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Division of  
Clinical Psychology  
Faculty of the Psychology  
of Older People

## Clinical Psychology in the Early Stage Dementia Care Pathway

*Reinhard Guss and colleagues*

*Collated on behalf of the Faculty of the Psychology of Older People.*

*A collaboration of people living with dementia and the  
Dementia Workstream Expert Reference Group.*

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# Foreword

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Dementia Challenge and the recent G7 summit have acted as catalysts for renewed energy and commitment. There are growing calls for action regarding timely diagnosis and post-diagnosis support, with the Alzheimer's Society calling for all areas of the UK to achieve a 75 per cent rate of diagnosis by 2017 and suggesting that minimum standards should be set for integrated post-diagnosis advice and support. These are important goals.

Making a diagnosis of dementia, however, can be a very complex process. Receiving a diagnosis of dementia is a life-changing event, and post-diagnosis support must be tailored to individual needs rather than taking a one-size-fits-all approach. All of these activities demand great skill from clinicians and carefully designed service models. Recognising the challenges inherent in responding effectively to the needs of people developing dementia and living with early-stage dementia, members of the Dementia Workstream of the British Psychological Society Faculty of the Psychology of Older People (FPOP) recently embarked on an initiative to provide evidence-based guidelines to support clinicians and clinical services.

FPOP identified four key areas of psychological practice where guidance would be useful – pre-diagnostic counselling, diagnostic assessment, communicating the diagnosis, and post-diagnosis support – and focused on these to develop the guidelines in this set of documents. These guidelines, which clearly demonstrate the contribution clinical psychologists make to the care of people with early-stage dementia, will encourage and stimulate good practice and provide an important basis for new developments that will enhance the services available.

As a result of consultation with people who have dementia and carers, a fifth strand of work was identified, leading to the development of a Guide to Psychosocial Interventions for people in the early stages of dementia. This accessible and informative guide is an exceptionally valuable resource for people with dementia and carers, and will also be useful for clinicians, service providers and service commissioners.

I would like to thank everyone who has contributed to the development of these documents, and especially Reinhard Guss for leading the Dementia Workstream initiative.

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Chair of the British Psychological Society Dementia Advisory Group.

# Clinical Psychology in the Early Stage Dementia Care Pathway

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## Introduction

The Dementia Strategies of the four Nations stress the importance of early diagnosis of dementia (Department for Health, Social Services and Public Safety, 2011; Department of Health, 2009; Scottish Government, 2010; Welsh Government, 2011), a policy priority further emphasised by the report of the All-Party Parliamentary Group on Dementia (All-Party Parliamentary Group on Dementia, 2012) and the Prime Minister's Dementia Challenge (Department of Health, 2012)) to increase diagnosis rate. Key advantages of diagnosing and treating dementia early are seen as better adjustment, slowing of progression, planning ahead and, ultimately, savings to the health economy due to prolonged independence and delayed need for care home or hospital admission.

The Faculty of the Psychology of Older People (FPOP) is responding to this agenda by publishing, in the form of four linked papers, good practice guidance for clinicians and recommendations for commissioning across the key components of care pathways in early stage dementia. Writing groups consisting of experts from the profession have examined pre-diagnostic counselling and informed consent, cognitive and neuropsychological assessment in memory clinics, communicating about a dementia diagnosis with those affected, and psychosocial post-diagnostic support and interventions.

The writing process was accompanied by extensive consultation with groups of people living with dementia, which has led to an additional position paper summarising the views expressed by service users and an overview of psychosocial interventions that provides information on types of treatments available, their evidence base and for whom they might be helpful. These consultations have influenced the content of the professional papers and quotes from participating service users are included throughout.

## Executive summary

Each of the four professionals' papers provides a more detailed summary of findings and recommendations.

- Across the four papers and the service user consultation there is agreement that any care pathway in early dementia has to consider the wide variation in the needs and preferences of people who are developing dementia. Care pathways should offer choices in the type and intensity of treatment and interaction with services. In turn, services should respond by assessing the individual patterns of need and meeting these in different ways and at varying points in the course of the development of the illness.
- Good practice in **pre-diagnostic counselling** and establishing **informed consent** sets the scene for successful future engagement with services and enables people to adapt in such a way that the advantages of early diagnosis are maximised.
  - While some people are keen to be assessed and have a diagnosis as soon as possible, for example, in a 'one stop shop' diagnostic clinic, several sessions of pre-diagnostic work are needed by others to feel confident to engage with the diagnostic process.

- While in later stages of dementia, and for those lacking capacity to make decisions about their assessment and treatment, the provisions of the Mental Capacity Act regarding best interest guidance come to bear. People in the early stages of dementia usually have capacity and are, therefore, entitled to decline further assessment following discussion of the advantages and possible disadvantages.
- The earlier in the development of dementia a diagnosis is attempted, the more likely it is that there will be a need for a complex **assessment of cognitive functioning**. This should involve a Clinical Psychologist with training and expertise in the neuropsychological assessment of people with suspected dementia.
  - Screening tests developed for use in Primary Care are effective in alerting staff to the presence of a more advanced dementia, particularly where this takes the form of Alzheimer’s disease or vascular dementia. Psychologists’ or Clinical Neuropsychologists’ role in situations where the decision is not complex is one of training provision, for example, on the use of standardised clinical screening instruments, clinical supervision and quality control.
  - Early-stage dementia and rarer forms of dementias such as Fronto-temporal dementia or Lewy-body dementia may not be detected by standard screening tests. This emphasises the need for specialist assessment services, including comprehensive neuropsychological assessment by a trained Psychologist.
  - It is essential for Clinical Psychologists to contribute to team discussions when decisions are being made about the level of testing needed to clarify whether dementia is present and if so which type of dementia is indicated.
- Clinical Psychologists are well placed to support teams with the difficult task of **communication about a diagnosis of dementia** and, where appropriate, undertake this, due to their background knowledge of cognitive difficulties and communication processes.
  - Factors such as previous personality and coping styles, cognitive profile, current appraisal of nature and extent of difficulties and a person’s personal preferences all affect how a diagnosis is discussed. This includes at which point in the assessment process the diagnosis is named, and what is required to support a person with cognitive impairment to process the information and adjust well.
  - Sharing and communicating a diagnosis of dementia requires a range of individualised approaches along the early dementia care pathway; recommendations are outlined and a checklist is provided to assist professionals.
- Successful **adjustment to a diagnosis of dementia** is key to the envisaged health and economic benefits of receiving a diagnosis early. However, whether successful adjustment takes place and how it can be maintained is dependent upon the availability of **post-diagnostic psychosocial interventions** and support, particularly for people who do not benefit from currently available medication.
  - There is a range of psychologically-based post-diagnostic interventions. However, due to limited resources availability is variable across the country. This leads referrers and people affected to doubt the helpfulness of referral and undermines the ability of early diagnosis to deliver the hoped for benefits.
  - An overview is given of good practice examples in psychosocial interventions and a model for matching complexity of intervention to needs is outlined.

