Uncharted Waters – Summary and Recommendations

Executive Summary

Helen Kara from We Research It Ltd, and Debs Sambor from Mercian Research Associates, were commissioned by Staffordshire LINk in March 2010 to investigate dementia services across the county. We spoke to people from the north and south of the county: eight people with dementia, 30 carers, 11 professionals, and one member of Staffordshire LINk who is also a carer. We also read and analysed numerous national and local documents.

We have called our report ‘Uncharted Waters’ because that is where it seems we are in relation to dementia: as a society, as service providers, as people with dementia and as their carers. None of us know exactly where we are going, or what the journey will be like along the way. However, we now have some information to guide us: the national dementia strategy, other national and local strategies, plans and consultations, and the lived experiences of people with dementia and their carers, as well as this research.

Our findings are laid out in the following pages, and we have made ten recommendations on the basis of these findings. We recommend that Staffordshire LINk should:

1. Work to ensure that support for people with dementia and their carers is focused around times of transition.
2. Focus efforts on the ten major gaps in services identified by the research.
3. Work to overcome the five main barriers to accessing services which were identified by this research.
4. Gather and monitor information about pressure on existing services.
5. Make use of existing evidence, or evidence collected by partners, where possible.
6. Use the findings of this research to influence decision-making about where to focus consultation efforts.
7. Use a range of techniques, as appropriate, to involve people with dementia in the consultation process.
8. Find, and use ways to consult, carers and people with dementia who don’t go to carers’ or other groups.
9. Help to publicise work that is being done in the county to improve and develop dementia services, as well as identifying further need for services.
10. Create an action plan with SMART objectives for the implementation of the above nine recommendations.

These recommendations, and the rationale for each of them, are discussed in more detail on pages 4–7 of this report. We know that our report is a very small piece in a very large jigsaw, but we hope it will make a positive difference for people in Staffordshire who are living with dementia and its consequences.

Recommendations and Discussion

We were asked by Staffordshire LINk to help it 'better understand current issues in relation to dementia services across the Staffordshire area' and to 'enable a patient and public viewpoint to influence how services are planned, commissioned and delivered in the future'. On the basis of the findings from this research, we have made ten recommendations for Staffordshire LINk:

Recommendation 1: work to ensure that support for people with dementia and their carers is focused around times of transition.

Times of transition include:

- At and immediately after diagnosis
- Whenever the behaviour of the person with dementia changes
- When paid care is first used
- When any respite service is first used
- When the person with dementia develops other health problems
- When the carer develops other health problems
- When the person with dementia goes into hospital, and during any recuperative period
- When the carer goes into hospital, and during any recuperative period
- When the person with dementia goes into residential care
- When the person with dementia dies, and thereafter

These are the times when carers and people with dementia need easy access to responsive support. Between these times, there may be periods of years when families can manage perfectly well with little or no support. At times of transition, crises can develop quickly if support is not available and effective. A quick tailored intervention can prevent the escalation of a situation into a stressful and costly hospital or care home admission.

Recommendation 2: focus efforts on the ten major gaps in services identified by the research.

This research identified ten major gaps in services, some of which are being addressed through existing work. These gaps are:

1. Little or no support at the times of transition identified above
2. An almost complete lack of services addressing the needs of younger people with dementia, who have different needs from the over 65s (there are an estimated 240 people in Staffordshire with early-onset dementia, and this group are recognised by the national strategy as in need of differently tailored services from those whose dementia develops later in life)
3. An almost complete lack of services addressing the needs of older carers – those over the age of 80 – who are increasing in number

4. No named key workers for people with dementia and their carers (even though this is defined as best practice both nationally and locally, and has been acknowledged and promised at "Your Voice" conferences each year for the past three years)
5. Usually no regular assessments of the needs of people with dementia, or their carers (although both of these are mentioned in the national strategy as essential – some work is being done locally on assessments for people with dementia, but apparently little on assessments for carers)
6. Lack of access to re-enablement services for people with dementia
7. Very little extra support for carers who develop health problems of their own
8. Very poor service in many hospital settings for people with dementia and, by extension, their carers (appendix 7 shows that this is beginning to be addressed through the appointment of specialist hospital staff in South and North Staffordshire, and by training of existing hospital staff in North Staffordshire)
9. No access to Admiral nurses – the nearest one is in Worcester
10. No effective service provision outside office hours, even to cater for emergencies – the burden here falls on GPs (there is talk of a helpline through Staffordshire Cares, but nothing concrete)

Recommendation 3: work to overcome the five main barriers to accessing services which were identified by this research.

