

How I manage dementia

As our population ages, so the incidence of dementia grows. At the same time, new forms of the disease target a younger age group. And people with pre-existing disabilities are living longer, presenting additional challenges for carers as symptoms of dementia appear.

Drug treatment is as yet limited to delaying the onset of symptoms in some people. Access to specialist and responsive services from the start of the illness to the end stages is not widely available. The role of speech and language therapists is still being developed. What approaches empower affected individuals, families and staff? How do we maximise independence in communication, eating, drinking and swallowing? Can we forge stronger partnerships between health, social services and voluntary agencies?

The following article is one of three contributions to this feature on management of people with dementia in the Autumn 01 issue of *Speech & Language Therapy in Practice*.

New Opportunities

*Training nurses to use a dysphagia screening tool reduced referrals to speech and language therapy by 75 per cent in three months, allowing **Mary Heritage** to focus on true dysphagia and specific communication needs of older adults in her mental health trust.*

I work with older adults in a mental health trust. Speech and language therapy provides a service to inpatient wards (assessment and continuing care), day care facilities and a community dementia outreach service. As our wards close over the next year, the work we have done in the hospital setting needs to be rolled out into community teams, nursing homes and family homes.

My main strategy is training. The underlying principle is that my input will make little difference to the patient's care unless I can influence the behaviour of the staff and relatives. People with dementia have impaired memory and often significant comprehension difficulties. Direct intervention with the person with dementia is unlikely to be carried over. By taking time to explain, demonstrate, coach and give feedback, I can enhance the carer's competence and confidence in communicating or in assisting with eating and drinking. Time spent with paid carers is valuable because they can carry over the skills they have learned from one person to another.

Speech and language therapists train people in a number of ways:

- formal lectures to large groups
- more informal workshops
- skills training with assessment of competencies
- coaching
- case discussion
- reports

and I use all of these in my work.

Nutrition in this Trust is managed by a multidisciplinary team including dietitian, catering staff and

pharmacist as well as nurses and speech and language therapists. Screening tools, dysphagia menus (including finger foods and snacks) and picture menus have been developed by the team which also audits the standards that have been set.

Allies

My main allies in managing dysphagia in this setting are the nurses we have trained to use our locally developed tool Screening for Dysphagia. This allows them to identify dysphagia, to write a care plan for food and drink provision for people with dysphagia, and to update the care plan as the person's condition progresses. I am currently preparing a research study to validate this screening tool.

Many of the people who do have dysphagia have oral stage dysfunction - for example, Feinberg (1992) found 71 per cent - and the nurses are able to help them through modifying the consistency of food and drinks. Those with complex or severe difficulties are identified using the tool and referred on to speech and language therapy.

The scheme is an extension of a larger project which originated in the Acute Hospitals Trust. The speech and language therapy service in the Mental Health Trust was introduced in 1998, following a period of heightened awareness about nutrition in the organisation. A set of screening tools was launched to manage the clinical risks around eating and drinking. The referral rate to speech and language therapy dropped by 75 per cent within three months of the first cohort of nurses being trained.

Eating and drinking difficulties in dementia are common; for example, Steele et al (1997) found 87 per cent. However, many of these difficulties are behavioural, such as cramming or needing cues to initiate eating behaviour. Nurses in this specialist setting are competent to deal with these behavioural difficulties but use the tool to identify true dysphagia. A small number of patients are referred to us for eating or drinking difficulties. This may be because they have a severe or complex dysphagia. While in the USA there is widespread use of PEG (percutaneous endoscopic gastrostomy) feeding for any condition in the older person, in the UK PEGs are often not available to people with dementia. A few people here have had a PEG and, in these specific cases, I feel that it is appropriate management (Barratt, 2000). I usually use a mealtime for assessment, observing the assistance provided by staff as well as the person's ability to eat and drink. I am then able to provide feedback and guidance as to what appeared to help or hinder them. The recommendations are usually made jointly by me and the nurse, following discussion on what we saw. This then enables us to:

- identify and manage risks
- maintain independent self feeding for as long as possible
- empower the nursing staff, and
- increase nurse ownership of the recommendations made. It is rare here for compliance to be a problem.

Assisting

Other ward staff need to access an ongoing programme of workshops aimed at raising awareness of eating and drinking difficulties and improving the skills of all grades of ward staff in relation to patients' mealtimes. The onset of oral stage dysphagia correlates with the onset of eating dependency (Siebens, 1986), so it is vital that staff and carers are skilled in maximising self-feeding and concentrate on 'assisting' rather than on 'feeding'. Training for them includes consideration to the environment as well as their own behaviour.

Because the number of direct referrals to speech and language therapy has fallen so drastically, I have been able to accept referrals for people with communication disabilities associated with dementia. Referrals usually come from the day hospitals and are for people whose communication is a specific area for concern for the person or their relatives, over and above their level of cognitive functioning. I use formal assessments but prefer to engage in or observe natural conversational behaviour. This is often only possible to do in the person's home environment where they feel more relaxed, and where cues for communication are at hand. I can observe the communicative strategies used by family members and feed back to them which are more successful and others that may also help. It is vital to be positive and concentrate on the strengths of the carer and the person with dementia. I hope to start to use video as a tool for this purpose. I write reports and recommendations that are aimed at the carers and copied to the other professionals. These give concrete examples of strengths and strategies; for example, ways of cueing that seem to help; aids for initiating or anchoring conversation. Life story work can help those who are trying to find something to talk about and a shared focus for conversation (Murphy, 1994). I am able to feed back the information gained on a home visit to the staff who see the person only in the unnatural setting of the day hospital or respite ward.

As the proportion of older people in this country increases, the number of people living with a dementing illness will increase. Awareness about communication disability and eating and drinking difficulties needs to improve, in both professionals (including speech and language therapists) and carers. The National Service Framework for Older People (DH, 2001) offers opportunities for speech and language therapists to work in new ways and in new areas. I hope more of us will be able to apply our skills to help those living with dementia as a result.

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