- This forms a starting point to address the Psychosocial Intervention Gap. It identifies practical ways of ensuring that people who are living with dementia and their families receive adequate support through structured, evidence-based pathways into psychosocial interventions.
- Extensive consultation has been undertaken with people living with the early to moderate stages of dementia. Workshops and focus groups were held in collaboration with DEEP (the Dementia Engagement and Empowerment Project), including groups from the South East, the Midlands, the North West and Scotland. People with dementia commented on each stage of the pathway stating that:
  - One size does not fit all – service responses need to be individualised.
  - Pre-diagnostic counselling is essential for many, and helpful for most.
  - Preferences for how diagnosis is shared vary greatly.
  - Post-diagnostic support and psychosocial interventions are essential, and choices need to be available about the type of intervention and whether it is delivered individually or in groups.
  - Insufficient information is available about the range of psychosocial interventions that have been shown to benefit people affected by dementia.
- In response to the views of service users, a **‘Guide to Psychosocial Interventions’** was developed, describing post-diagnostic support and interventions that have a significant psychological component and apply to the early stage dementia pathway. This excludes medication, physical exercise and purely activity-based interventions and those mainly used in care home environments and in later stages of dementia.
  - The Guide to Psychosocial Interventions can be used as a catalogue with interventions listed alphabetically.
  - The Guide to Psychosocial Interventions is also designed to be useful to people with a diagnosis of early stage dementia and their families, who can inform themselves about interventions to address specific needs.
  - The Guide to Psychosocial Interventions will need to be updated as new evidence and new interventions become available, and a web-based resource is under development to facilitate this.

### **Reinhard Guss**

FPOP Dementia Workstream Lead.

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# Early and timely intervention in dementia: Pre-assessment counselling

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## Introduction

An important aspect of living well with dementia involves the provision of a timely diagnosis and intervention to enable people and their families to make appropriate choices; to access support in order to live well with dementia and to make decisions about the future (Banerjee et al., 2009; Prince et al., 2011). However, in spite of the recognition of the need for effective interventions in dementia, it is suggested that services have often failed to provide adequate support (Alzheimer's Society, 2012; National Audit Office, 2007). The considerable economic and personal costs of dementia combined with evidence of patchy service provision have provided a powerful argument for the need for services to do more, including the need to raise awareness and reduce the stigma associated with dementia (Alzheimer's Society, 2012; National Audit Office, 2007, 2010). In this context National Dementia Strategies for England, Wales, Scotland and Northern Ireland were launched between 2009 and 2011, identifying a range of key objectives (Department of Health, 2009; Department of Health, Social Services and Public Safety, 2011; NHS Wales, 2010; The Scottish Government, 2010). These objectives included raising awareness of dementia; providing early assessment and diagnosis for people with suspected dementia; approaching diagnosis in a sensitive manner and providing high quality, accessible information to people with dementia and their families about the illness. Subsequently, further policy objectives have set out the need for good quality, early diagnosis and intervention (c.f. Department of Health, 2012). Given that it is recognised that an earlier and timely diagnosis has not been the norm within the UK, an important area of research and practice development has sought to understand the factors influencing the journey to help-seeking for people with suspected dementia and the practice of professionals when delivering an assessment and diagnosis. This has included considering the way in which a diagnosis of dementia is shared.

Werner et al. (2013) suggest that research in this area has progressed through a number of stages, beginning with whether people with dementia wanted to know their diagnosis, which included considering whether they should be told (c.f. Bamford et al., 2004;



Husband, 2009; Pratt & Wilkinson, 2003). Subsequently research has considered what best practice in a diagnosis of dementia should be and what influences the experience. Such research has culminated in the recognition of the diagnosis of dementia as a journey, which begins when the person and/or their family notice changes and seek help (Derksen et al., 2006a, 2006b; Lecouturier et al., 2008; Werner et al., 2013). The majority of this research has indicated that many people with dementia want to know their diagnosis and do have the potential to live well with dementia (Bamford et al., 2004; Pratt & Wilkinson, 2003). Nevertheless, it is also clear that for many, a difficult emotional journey occurs alongside assessment and diagnosis. This journey is influenced by many factors, including the considerable stigma associated with dementia, all of which need to be addressed if we are to achieve a timely and earlier diagnosis (Batsch & Mittelman, 2012; Gibson & Anderson, 2011; Moniz Cook et al., 2006; Moniz Cook & Manthorpe, 2009; Vernooij-Dassen et al., 2006).

Consequently in considering what can enable people and their families to live well with dementia, recent research and practice has begun to address how a diagnosis of dementia should be shared, considering the methods of delivery, what should happen following diagnosis, the skills of practitioners involved and the processes required to facilitate adjustment (Karneili-Miller et al., 2012a, 2012b; Manthorpe et al., 2011; Robinson et al., 2012; Werner et al., 2013).

Throughout these three phases, a growing body of evidence has highlighted the need to place the perspectives and experiences of people with suspected cognitive difficulties and their families at the centre of the process. This is particularly important because significant psychological and social adjustment is needed to manage the transition to living well with dementia beyond the diagnosis and also to challenge the stigma associated with dementia (Bunn et al., 2012; Cheston, 2013; Manthorpe et al., 2011; Prince et al., 2011; Robinson et al., 2012). This evidence highlights that people living with dementia and their families have experienced shock, stigma and distress when a diagnosis has been disclosed and were often unprepared for the outcome of an assessment (Bamford et al., 2004; Karneili-Miller et al., 2012a, 2012b; Manthorpe et al., 2011; Robinson et al., 2012). It is also important because the outcome for some may not be a diagnosis of dementia. Therefore, a number of authors have argued for the provision of pre-assessment counselling prior to assessment and diagnosis which can facilitate preparation for possible outcomes and offer choice about assessment (Derksen, 2006b; Lecouturier et al., 2008; Williams, 2004).

This briefing paper reviews current opinion, emerging research and practice on pre-assessment counselling, offered prior to the commencement of assessment and diagnosis. This begins by considering the factors influencing the journey from first noticing symptoms to help seeking, the impact this may have on the way in which people present for assessment and the implications of this for practice. The processes, principles of practice and theoretical frameworks informing pre-assessment counselling are then described. This includes discussion of a number of key issues arising in the initial contact with persons with cognitive difficulties and their family members, including openness and honesty, achieving informed consent, managing expectations and family involvement.

### *Limitations*

Although literature concerning diagnostic disclosure has increased over the past decade, limited evidence concerning interventions and practice in the period prior to assessment and diagnosis exists. Furthermore, this evidence base uses a range of methodologies including reviews, small scale qualitative research and some quantitative studies, thus it is only possible to provide a narrative review at this time. Of those references included in this briefing paper few explicitly address the perspectives of minority communities, such as people from migrant communities. Furthermore, many of the early studies concerning the experiences and perspectives of people receiving diagnostic disclosure were studies of family members in care-giving roles, thus the perspective of people with cognitive symptoms or a diagnosis of dementia are less well represented.

