

How... I manage dementia

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Read this

if you

are a speech and language therapist
 working with people with learning disabilities
 who are using a person-centred planning
 approach to service provision
 • are pioneering a service

“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? Our contributors discuss why they would encourage more speech and language therapists into this often neglected field.”

The GOLD Programme

The high risk of dementia for people with Down's syndrome is one of the main concerns of the GOLD programme. GOLD (Growing Older with Learning Disabilities) is a four-year project at the Foundation for People with Learning Disabilities. It aims to draw attention to - and provide practical way of meeting the needs of - older people with learning disabilities. In addition to a Briefing for Commissioners, an information pack will be published in the Autumn providing advice on the kinds of problems seen at the different stages of dementia and how best to respond to these. Other areas of the programme are looking at helping older family carers of people with learning disabilities make plans for the future, and ensuring that people's social lives are not neglected as they age.

The Foundation for People with Learning Disabilities is part of the Mental Health Foundation. This charity aims to improve the lives of people through funding research and innovative service development projects. For further information or a free newsletter on the GOLD programme contact David Thompson, 020 75357412, E-mail dthompson@mhf.org.uk or www.learningdisabilities.org.uk.

Person-centred care, collaborative care planning, carer support, well-being, evidence-based practice, quality of life...a few of the 'buzz' words we are all bombarded with these days if we are involved in the care of the elderly mentally ill. But what do all these mean for the average speech and language therapist, and how do we weave them all into a service that we can reasonably and effectively deliver? Why, in fact, do we provide a service at all?

Like many other speech and language therapists, I found myself faced with a large population of severely mentally ill patients, spread across a wide geographical area covering four separate hospitals and five wards, and with an inadequate time allocation of two sessions a week, term-time only. How could I provide an equitable and efficient service and yet 'make my mark'?

Sadly, this group of people with dementia are so often forgotten or only responded to 'on demand' when care staff are at the end of their tether, with the speech and language therapist called in as a last resort. Many professionals feel there is nothing more to be done, and relatives watch from the sidelines as their loved ones deteriorate into un-communicating, unresponsive and unrecognisable beings.

Evolving service

The service which has evolved during the past two years has begun to address some of these issues.

In partnership with ward staff and relatives I have produced Life Story Books for those people who show some remaining language skills and who have a relative visiting regularly. These have provided the opportunity to:

- share important life events and reminisce
- focus conversations around a shared theme
- rekindle the relationship between spouses
- provide a means of carer support
- provide activity-based training in communication skills for care staff
- acquire detailed knowledge of people which can, in turn, be used in the planning of more person-centred care and other ward activities.

Many of these are in line with the aims and principles of service delivery as set out in Communicating Quality 2 (RCSLT, 1996) in the section on dementia.

Life Story Books have been widely used (Murphy, 1994) with a variety of client groups in a range of settings. However, their use at this stage of dementia is little reported in the literature. Evaluation of this project has revealed some outcomes that were not anticipated at the outset (Baker, 2001). I was particularly astounded by the collaborative approach which rapidly developed between ward staff, management, the relatives and myself. Although initially a relatively labour-intensive project, once it was established on the wards it did to some extent run itself, enabling me to concentrate on other aspects of intervention.

Close working relationship

After this project had been running for 18 months, funding was secured through the Shropshire and Staffordshire Education and Training Consortium to train staff in Sonas aPC (Threadgold, 1999) a multi-sensory group approach that was originally developed by Sister Mary Threadgold for use with people with learning disabilities. It was felt this approach would extend the training in communication skills and environmental modification that had started with the Life Story Books. Many of the staff that attended the Sonas training course were ones with whom I had developed a close working relationship simply by being involved in Life Story work

together. We trained 21 staff from mental health ranging from a senior clinical nurse and ward / day hospital managers (25 per cent) to occupational therapy assistants (10 per cent) and health care assistants (33 per cent).

After the initial rush of enthusiasm by all concerned there followed a 'winter of discontent' when a combination of nurse staffing levels at an all time low, high levels of staff and patient sickness and uncertainty over ward closures meant that the groups were not implemented as often as we would have liked. However, this is the real world we live in, and it is issues and challenges such as these that we are faced with on a regular basis. Luckily I have the tenacity of a terrier and have persevered with the approach, choosing to give each location in turn an intensive input whilst providing a supervisory service to the others. This has worked and good professional relationships have been extended. The Sonas groups are running an average of three times a week on each ward and several new staff have expressed a desire to become trained in the approach.

Particular benefit

The information acquired during the compilation of the Life Story Books - such as a person's favourite song or poem - is proving to be useful material for the groups. In turn, I have made some alterations in the type of information I collect from relatives if a person has both a Life Story Book and is participating in a Sonas group; for example, asking what a lady's favourite perfume is. For some people on the wards, the group sessions are not suitable and Sonas also has structured individual sessions which focus on music, touch and relaxation. I have found these sessions to be of particular benefit for agitated and anxious patients. The combination of these approaches aims to heighten staff awareness of the role of the speech and language therapist and accommodates the fluctuations in behaviour that occur in dementia.

Both approaches are being evaluated - the Life Story Books by user questionnaires and Sonas by the range of evaluation materials they provide. Later in the year members of the nursing team will be using Dementia Care Mapping (Bradford Dementia Group) to look at patients' behaviour before, during and after group sessions which early indications suggest may provide a further evidence base for this approach.

We are setting up a Sonas users' group aimed at all staff involved in implementing the approach. We intend to meet every four to six months to exchange ideas, solve problems and provide peer support. As Allan (2001) observed, "For staff to provide high quality care they needed appropriate support, such as regular opportunities to talk about what was happening and how they felt about it." I look forward to seeing what evolves from this group in terms of working practices and relationships.

I also carry out individual language assessments to ascertain level of functioning and change over time. This is a combination of observational, qualitative measures and more formal assessments where appropriate. However, the Sonas group situation is often an opportunity to acquire a more accurate picture of a person's communicative abilities, and I am hoping to develop this further.

My role as a speech and language therapist with the moderately and severely mentally ill is one that can be applied in continuing care settings, nursing homes, and day hospitals and, to some extent, in the community. It enables most patients to be involved in some form of intervention as well as promoting active roles for their relatives and care staff at all levels. It ensures a personalised, individual approach that is beneficial for patients and hopefully enhances their quality of life, and gives a high level of job satisfaction for me. ▶



Living in the real world

Julie Baker works with elderly people who are moderately or severely mentally ill. The past two years has seen a transformation in the service provided, with benefits for patients, relatives and staff.



References

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Resource

Information and training in Dementia Care Mapping from Bradford Dementia Group, tel. 01274 233996, www.brad.ac.uk/acad/health/bdg/dementia.htm. ■ □ □