

**Post-diagnostic support for people living with dementia - Faculty of
Psychologists**

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**An interim report prepared for the Faculty of Psychologists
working with Older People and the Dementia Action Alliance**

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26th March 2013

Executive summary

“I have lost myself” Frau Auguste Deter, (1901) quoted in the notes of her doctor, Alois Alzheimer, one day after admission to the Irrenschloss or Institute for the Mentally Ill and for Epileptics in Frankfurt am Main

1. There has been consistent pressure within NHS Services towards making the diagnosis of dementia at an earlier stage, and for more people. This has been driven both by an awareness that an early diagnosis maximises the opportunity for people to adjust to the illness. Research also suggests that there are potential savings to the health and social care economy
2. However, there is no clear guidance about what post-diagnostic support should be available to people living with dementia and their families. This is especially problematic for the significant numbers of people with dementias, for whom prescribing is not an option and where non-pharmacological approaches are the only available treatments
3. Good psychosocial support needs to be timely and provided at a pace that is acceptable for the person living with dementia. It includes working at different levels, such as:
 - a. breaking the news to the family in a sensitive and thoughtful manner;
 - b. providing opportunities for rehabilitation and adjustment, possibly through the provision of psychotherapy or peer support groups; and
 - c. working with the person with dementia/their carer/system
4. A range of good psychosocial practice has been identified including the provision of Alzheimer’s cafes, the use of individual and group support and psychotherapy and cognitive rehabilitation techniques. There is a growing evidence base to support their use, as well as evidence that early intervention reduces the risk of institutionalisation later in the course of the illness
5. Access to post-diagnostic psychosocial support should be equal for all, regardless of age, ethnicity or diagnosis.
6. In order to balance the need for individualised interventions, with finite resources, a stepped care model of support should be introduced
7. The time seems right therefore, to address the Psychosocial Intervention Gap, and to identify practical ways of ensuring that people who are living with

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dementia, and their families receive adequate support from structured, evidence-based pathways

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Psychosocial Adjustment and Dementia

Nationally a broad range of consumer groups, voluntary and statutory organisations and a cross-party consensus all support a drive for the early identification of dementia for as many people as possible. This has been influenced by:

- individual accounts of difficulties arising from delays to diagnosis
- attempts to improve prompt access to medication for people with dementias such as Alzheimer's Disease
- evidence of savings to the health and social care economy arising from early diagnosis

Commissioning Guidance has been issued to assist Clinical Commissioning Groups, NHS Trusts and other providers in developing services that can deliver early diagnosis. However, the Department of Health Service Specification for Dementia (2011) and commissioning guidance, and in many cases the services themselves, have a focus on just that: early diagnosis. While there is detailed guidance on referring, timescales for different stages of assessment and number targets, it is less clear what services should be available after diagnosis. The post-diagnostic support stages lack clear guidance around content, especially in relation to non-pharmacological approaches. This is especially problematic for the many people with dementias for which non-pharmacological approaches are the only available treatments. Unfortunately, many hard-pressed services discharge those people with dementia for whom prescribing is not an option, which also means that they do not receive follow up and on-going contact with specialist services. Adjustment to diagnosis is a process – as recognised by the Payment by Results Cluster 18 pathway - that may take up to two years. If people are discharged early, opportunities for support towards positive adaptation and living well with the dementia are missed and risks of maladaptive coping strategies, leading to additional mental health issues and costs later on, are overlooked.

The absence of clear guidance about post-diagnostic support not only represents a missed opportunity to provide support for people living with dementia and their families, but also has economic costs. The service models which have inspired the movement towards early diagnosis, and offered the hope of economic savings, also offered a broad range of post diagnostic support for people with dementia and their carers. Thus the Commissioning Guidance neither

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incorporate a realistic model of the support needed post diagnostically, nor provides the time and resources required to realise these potential savings.

Early diagnosis with little psychosocial support

There is evidence that the main focus of many assessment services are on the process of achieving a diagnosis, and that limited staff training and resources are available for post-diagnostic support. There are a number of possible explanations for this, including the increase in referrals, and an emphasis on pharmacological treatment. However, with only limited time available and a restricted range of support options, there is little scope for such services need to be tailored to the needs of each individual and their family. This situation has led to recent concerns being raised (Illiffe and Manthorpe, 2010; Manthorpe et al, 2011) that diagnosis without adequate support may not be beneficial, and in some respects be detrimental.