### **Recognising Early Signs: The journey to help seeking**

In recent years, a wide range of research and auto-biographical literature documenting the experience of living with dementia has emerged (c.f. Christine Bryden, 2006; Lucy Whitman, 2009). These narratives have presented a nuanced understanding of the person and family members' experiences, highlighting that while there are considerable difficulties associated with dementia, there is also room for hope, wellbeing, maintenance of identity and continued success. Furthermore, they emphasise that the journey through dementia involves considerable changes and challenges, and that each family's journey is unique, for them as a whole and for each person within that family. The changes and challenges brought about by dementia require that the person with dementia and their family engage in an on-going process of assimilation, adaptation and adjustment (Cheston, 2013; Hellström et al., 2007; Keady & Nolan, 2003; La Fontaine & Oyebode, 2013; Manthorpe et al., 2011).

Recent research has highlighted that people commonly experience changes for at least two years before presenting concerns about cognitive difficulties to a health care professional. Thus in considering the pre-assessment phase, it is necessary for us to understand the factors influencing the journey to help seeking as these will impact upon when, whether and how people seek help and the expectations they have when approaching services (Chrisp et al., 2011). These authors indicate that the process may begin by the person with symptoms recognising something might be wrong. However, it may be some time before the person discusses their concerns with a family member (Chrisp et al., 2011). During this time changes may also be recognised by family members (Chrisp, Taberer & Thomas. 2013; Chrisp et al., 2011; Koppel & Dallos, 2007; Leung et al., 2010; Manthorpe et al., 2011). However, the decision to seek help, and who does this will be strongly influenced by a range of factors including:

- The gradual progression of symptoms and attribution of changes to normal ageing (Boustani et al., 2006; Chrisp et al., 2012; Jones et al., 2010; Leung et al., 2010).;
- Viewing changes as associated with other health problems (Chrisp et al., 2012; Jones et al., 2010; Leung et al., 2010).;
- Unwillingness to recognise the severity of the difficulties by the person with symptoms and/or their family members (Chrisp et al., 2012; Jones et al., 2010).;
- Stigma (Batsch & Mittelman, 2012; Boustani et al., 2006; Iliffe & Manthorpe, 2004; Leung et al., 2010).

- Relationships with health care professionals (Chrisp et al., 2012; Jones et al., 2010).;
- Knowledge, understanding and previous experience of dementia in family members (Jones et al., 2010; Leung et al., 2010).;
- Cultural conceptualisations of dementia, including the presence of the word in different languages (La Fontaine et al., 2007; Seabrooke & Milne, 2009; Tilki et al., 2010).

Research emphasises the difficult emotional and psychological processes occurring for the person and their family members during this period, which may involve distress, disagreement and conflict, fear for the future, concerns about loss of self and identity and the experience of stress (Chrisp et al., 2011; Chrisp et al., 2012; Manthorpe et al., 2011; Moniz-Cook et al., 2006; Rosness, Ulstein & Engedal, 2009). This complex emotional journey can result in considerable challenges within the family context. While some families are able to work together to achieve a way forward, it is evident that such challenges can also result in the person with symptoms and their family members working apart or separately (Chrisp et al., 2012; Keady & Nolan, 2003).

It is evident then, that the initial contact with health care professionals may be made by family members rather than the person with cognitive symptoms, particularly where the person has been experiencing symptoms for some considerable time. While people with cognitive symptoms may seek help, this is often with prompting from family members who were concerned and had noticed changes (Chrisp et al., 2013; Koppel & Dallos, 2007; Leung et al., 2010; Manthorpe et al., 2011).

The first contact is generally with the family doctor or other primary health care professional whose response to the concerns is of critical importance. Evidence suggests that the knowledge, attitudes and skills of health care professionals can act as a barrier to timely help seeking. Consequently improving knowledge and skills among family doctors, primary health care professionals and others who may be in a position to recognise early and timely cognitive changes is of particular importance if people are to come forward for assessment and diagnosis (Belmin et al., 2012, Hansen et al., 2008, Koch & Iliffe, 2010, Martinez-Lage et al. 2010, Mitchell et al., 2011).

The complexities involved in the journey to initial assessment as highlighted above would suggest that when people finally present for assessment, it is likely that they and their families will have a range of concerns, expectations and fears and may be more or less willing to undergo assessment. Accordingly, the need for pre-assessment counselling is of fundamental importance in addressing these issues. Intervention at this stage would seek to ensure that the person is empowered and enabled to make an informed decision concerning further assessment and diagnosis; make decisions about the involvement of their family in this process and begin to address the psychological and social implications of the difficulties they are experiencing. The principles of pre-assessment counselling are now discussed.

## Principles of practice in pre-assessment counselling

Pre-assessment counselling involves providing the opportunity for the person with suspected dementia and their families or significant others to fully understand:

- The reasons for referral;
- What assessment will involve;
- The possible outcomes of an assessment; and
- Implications for other areas of life including, driving, work and insurance.

These are necessary steps to achieving an informed decision about undergoing an assessment that may lead to a diagnosis of dementia (Cheston & Bender, 1999; De Lepeleire et al., 2008; Derksen et al., 2006b; Doncaster, Hodge & Orrell, 2012; Moniz-Cook et al., 2006; Williams, 2004).

Pre-assessment counselling generally involves meetings between the person with cognitive difficulties and (with their permission) family members or significant others prior to the commencement of assessment (Aminzadeh et al., 2007; Derksen et al., 2006b; Manthorpe et al., 2011; Moniz-Cook et al., 2006). It will also frequently include providing information and education, which also has the goal of challenging stigma. While this process frequently facilitates significant information about the person and their family that can inform assessment, it is not intended that formal assessment of cognitive function should take place at this stage, unless the person indicates a desire for this to take place.

Given the complex psycho-social processes taking place for the person and their family, pre-assessment interventions should also include the opportunity for the person and their family/significant others to discuss their experiences, concerns and fears. Creating the space for articulation of these concerns is critical to enabling the person and their family to make an informed decision and begin the process of understanding and adjustment. Furthermore, such discussions can assist practitioners in tailoring assessment and diagnosis, understanding the strengths and well-being needs of the person and their family, providing tailored information and education and can inform future planning.

The complexity of this process requires that practice is informed by appropriate theoretical frameworks. Commonly, person-centred care (Brooker, 2008; Kitwood, 1997) informs practice within dementia care. The principles of person centred care have recently been applied to early and timely diagnosis, and emphasise the necessity of timely diagnosis which:

- Places the rights and wishes of the person with cognitive symptoms as paramount in engaging with the process of assessment and diagnosis;
- Emphasises the importance of assessment and diagnosis as key interventions in adjustment to living with dementia, thus the needs of the person and their family should be central to the whole process; and
- Creates opportunities to challenge the stigma and discrimination associated with dementia (Brooker et al., 2013).

These authors further describe the principles that underpin person centred practice in timely diagnosis, including pre-assessment counselling.