The five main barriers identified by this research are:

1. The stigma associated with dementia
2. Lack of awareness of dementia and of services
3. Funding constraints and continual service reconfiguration
4. Physical barriers to accessing services
5. Barriers created by some GPs

Talking about dementia, and increasing awareness of the illness and of services available for those affected, will help to overcome the stigma.

In the current economic climate, funding constraints are inevitable. Some service reconfiguration is necessary to create efficiencies and free up funds for much-needed extra services. However, service reconfiguration that adversely affects services provided directly to people with dementia and their carers should be avoided as far as possible, because of this group's particular need for continuity and familiarity.

Where physical barriers to accessing services exist, generally service providers were aware of these barriers and taking steps to manage or remove them.

A few GPs in Staffordshire are demonstrating excellent and even innovative practice with people with dementia and their carers. However, many carers report lack of information and support from GPs at and after diagnosis. It would also be interesting to know the extent of GPs' role in the large number

of undiagnosed cases of dementia in the county. This is not particular to Staffordshire. Research cited in the national dementia strategy describes it as a national problem, saying:

“A review of the evidence confirms that there is a marked reluctance on the part of primary care to be directly involved in the diagnosis of dementia for reasons that include: the belief that nothing can be done for dementia; risk avoidance; concerns about competency; and concerns about the availability of resources.” (p. 36)

Professionals in Staffordshire report a lack of awareness of dementia services on the part of GPs, and GPs’ unwillingness to share their carers’ registers. We would hope that the training for GPs which is being undertaken by South Staffs PCT will help to overcome the difficulties reported by carers and professionals in that area, as well as making those GPs’ complex and difficult working lives a little easier.

Recommendation 4: gather and monitor information about pressure on existing services.

This research found that existing services are under increasing pressure, often with long waiting lists. The scope of this research did not allow for a comprehensive assessment of pressure on existing services, but the findings indicated the presence of a serious and growing problem which would merit further enquiry.

Recommendation 5: make use of existing evidence, or evidence collected by partners, where possible.

Consulting people with dementia and their carers can be challenging. Some people with dementia find communication difficult, so extra time and special techniques may be needed to consult effectively with them. Carers may be overwhelmed by the demands of their role and/or unable or unwilling to express their needs in front of the person they care for. They may also have little or no time away from their caring role, and may be reluctant to use any free time they do have for participating in consultation.

These factors should not be used as an excuse to avoid consulting people with dementia and their carers. However, any consultation must be approached with sensitivity and awareness that people with dementia and their carers may be more prone to ‘consultation fatigue’ than other sectors of the population. People with dementia and their carers should only be consulted when necessary, not tokenistically, to tick a box, or in work which has been or is being duplicated elsewhere in the district or county.

Recommendation 6: use the findings of this research to influence decision-making about where to focus consultation efforts.

There are already sizeable bodies of evidence on a number of key issues, such as the need for better support for people with dementia in hospitals, and

the need for more support for those caring for people with dementia. Rather than collecting further evidence on such issues, Staffordshire LINk should focus on monitoring services to assess levels of improvement, using the elements of best practice identified in this report for guidance.

Recommendation 7: use a range of techniques, as appropriate, to involve people with dementia in the consultation process.

Some people with dementia are able to take part in a conversation, interview or focus group, or complete a questionnaire. Others find conventional communication more difficult, and for these people, pictorial or symbolic methods, or tools such as ‘Talking Mats’, may be more appropriate. People with dementia should always be consulted in surroundings which are familiar to them, by non-judgemental people who are informally dressed, and without being rushed.

Recommendation 8: find, and use ways to consult, carers and people with dementia who don’t go to carers’ or other groups or services.

For this research, service users were consulted at existing groups and services for carers and people with dementia. This is a valid way of consulting people, and was endorsed by those consulted for this research. However, there are a large number of carers and people with dementia who do not use existing groups and services, whether because they do not choose to, or because the existing services are full, or for some other reason. The views of those who do not currently use services, whatever the reason, should also be included, as they may give quite a different picture. It should be possible to make contact with such people through specialist staff and organisations such as dementia navigators/advisers/support workers and carers’ associations.