Good Quality Psychosocial support

This term reflects a broad range of individual and group approaches with differing therapeutic style and focus, and covers different aspects of memory service provision, which need to be timely and provided at a pace that is acceptable for the person living with dementia. It includes working at different levels, such as:

- breaking the news to the family in a sensitive and thoughtful manner;
- providing opportunities for rehabilitation and adjustment, possibly through the provision of psychotherapy or peer support groups; and
- working with the person who is living with dementia, and their carer

Initially after diagnosis, people with dementia often describe moving from frustration and embarrassment through feelings of shock, grief and a wish to withdraw. For some people, there may also be a sense of relief as they at last have an explanation from which to make sense of their problems. Nevertheless, despite the emotional threat inherent in receiving a diagnosis, research suggests that if given the choice most people would want to know if they had dementia. This seems to be true both of people who attend a memory clinic and of the population in general. Thus in a Canadian study 98 per cent of people over the age of 65 would want disclosure for themselves if they were diagnosed with dementia (Ouimet et al, 2004). Similarly, most people who attend a memory clinic want to know the outcome of their assessment (Elson, 2006; Johnson, Pinner and Bouman, 2003; Jha, Tabet and Orrell, 2001, although a minority are clear that they don't want to know. A fundamental part of this wish to understand is that with this knowledge comes the ability to prepare. For some people, the process

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of receiving a diagnosis, although difficult, can lead to significant changes in their lives. Thus James McKillop, quoted in Mountain (2008) says:

“Being told I had dementia was like a door re-opening after a difficult time in my life –new challenges, new opportunities ...I want people to understand that dementia isn't an end, it's a new beginning where you do things differently. While some things change forever there is a lot you still can do.”

There is an evolving literature describing effective psychosocial interventions for the early stages of dementia. Moniz-Cook & Manthorpe (2011) provide a comprehensive overview of the range of evidence based early interventions with people with dementia and their carers, targeting the range of emotional, cognitive and behavioural issues arising at this stage. Table One summarizes the main types of intervention and key references.

Table One: Examples of Good Practice

Type of Intervention	Selected references
Guidelines for disclosing the diagnosis	(Lecouturier et al., 2008)
Mild Cognitive Impairment interventions	(Tuokko and Hultsch, 2006; Cantegreil-Kallen et al., 2009)
Direct therapeutic interventions, to help the person with dementia adjust to their diagnosis and forthcoming life changes.	(Cheston and Jones,2009; Sorensen, Waldorff and Waldemar, 2008; Sadek et al., 2011)
Peer support groups facilitated/not facilitated	(Logsdon et al., 2010)
Education about the symptoms of dementia and coping strategies	(Moniz-Cook et al, 2006;2008)
Specific psychological therapies for depression, anxiety in the person with dementia following diagnosis (e.g. CBT in	(Lipinska, 2009; Miller and Reynolds, 2006)

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mild dementia)	
Life Story	(Young, Howard and Keetch, 2013)
Reminiscence	(Cochrane Collaboration Review: Woods et al, 2009)
Dementia Cafés	(Jones, 2010)
Group and individual adjustment work with carers	(Cochrane Collaboration Review: Vernooij Dassen et al., 2011; Charlesworth et al., 2009)
Coping strategies and stress management for carers	(Cooper et al., 2012)
Understanding ‘challenging behaviours’	(Selwood et al., 2007)
Cognitive Stimulation Therapy, a programme of ‘mental exercise’ – group and developing individual approaches (iCST)	(Cochrane Collaboration Review: Woods et al., 2012) (Orrell et al., 2012)
Cognitive rehabilitation in early dementia Interventions to support maintenance of activities of daily living/lifestyle e.g. Occupational Therapy	(Clare et al., 2010; Kurz et al., 2011) (Graff et al., 2006; 2008)

Although Table One indicates that there are many potential examples of good practice, there is evidence that this support is not consistently provided. For instance, perhaps the most basic form of advice involves telling people about their diagnosis. While the manner and sensitivity with which their diagnosis is given is important, unfortunately people with dementia and their family carers give a mixed picture about how well this is done (Lecouturier et al., 2008). For instance, often health professionals either ignore or under-estimate the emotional impact of the diagnosis. Thus Connell et al. (2004) carried out focus groups with both care givers and doctors. The care givers recounted a highly negative emotional response to the disclosure, whereas many physicians reported that families handled the information well. Similarly, even when people are informed about the diagnosis in an appropriate manner, there remains concern about how

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much information, and of what quality they are subsequently provided with. Thus, the National Audit Office report of 2007 found that roughly half of the community services they surveyed had no policies around discussing with people with dementia and their carers about the likely progression of the illness, or options for support and care.