Other theoretical frameworks can also usefully inform practice in this area. Cheston (2013) and Betts and Cheston (2012) have recently discussed the assimilation of problematic voices model of change (Stiles, 1999) and describe its potential value in working with people living with dementia. This framework describes three tasks:

1. Helping the person to acknowledge the experience of dementia without becoming emotionally overwhelmed. The person is described as progressing from warding off, to achieving vague awareness;
2. Identifying dementia as the problem while gaining distance and perspective, which is described as enabling the person to understand the impact that dementia is having upon themselves;
3. Working through and trying out problem solutions, which involves the person's active engagement in the development and assimilation of new strategies and ways of being (Betts & Cheston, 2012).

The assimilation model can be appropriately applied to understand the experience of people who present with cognitive symptoms in the pre-assessment phase. Many of the early experiences identified in the literature, such as attributing difficulties to physical health or normal ageing could be understood in part as attempts to 'ward off' the emerging concerns and the associated emotional trauma this brings. Therefore, a key task in pre-assessment intervention is to begin the process described in stage 1, of helping the person to acknowledge the experience of cognitive change and what this might mean for them, and importantly, assisting them to contain the emotions associated with this experience. It would appear that this process could equally be applied to the experience of family members, who as a consequence of the changes in the person with cognitive symptoms may also be undergoing considerable challenges to their own identity and the relationships between family members.

Finally, given the relationship challenges brought about by the experience of dementia, application of family theories may also inform interventions at this stage. Rolland (1994) describes a family systems illness model, which articulates:

1. The impact of chronic illness upon the normal developmental life cycle of the family;
2. A psychosocial typology of illness including the onset, course, outcome and level of incapacitation experienced;
3. The time phases of the illness, including an articulation of the crisis phase occurring prior to assessment, through to initial adjustment following diagnosis; and finally
4. How family adaptation and resilience can be supported in order that they can manage the impact and experience of chronic illness.

In the pre-assessment phase, the application of this model is helpful in assisting practitioners to understand how the cognitive changes are impacting upon family functioning, and furthermore to identify how the family have responded to challenges such as ill health in the past. This can facilitate an exploration of how and in what way family involvement in the process of assessment and diagnosis can be supported, while retaining the rights of the person with cognitive difficulties to make decisions about whether to go forward for assessment and diagnosis. Furthermore, learning about family experiences and strategies for managing ill health and other transitions can support post-diagnostic interventions.



A number of challenges are known to exist in engaging in pre-assessment counselling, including:

- Honesty and openness, including using the word dementia;
- Expectations, fears and coping strategies;
- Facilitating informed consent;
- The involvement of family members.

Each of these issues are now addressed in detail.

### *Honesty and openness, including using the word 'dementia'*

Dementia is among the most feared diseases associated with getting older (Batsch & Mittelman, 2012). Stigma can influence the meanings associated with dementia and can discourage people from seeking help or pursuing an assessment of cognitive difficulties (Batsch & Mittelman, 2012; Boustani et al., 2006; Bunn et al., 2012; Chrisp et al., 2011, 2013; Moniz-Cook et al., 2006). In addition to this, once diagnosed, people can feel stigmatised by the label of dementia (Robinson et al., 2011).

Despite this, research with people with dementia suggests that they want to know their diagnosis (have it named), or to have a choice about whether or not they receive this information (Harman & Clare, 2006; Manthorpe et al., 2011). It has been suggested that the majority of people with dementia wish to be told their diagnosis (Manthorpe et al., 2011; Robinson et al., 2011), however, people with cognitive symptoms and their families can also experience ambivalence and conflict in this respect. People with symptoms may experience a dilemma between wanting to find out more and a wish to avoid thinking about the future or having 'too much' information (Harman & Clare, 2006). Research has also highlighted that differences can exist between the view of the person and their family about whether they should be told about their diagnosis (Robinson et al., 2011).

The pre-assessment process allows these issues (where appropriate) to be identified, named and discussed and allows people to decide whether or not they wish to progress with an assessment and receive the results of this.

This requires a willingness to be open on the part of professionals. However, research identifies considerable difficulties associated with honesty and openness, and disclosing a diagnosis has been rated by professionals as amongst the most difficult aspects of dementia management (Bamford et al., 2004). This is thought to be challenging because of the incurable and stigmatised nature of the illness, along with the emotional aspects, familial and personal costs (Werner et al., 2013). Professionals report difficulty in discussing the diagnosis openly with persons (Bamford et al., 2004; Kaduszkiewicz et al., 2008).

Furthermore, some studies with health professionals (primarily doctors) have specifically identified how clinicians may be reluctant to use the word 'dementia' during their conversations with persons and their families (Lecouturier et al., 2008b). While some report using terms such as 'dementia' or 'Alzheimer's disease', others prefer to use more vague descriptions such as 'confusion' or 'memory problems' (Bamford et al., 2004; Kaduszkiewicz et al., 2008). It is suggested that these euphemisms may be a way of professionals 'dulling the negative understanding' of a diagnosis of dementia (Karnieli-Miller et al., 2007).

While professionals may report positive views about honesty, they also sometimes report conflicting approaches to this in their clinical practice (Kaduszkiewicz et al., 2008; Werner et al., 2013). Lecouturier et al. (2008b, p.95) highlighted that while professionals identify the importance of explicitly naming dementia and avoiding euphemisms, they also reported *'using terminology carefully as a way of getting information across without telling patients what they don't want to hear'*. Maguire (2002) summarise the dilemma often felt by health professionals of being truthful, but at the same time not causing harm.

However, the implications of avoidance or use of euphemisms is significant for the person with cognitive symptoms. People with dementia have reported vague terms to be upsetting, confusing and difficult to interpret (Bamford et al., 2004). Ultimately, if the word dementia is not used by professionals, people with cognitive symptoms are rendered unable to make an informed decision about whether they wish to pursue an assessment (Kaduszkiewicz et al., 2008). There is also the danger that if professionals avoid using the word dementia, this may exacerbate the stigma surrounding the diagnosis. By using the word dementia at the pre-assessment stage, professionals allow people to discuss their thoughts and fears and make the best decisions for them and their situation at that time.

It should be noted, however, that despite research highlighting the importance of honesty and clarity when discussing dementia, this is not necessarily implemented in practice, and evidence suggests that avoidance or inappropriate practice in this regard has been found to induce additional stress on the person and reduce trust in the professional (Karnieli-Miller et al., 2007; Street et al., 2009).

For example, Phillips et al. (2012) draw attention to the fact that whether or not the word dementia is used by professionals, being referred to a specialist service may itself indicate that a diagnosis of dementia is a possibility. This has implications for services, few of which have the word 'dementia' in their title, with many called Memory Clinics or Services.

In terms of 'introducing the idea of dementia', Cheston (2013) provides a framework which discusses how this might be raised, as described earlier. It is suggested that this should take place at the pace a person can manage; that symptoms are discussed before syndromes; and that taking an indirect approach ('some people worry they may have an illness like dementia, is that something that has ever worried you?') might be helpful in allowing a person to explore this as a possibility for themselves.

Some authors identify the importance of retaining a focus on positives and skills within these discussions, which can often draw attention to limitations, losses and difficulties. The process of assessment can be stressful because it uncovers limitations and cognitive deficits (Derksen et al., 2006b) and it is, therefore, suggested that it may be important to also focus on positive aspects of life within the context of the process (Robinson et al., 2011).