Recommendation 9: help to publicise work that is being done in the county to improve and develop dementia services, as well as identifying further need for services.

Of course it is part of the role of Staffordshire LINk to identify further need for services. However, it would be reassuring for people with dementia and their carers, and might help to remedy consultation fatigue, if as part of every consultation exercise Staffordshire LINk helped to raise awareness of the considerable amount of work that is being done at county, PCT and district level to improve and develop dementia services.

Recommendation 10: create an action plan with SMART objectives for the implementation of the above nine recommendations.

This will enable the recommendations to be followed through, and provide lines of accountability for Staffordshire LINk and its constituents.

Best Practice

In April 2007, the National Care Forum published a statement of best practice in person-centred dementia care. The key indicators of best practice that they defined were:

- A full assessment is undertaken prior to a service being provided
- Evaluation and reassessment is ongoing
- All relevant documentation used by the organisation demonstrates that the individual is fully involved
- Cultural needs are appropriately considered
- Well-being for the individual is actively promoted
- The language used will be acceptable to the person receiving care
- Care plans are used as communication tools – evaluation is meaningless in the absence of well documented care
- A key worker system matches individuals and staff
- Relatives (and significant others) feel involved and supported.

The Department of Health Implementation Plan for the National Dementia Strategy, published in July 2009, identifies best practice in specific areas of work relating to people with dementia and their carers and covering most of the objectives of the Strategy. Examples of these areas of work include:

- Assessing dementia
- Awareness of carers' needs
- Importance of communication skills
- Offering choices around the outcomes that have been shown to be particularly important to older people with dementia, which include: personal safety, social contact, opportunities to be active, having control over everyday life, and feeling valued and respected
- Providing appropriate services for people with dementia from minority ethnic groups
- Information for paid carers
- Dementia care in sheltered housing
- The care of adults who are malnourished, or at risk of malnutrition, in a hospital, care home or community setting
- Assistive technology
- Staff training
- Integrating health and social care services

Best practice identified by Staffordshire's people for this research includes:

- Mental wellbeing clinics, like those operating in Stoke-on-Trent, run by a community psychiatric nurse, and ideally offering regular mental wellness checks for all to facilitate early diagnosis of dementia

- Memory clinics, based in the community, with a dementia adviser to support each family from before a formal diagnosis is made, and a full care plan for each person with dementia, reviewed annually
- A named key worker for every person with dementia and their carers
- Regular needs assessments for every person with dementia and their main carer
- Information about carers and support for carers to be readily available in all GPs' surgeries
- Dementia support workers/advisers/navigators throughout the county
- Carers' support throughout the county
- Dementia cafés throughout the county
- Providing stimulating activities for people with dementia, both within and outside the family
- Access to re-enablement services for all people with dementia
- Helping people with dementia to continue contributing to society for as long as possible
- Supporting people with dementia to maintain their links with existing social groups and activities (church, pub darts team, line dancing, whatever they may be) for as long as possible
- Providing services at local level, even in villages where there may only be a few people with dementia
- Access to Admiral Nurses
- Contact names and numbers for help in emergencies
- Responsive support in the community to be provided by community psychiatric nurses
- Training for carers as soon as possible after diagnosis, covering the topics that carers have defined as being important, e.g. what is dementia, different kinds of dementia, how to deal with unexpected behaviour and new patterns of behaviour, legal issues such as dealing with estates, medication – what's available, the importance of keeping healthy, nutrition, lifting and handling, support available for carers, benefits and finance, etc
- Life story creation: familiar photos, souvenirs, letters etc, collected in a book, box or file, together with details of the likes and dislikes, choices and preferences of the person with dementia, to help that person remember, and to help new people to get to know them and work with them in ways that will suit them
- Training for all GPs
- Training for all hospital staff who could be involved in caring for someone with dementia
- Training for all day care staff who care for people with dementia
- Training for all care home staff who do, or may, care for people with dementia
- Training for all other staff who do, or may, care for people with dementia, such as those working in sheltered housing
- Providing support for people with dementia and their carers at times of transition
- Respecting and valuing people with dementia