Equality of access to Post-diagnostic Support

Some specific groups may be more disadvantaged in terms of support provided than others. Significant numbers of people are identified with Mild Cognitive Impairment (MCI) through Memory Services. These people are usually seen as low priorities for support, and yet may remain for some years in a state of uncertainty as to whether this will progress to dementia, and whilst living with the consequences of changed memory and thinking abilities.

People not in receipt of medication and with rarer diagnoses may also be at risk of being discharged from memory services, or of being excluded from support aimed at people with Alzheimer's disease or vascular dementia. This may particularly impact on younger people, including those with a diagnosis of Frontal-temporal dementia, or people with a learning disability. Similarly, services for people from Black and Ethnic minorities may also be less likely to receive support that adequately meets their needs.

When adequate support is provided, then this not only improves quality of life, but also enables them to make choices about their life, reduces stress for their families, and means that people are less likely to be admitted to care homes or in-patient wards (Spijker et al., 2008; Brodaty et al., 2003).

Stepped Care Model for Post-diagnostic Support

To deliver support that is both clinically and cost-effective, it is important that Memory Services can target these approaches according to the needs and preferences of the individual with dementia and their family. It is not only a question of what is offered by services, but also one of the pacing and timing of what is offered, and needs to take into account the importance of relationships and continuity in staff delivering this aspect of care. Adjustment is a process, not a set of boxes to be ticked at a pre-determined point. Services need to be able to work flexibly with families around the support they need. At the same time, memory services only have a finite amount of resources, and realistically will be able to provide only a limited range of interventions. Thus it is essential that access to different levels of intervention is based upon an accurate assessment of psychosocial need.

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In order to meet this dilemma of how best to meet individual need within limited resources, Moniz-Cook and Manthorpe (2009), have suggested a stepped model of intervention spread across four tiers (see Table 2). More recent work in this area, has concerned the development of psychosocial diagnostics and pattern recognition. Psychosocial diagnostics refers to individualised (and/or family-centered) psychosocial profiling leading to patterns of care 'prescriptions' based on high and low patient / family need. These patterns of patient and family need comprise up to 8 groups of prescriptions to address psychological and social needs in the person and the family carer. These allow for delivery within a stepped care model. (Rewston & Moniz-Cook, 2013: personal communication).

Table 2: Based on Moniz Cook & Manthorpe, 2009

Step 4 High need Interventions	Individual and Group Therapies for person with dementia who is distressed and requires support or psychological treatment to adjust
Step 3 Interventions	Enhance social inclusion/peer support e.g. Dementia Cafes
Step 2 Interventions	Prophylactic approaches, for people who are not currently distressed (e.g. Cognitive Stimulation Therapy and Reminiscence Therapies)
Step 1 Low need Interventions	Address stigma, promote health and well-being, basic cognitive rehabilitation or training, social support networks and activity

Essential Standards for Psychosocial Adjustment in Memory Services

Memory Services should not be assessed solely against the criteria of speed, accuracy and volume of diagnosis. The National Dementia Strategy and other documents have acknowledged the need for improved experience of services for people with dementia and their families, but how this can be achieved has not been incorporated into the Service Specification Guidance. The Memory Services National Accreditation Programme (MSNAP) Psychosocial Interventions Module provides a first attempt at a set of quality standards to address the current gap in commissioning guidance (Doncaster et al., 2012). These

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standards and accompanying examples of practice should be integrated into the diagnostic pathway:

- Access to psychosocial interventions is based on the needs and preferences of the person with dementia and, where appropriate, their carer
- The service provides access to psychosocial interventions for cognitive aspects of dementia
- The service provides access to psychosocial interventions for emotional aspects of dementia
- The service provides or can signpost/refer people and their carers on to interventions for more complex needs, if required
- The service provides access to psychosocial interventions for carers of people with dementia
- Staff delivering psychosocial interventions are appropriately trained and supervised
- The service monitors people's responses to psychosocial interventions

The end result of post diagnostic adjustment should be to help people reach a point at which they feel that they have done the right thing by having a diagnosis. That is to say that they can see a way forward in their lives once again, towards Living Well with Dementia.

Conclusion

While, nationally, much attention over the last ten years has been focused on bridging the so-called Dementia Diagnosis Gap, there are concerns that the focus on improving early access to diagnostic services has not been matched by attention to the need for adequate post diagnostic support. Although there are many examples of good practice, and a growing evidence base to support this, nevertheless there are concerns that many services have had to prioritise pre-diagnostic assessment over post-diagnostic support

The time therefore seems right to address the Psychosocial Intervention Gap, and to identify practical ways of ensuring that people who are living with dementia, and their families receive adequate support from structured, evidence-based pathways.

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