While reinforcing the strengths of the person with dementia appears to be beneficial for the relationship between the person and their family (Vernooij-Dassen et al., 2006) and hope can be important for quality of life, Lecouturier et al. (2008) warn against minimising the seriousness of dementia and avoiding detailed discussions if that is what the person requires.

It therefore appears that balancing honesty and hope, or 'fostering a (realistic) sense of hope' (Lecouturier et al., 2008, p.4) is an important (and difficult) balance within these



interactions (Fisk et al., 2007; Milne, 2010). ‘The move between truth telling and being honest while being sensitive and showing concern to persons’ abilities and needs and fear of doing no harm is a continuing struggle that no simple guideline can resolve’ (Werner et al., 2013, p.82).

This is evidently skilled and emotional work, which presents challenges for the person with cognitive symptoms and their families. Gomes Martins and Palmares Carvalho (2013, p.67) also highlight the potential impact of this on professionals, noting that if staff feel insufficiently trained in communication skills, they are more likely to experience distress ‘when faced with patient’s suffering’.

*Exploring expectations and experiences, fears and previous ways of coping with difficulties*

Significant factors influence a person’s willingness to seek help regarding their cognitive problems and to consent to an assessment (which may result in a diagnosis of a dementia) including their expectations, fears and previous ways of coping with difficult life events. People have different expectations and fears which may influence whether they choose to pursue an assessment, how they experience this and subsequently how they respond to a diagnosis of dementia should this be the outcome. Chrisp et al. (2011) highlight how people may have low expectations about what can be achieved by seeking a diagnosis (that the situation is hopeless and nothing can be done). It is possible that in these circumstances, people may be more likely to decline an assessment, or not seek help in the first place, and experience low mood.

Meanings attached to dementia and beliefs about this are likely to be influenced by a person’s current situation, past experiences and exposure to others with dementia (Bunn et al., 2012; Manthorpe et al., 2011; Moniz-Cook et al., 2006). Societal, familial and personal experience, expectations of normal aging and current health status (Moniz-Cook et al., 2006; Robinson et al., 2011) have all been implicated in influencing expectations and fears about dementia, whether a person wishes to know their diagnosis and how this is processed (Chrisp et al., 2012; Manthorpe et al., 2011; Robinson et al., 2011). The influence of information from the media has also been highlighted as an important factor in this regard, especially when people do not have personal experience of dementia (Manthorpe et al., 2011; Moniz-Cook et al., 2006).

It is necessary, therefore, to know what a person’s expectations about a diagnosis of dementia are before they are given this information (Derksen et al., 2006a, 2006b; Karnieli-Miller et al., 2012; Milne, 2010). Lecouturier et al. (2008b) note that some of the distress caused by a dementia diagnosis relates to a person’s negative attitudes and preconceptions. It has therefore been recommended that ‘Before disclosing a diagnosis of dementia, health professionals should explore the concerns of both the person and their family as to what they think the cause of their cognitive difficulties may be and identify any particular individual concerns around diagnosis’ (Robinson et al., 2011, p.1041). It is also suggested that health professionals need to not only identify concerns and expectations, but also offer a more balanced or realistic view where appropriate (Karnieli-Miller et al., 2012; Lecouturier et al., 2008b).

Exploring a person’s point of view in this way also allows any explanations to be linked to their personal experience, which may enhance their understanding of a diagnosis of dementia should they receive one (Lecouturier et al., 2008b). Pre-assessment counselling,

therefore, provides the opportunity for people to talk about expectations, express their fears and potentially address inaccurate beliefs (Moniz-Cook et al., 2006). These may differ in families (Fisk et al., 2007; Karnieli-Miller et al., 2012). For example, Moniz-Cook et al. (2006) identified fears around losses for both the person receiving an assessment and their carer, with a slightly different emphasis for each. It also allows these conversations to start at the person's understanding so that further discussions are at their pace and are meaningful to them.

In addition, this pre-assessment process allows professionals to use the information and understanding gained at this stage to plan their approach to assessment and sharing of the diagnosis and to start to identify possible needs for the person and their family where appropriate (Derksen, 2006; Lecouturier, 2008). This allows their care throughout this process to be based on actual rather than perceived needs (Wilkinson, 2002), or a 'one-size-fits-all' approach. Pre-assessment counselling further raises the diagnosis of dementia as a possibility and, therefore, allows a process of disclosure (Manthorpe et al., 2011). Involving people in pre-assessment discussions about expectations regarding possible outcomes of assessment can reduce feelings of shock if a diagnosis of dementia is received (Beattie et al., 2004; Derksen et al., 2006; Lecouturier et al., 2008; Manthorpe et al., 2011; Robinson et al., 2011, Vernooij-Dassen et al., 2006) and research indicates that people who receive informal feedback about the possible diagnosis before the formal disclosure were less anxious (Carpenter et al., 2008; Lecouturier et al., 2008, 2008b; Manthorpe et al., 2011).

In addition to this it can be helpful to identify a person's expectations, hopes and fears about the assessment itself and prepare them for the reality of what this might involve. Several difficulties with the assessment and diagnosis process have been identified and prior discussion about expectations and what will happen when, may avoid these problems.

- Manthorpe et al. (2011) note that waiting can be a time of great uncertainty and worry for people, commenting that for participants in their research it was not generally the waiting that caused distress but the 'lack of information about why that was occurring'. People sometimes felt that the pathway was fragmented and feared never getting a conclusion (Manthorpe et al., 2011). This is echoed by Koppell et al. (2007) who found that people often expected that clarification of memory problems would happen at assessment and that how far they felt they had an explanation at this time influenced their satisfaction, along with how much they felt involved in the process. Robinson et al. (2010) found high levels of anxiety regarding what to expect and when and that participants wanted to be informed about what was happening at every stage, highlighting the relationship between uncertainty and anxiety.
- Inaccurate expectations of scans as diagnostic tools may also be present (Manthorpe et al., 2011) and research has also identified that people are often not prepared for the possibility of diagnostic uncertainty. Many people seek assessment because they believe there will be an answer and experience disappointment when this is not provided (Karnieli-Miller et al., 2012; Manthorpe et al., 2011).
- Research also suggests that people may have unrealistic expectations regarding 'solutions' such as medication or other treatments (Bunn et al., 2012; Karnieli-Miller et al., 2012; Manthorpe et al., 2011; Milne, 2010; Moniz-Cook et al., 2006).

Discussions at the pre-assessment stage therefore enable these expectations to be identified and explored. People frequently experience anxiety and frustration when their expectations are not met (Manthorpe et al., 2011) and this process may, therefore, aim to 'reduce or manage the gap between the information to be disclosed and [the person's] beliefs and expectations' (Lecouturier et al., 2008, p.4). This in turn may facilitate engagement, adjustment and coping and reduce anxiety and distress.

