliative medicine, 7 (5). pp. 694-702.  
Roe, J.W. 2007. Dysphagia in advanced malignancy – beyond head and neck. American Speech Hearing Association Annual Convention. Boston. USA. ASHA.