In terms of the impact of a diagnosis of dementia, coming to terms with loss on multiple levels (psychologically, socially and functionally) may be the greatest difficulty people with dementia face (Manthorpe et al., 2011; Robinson et al., 2011). It is, therefore, possible that previous experience of loss may influence this experience. In addition to this, family members in caring roles may also increasingly have to cope with greater responsibility while maintaining 'emotional status quo' (Robinson et al., 2011).

Dementia can represent 'a profound existential threat' (Cheston, 2013) and a range of ways of coping with these experiences and feelings has been identified in the literature, including feeling empowered, experiencing difficulty accepting the diagnosis, ambivalence in this respect and active denial (Cheston, 2013; Manthorpe et al., 2011; Robinson et al., 2011). These ways of coping may be conducted individually, in couples or wider systems (Hellstrom et al., 2005).

Taking notice of a person's awareness of their cognitive problems prior to diagnosis (Derksen et al., 2006) might be beneficial in supporting them following this. Working with people at the pre-assessment stage may help to identify how people might cope with a diagnosis of dementia (and build on their natural strategies), and also to highlight those who may experience greater difficulty adjusting. Previous ways of coping may indicate how a person might cope with this news (Cheston, 2013). If it is possible to understand how people naturally cope and adjust we may, therefore, be able to build on these strategies to support them in adjusting to a dementia diagnosis (Clare, 2002). It has also been noted that people sometimes develop ways of coping with dementia prior to diagnosis (Moniz-Cook et al., 2006) and describe how they might cope or 'achieve positive outcome for the 'self' in the face of the threat [of dementia]' (Moniz-Cook et al., 2006, p.387), again supporting the possible benefits of an awareness of these issues at the pre-assessment stage.

Different ways of coping may, of course, be helpful in different circumstances, for different people and at different times (for example, problem solving versus reframing (Ducharme et al., 2009)). Research has identified people, couples and systems that may be more likely to experience greater difficulty in adjusting to, or coping with, a diagnosis of dementia. In particular, those whose worth depends on what they do, rather than who they are (Cheston, 2013; Manthorpe et al., 2011) and those with a family history of conflict (Manthorpe et al., 2011). In addition to this it has been suggested that those with poor previous marital relationships might experience increased fear about the future of the relationship (Manthorpe et al., 2011).

It may, therefore, be beneficial to assess the 'potential for adverse psychological consequences [which] may be avoided or moderated through educational interventions early in the diagnosis process' (Fisk et al., 2007, p.408). Therefore, pre-assessment may offer the opportunity to provide people and families time for support with recognition and change (Moniz-Cook et al., 2006) and facilitate the timely identification of those who need

specialist psychological support as has been recommended (Manthorpe et al., 2011; Milne, 2010; Robinson et al., 2011).

### *Informed Consent*

A fundamental aspect of pre-assessment counselling is providing the person with cognitive symptoms with the opportunity to make an informed decision about going forward with assessment and diagnosis. The Mental Capacity Act (MCA) (2005), Adults with Incapacity (AWI) (Scotland) Act (2000) and Human Rights Legislation (1998), therefore, have particular relevance to the provision of pre-assessment counselling. Human Rights Legislation indicates that the rights of the person must be respected when delivering care and that professionals are morally and legally bound to ensure that the person is able to express their opinion and have choice and control over their lives. Furthermore, both the MCA and the AWI provide a structure for working with people to maximise their involvement in decision making concerning their own lives. These acts are underpinned by the following five key principles:

- A presumption of capacity;
- The right for people to be supported to make their own decisions;
- Retain the right to make what may be seen as unwise or eccentric decisions;
- Best interests; and
- Least restrictive interventions (Mental Capacity Act 2005; Adults with Incapacity, Scotland, 2000).

A person must give their permission before they receive any type of intervention, regardless of what intervention is required. These acts provide a statutory framework for working with people to support their involvement in making specific decisions, and to assess the person's ability to make the particular decision. They also ensure good practice when a decision must be made on a person's behalf due to loss of capacity.

Legislation, therefore, provides a foundation for the professional when delivering pre-assessment counselling, firstly that professionals should begin with an assumption that capacity is present and secondly to ensure that the person with cognitive difficulties is assisted to make an informed choice about whether they wish to pursue an assessment of their cognitive abilities. The process of informed consent should be an ongoing process which begins when the person with cognitive symptoms makes contact with a primary care health professional, as it is at this point that a person may give consent to a referral for assessment.

Seeking valid consent during pre-assessment counselling involves a discussion which ensures that the person understands that any further involvement with the service is with their consent and that they understand the options available to them. To provide valid consent the person must understand what they are consenting to, which requires that good quality, personalised information is provided.

Therefore, the pre-assessment appointment begins with a discussion of their concerns which led them to seek support from their GP. This provides the opportunity to sensitively explore the person's understanding of the word dementia and conditions that can cause dementia. Evidence suggests that people who refuse a clinical diagnostic assessment for dementia after screening do so, in part, because of the stigma associated with mental health (Boustani et al., 2006). Therefore, in addressing informed consent within

pre-assessment counselling, it is important that information giving incorporates explanations about the physical changes that occur in the brain with conditions such as Alzheimer's disease and vascular dementia, which can help to address the stigma and fears associated with dementia including pre-conceived beliefs about losing one's mind.

Information should be provided on what will be offered should a diagnosis of dementia be confirmed. This includes information concerning treatments, interventions, information and support available and discussing the advantages of future planning. It is also important that people understand that at times diagnostic uncertainty is a possibility. The person is also encouraged to consider whether they wish to be informed of their diagnosis and with whom this information can be shared, where they wish to receive the outcome of their assessment and who they want to be present when outcomes of assessment are disclosed. This information should be shared with colleagues involved in assessment and diagnosis to ensure all are aware of the person's wishes.

Facilitating informed consent involves considerable skill, as professionals are involved in emotionally charged communication about an incurable and stigmatised condition that is associated with personal, familial and societal costs (Karnieli-Miller et al., 2007; Werner et al., 2013). Studies in other chronic disease showed that interpersonal ability and the professional skill of the professional involved in 'disclosing the news' had a profound effect on the level of hope and anxiety in adapting to the condition identified. The nature of pre-assessment counselling may hold considerable fear for people and may in itself be misconstrued as 'the beginning of the end'. It may be that more than one appointment will be required, to sensitively explore, for example, concerns about loss of a driving licence or the impact on travel and independence before the person is ready to make a decision. A person may change their decision at any point in this process.

Nevertheless, for some people, the appointment can be a difficult experience (Keady & Gillard, 2002) and for their own reasons the person may choose to not continue with the assessment process. Professionals at this stage may need to explore reasons including for example, an inability to recognise the symptoms others have observed or the potential implications of receiving a diagnosis of a dementia, such as having to inform the DVLA and increased holiday insurance premiums.

As autonomy is easily compromised by cognitive difficulties, a loss of personal freedom can be encountered, particularly when the referred person is facing an increased need to be dependent on others. In these circumstances, there are risks that other people may take over in talking for that person, thus their rights and autonomy can be denied. A skill for professionals involved in the pre-assessment phase is therefore to ensure a person's autonomy is respected and that their decision making ability is supported. It is important that the professional treats consent as an ongoing process and ensures that the person is aware that they can withdraw from the assessment process at any stage. Following pre-assessment counselling, as long as the person has the capacity to consent, their right to refuse to continue with assessment should be respected. Where their decision to refuse is in conflict with those supporting them, opportunities should be given to explore ways of providing information and support to family members/significant others.

Providing information for people with cognitive symptoms where they have refused assessment following pre-assessment counselling will be necessary. It is important to enable



people to realise that they can come back to the service at a later date. Indeed, evidence from service evaluation in one area suggests that those people who initially refused assessment following pre-assessment counselling, do return when the time is right for them to undertake assessment and diagnosis (La Fontaine et al., 2011).

### ***Involvement of Families or Significant Others***

As highlighted previously, family members also experience difficulties associated with the onset of cognitive difficulties (Manthorpe et al., 2011; Robinson et al., 2012). They experience considerable changes in relationships and roles, including the transition to becoming a carer; all of which can negatively impact upon their own health and wellbeing (Gallagher-Thompson et al., 2012; Prince et al., 2011). Close family members may notice changes before or at the same time as the person and may also have difficulty in exploring these for similar reasons to those impacting upon the person's help seeking. Family members may also seek help at a point when the person with cognitive symptoms is not ready in an effort to make sense of the changes, with the resulting risks to personal autonomy (Chrisp et al., 2012). While it is important to support the autonomy of the person with cognitive symptoms, as dementia impacts upon relationships and remaining at home is largely predicated on family care and support (Brooker et al., 2013; La Fontaine & Oyeboode, 2013), including family members in the process of assessment and diagnosis is an important consideration in the provision of pre-assessment counselling.

To engage family members in the pre-diagnostic stage of an assessment requires consent from the person with cognitive difficulties. However, there is frequently a family member present at initial contact with services, indeed family are regularly called upon for collateral history (Tuffrey-Wijn, 2012). This is often invaluable, as the nature of cognitive difficulties may mean that the person themselves is not aware of subtle changes (Chrisp et al., 2011; Koppel & Dallos, 2007). Their involvement in the pre-assessment counselling process also provides family members with the opportunity to discuss their concerns, express their expectations of the service (Williams, 2004) and highlight their agenda, which may or may not be similar to the person with cognitive difficulties. However, family members can find it very difficult to talk about their concerns and what they have observed in front of the person with the symptoms or vice versa. Therefore, it may be necessary to provide space to talk separately.

It is not uncommon for family to encourage an assessment, the reasons for which include wanting clarity and understanding (Lecouturier et al., 2008), access to treatment (Fisk et al., 2007), planning for later life (Lecouturier et al., 2008) and to provide guidance for suitable care provision (Connell et al., 2004). Some family members may not wish to proceed with assessment, often through fear or previous experience (Vernooij-Dassen et al., 2005), denial of difficulties or due to the geographical distance lived from the person with cognitive difficulties (Teel, 2004). Some relatives fear the change of a relationship from being a spouse, a son or a daughter to a 'carer' and the implications this carries regarding shift in decision making and responsibilities (Adams, 2008; Robinson et al., 2011). On occasions family members will encourage a person with cognitive difficulties to decline an assessment when they realise there is no cure and view this negatively as a service's inability to meet their expectations. This has at times been due to a drive by the media which has produced unrealistic expectations (Bunn et al., 2012) and treatments being symptomatic rather than curative (Moniz-Cook et al., 2006).

During the pre-assessment counselling appointment, it is not uncommon to experience a family member who is anxious to 'protect' the referred person and will rationalise the symptoms that led to the referral. Chrisp et al. (2012) suggests this to be 'normalising the problem' and Moniz-Cook (2008) refers to this as 'protective care giving', where the spouse is protecting the self image of their partner developing a dementia. Subsequently at a post diagnostic stage Bunn et al. (2012) observed carers continuing to balance protection and independence. Where such reactions are occurring, it is helpful to consider strategies which may assist both parties to acknowledge the difficulties occurring, and on occasions, it may be helpful to carry out an initial assessment such as the ACE III in order that the person and their family member supporter are able to move towards acknowledgement of the cognitive changes (Chrisp et al., 2012), as well as highlighting the strengths of the person in order that meaningful discussions can take place about a way forward.

It is necessary to acknowledge that all present will have a personal agenda and varied levels of knowledge (Williams, 2004), which may also include children. Managing expectations, frustrations and emotional distress of the family members (Bamford et al., 2004) can be a challenging service to deliver. This is best met with open dialogue, partnership approaches and continual assessment of the dialogue between the person, their family members and the professional.

## Conclusion

Adjustment to a diagnosis of dementia (for the person and their family) is a process which is likely to be influenced by many factors including societal and cultural perspectives, individual expectations, previous experiences and fears and a person's current situation, including whether they present early or later in the disease process. (Manthorpe et al., 2011). A person's experience of adjustment is likely to change over time and will influence their needs and facilitating transitions (particularly role transitions) has been indicated as being potentially one of the key roles played by nurses and other professionals (Ducharme et al., 2009).

This adjustment process begins before people come into contact with specialist services. People, couples and families have been through a process of becoming aware of difficulties, discussing these and seeking help, before being referred for assessment (Bunn et al., 2012; Chrisp et al., 2011, 2012; Moniz-Cook et al., 2006). There may be two-and-a-half years from noticing changes to seeking help, a period of time which may involve psychological, practical and relational processes (Chrisp et al., 2011; Derksen et al., 2006) and may influence what each person needs from services.

It is important to note that the person and their family may have different needs, which could be in conflict with each other and consequently difficult to manage. This may require support from two or more professionals over more than a single encounter (Karnieli-Miller et al., 2012). For example, it may not be the person with the possible dementia who has sought a referral (Chrisp et al., 2012) and it may, therefore, be that they and their family members have different perspectives, hopes and expectations and, therefore, needs (Bunn et al., 2012; Chrisp et al., 2012; Derksen et al., 2006b; Ducharme et al., 2009; Gibson & Anderson, 2011; Lecouturier et al., 2008; Manthorpe et al., 2011). These may also be influenced by wider cultural factors (Bunn et al., 2012; Fisk et al., 2007; Koppell et al., 2008; Manthorpe et al., 2011; Robinson et al., 2011; Werner et al., 2013).



Some people will seek information and others will reject this (Bunn et al., 2012), preferring little or no information (Milne, 2010), and giving information at the wrong time may be unhelpful. For example, Boustani et al. (2006) reported that 48 per cent of those screened refused further assessment for dementia. Not all of these people had presented with concerns about their cognitive function, suggesting that this may not have been a concern to them at this stage, or they were not ready to engage in this process.

More generally research has highlighted the need for personally tailored, timely information as critical and noted that needs are likely to evolve over time (Bunn et al., 2012; Ducharme, 2009; Koppell et al., 2008; Lecouturier et al., 2008, 2008b; Manthorpe et al., 2011; Moniz-Cook et al., 2006; Robinson et al., 2011; Werner et al., 2013).

The process of adjustment is supported by delivering pre-assessment counselling, which allows for the opportunity to:

- Explore the perspectives and views of the person with cognitive difficulties and their family prior to disclosure in order to determine how best to communicate the diagnosis (Connell et al., 2004; Karnieli-Miller et al., 2007; Robinson et al., 2011);
- Enable people with cognitive symptoms to retain autonomy and be in control of the process, including the pace of information, assessment and disclosure of the diagnosis should this be relevant (Manthorpe et al., 2011, Werner et al., 2013);
- Enable the process to be personally tailored to the person and their family members' needs, including, for example, written information (Carpenter et al., 2008; Derksen et al., 2006b; Gibson & Anderson, 2011; Lecouturier et al., 2008b; Milne, 2010; Robinson et al., 2011; Werner et al., 2013);
- Avoid the negative outcomes associated with unmet need at diagnosis (such as feeling that information and support were inadequate) (Bamford et al., 2004; Werner et al., 2013); and
- Provide specifically tailored information to meet needs (Robinson et al., 2010).

Successful diagnosis giving and post-diagnostic support may be facilitated by good quality pre-assessment counselling, which highlights the person's needs and engages people in this process (Fisk et al., 2007), which it appears must be integrated in order that services can respond flexibly to needs from referral to discharge (Jha et al., 2013; Werner et al., 2013).

It is evident that in order to sensitively deliver pre-assessment counselling, the skills of the professionals will need to be addressed. The skills, attitudes and knowledge required of professionals working in this way are considerable, and evidence suggests that professionals working in primary and secondary mental health care do not necessarily feel prepared to deliver such interventions or to manage the emotional impact of such work (Buckell, 2007; Burgers et al., 2012; Kaduskiewicz et al., 2008; Karnieli Miller et al., 2007; Lecouturier et al., 2008; Werner et al., 2013). Supervision and appropriate exploration of personal beliefs concerning dementia are likely to be a necessary part of enabling professionals to work in this way.

Person-centred approaches to enhance control and dignity (Zaleta & Carpenter, 2010) and the benefits of a person- and family-centred approach in disclosing 'grave medical conditions' has long been advocated along with the importance of communication skills and ability to respond to potential differences in needs among family members (Karnieli-Miller et al., 2012). Werner et al. (2013) identifies the positive effects of communication

skills training for staff members (increasing their willingness and desire to discuss diagnosis and prognosis) and the potential need for training around communicating in triads (the person, carer and professional), which may enhance the ability of clinicians to take account of cognitive impairment in communication, build emotional rapport (Zaleta & Carpenter, 2010) and respond flexibly to need.

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## Appendix 1: Service user quotes around pre-diagnostic counselling and informed consent (from FPOP and DEEP service user consultation, 2014).

### 1.1 First contact with clinicians

*'You go to the GP when you're ill or injured... you only bring up your memory as an afterthought.'*

Several points highlighted in discussions concern how people were first referred to memory or diagnostic services, in most cases being referred by a GP:

- Many felt that GPs needed training in dementia, as some seemed to lack knowledge on the subject. *'We need specialist GPs in dementia... And all staff need training really, including receptionists!'*
- Some felt that many clinicians were behind an impenetrable wall of professionalism. Empathy was highlighted as an important factor in positive experiences with health care professionals. *'It's important that professionals are good at just being human... it makes a difference being a human being.'*
- Certain GPs were praised for their knowledge and understanding. *'My GP was fantastic. He said he knew exactly what was wrong with me and would pass me onto people who could help me even more.'*
- It helps to stay with the same clinician throughout the process, rather than being transferred repeatedly. *'I didn't always have the same GP every time I visited, so I didn't really have any time to build up a relationship with anyone.'*

*'I think everybody's different. I think there needs to be an understanding by the GPs that people are different.'*

### 1.2 Pre-diagnostic information and consent

*'We had no information given to us before testing. We just went and they asked us questions. They didn't mention dementia.'*

Informed consent was highlighted as ethically imperative as it allows people to assess whether or not they wish to continue, and whether or not they would wish to know that they have a dementia. The following points are important in allowing informed consent:

- Provide time and space to absorb pre-diagnostic information. It is important not only that information is provided, but also that it is made easy to absorb and that time is given to do so. *'Because of the dementia, there was trouble absorbing verbal information. You need written information to take away.'*
- Give information about types of dementia other than dementia in Alzheimer's disease, including the possibility that memory may not initially be the most pressing issue. *'...all professionals seem to just emphasise memory! I was doing my own research. In the end I was informing my GP about dementia!'*
- Consent must be given at every diagnostic and pre-diagnostic appointment. *'[The psychologist] was constantly giving me a 'get out of jail free card'. I think that's very important.'*

- Ensure that the diagnostic process is collaborative and clients know what the purpose of each test is, and what the final diagnosis might be. *[Carer] 'We went through the GP who referred us. He [husband] was sent for a brain scan. I never saw this and the consultant never explained the scan or the process, but just diagnosed Alzheimer's.'*
- Highlight the possibility of diagnostic uncertainty. *'The consultant warned me. That helped me because when the scans came back not showing anything wrong, I was prepared for the possibility it was still dementia.'*

***'The sooner you use the word [dementia], the better. If a medical person avoids using the word, it puts it way up there.'***

# Cognitive assessment of people who may be developing dementia

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## Key messages

- Cognitive assessment of people at risk of dementia should be a supportive and informative experience.
- A range of cognitive assessment tools are available, all with strengths and limitations.
- Training, experience, and supervision are needed at all levels of practice.
- Clinical Psychologists and Neuropsychologists have the highest levels of expertise in conducting comprehensive cognitive assessments.
- Good services have effective systems to ensure that people have the best level of assessment to meet their needs.
- Good services recognise the potential for harm through inaccurate cognitive assessment and act to minimise this.

## Introduction

*'When you have a test you automatically think, 'Well I want to pass this test!'... You're constantly thinking, 'Am I passing this test or am I failing?'... I thought about what they asked me last time... so I revised and practised!'*

*'I fought it to the end because I didn't believe it. No one pressured me into doing the tests though, and I came to terms with it.'*

Cognitive assessment should be a supportive and informative experience for the person being assessed. As well as a route to a diagnosis, it should be able to answer questions that people may have about their cognitive abilities and provide them with an account of their strengths and potential (Borson, S. et al., 2006; Galton et al., 2005; Samsi et al., 2014; The National Collaborating Centre for Mental Health, 2007; National Institute for Health Research, 2011; Woodford & George, 2007).

This will give them the best chance of making the most of their abilities, irrespective of the type or stage of dementia they may be facing (Bahar-Fuchs et al., 2013; Clare, 1999, 2008; Clare & Woods, 2004; Clare et al., 2010, 2013). Whilst this paper is focused on assessment, the timely, accurate and sensitive feedback of findings from cognitive assessment is an intervention in itself. It has the potential to help people and their families adjust to changes, as well as direct them to the best post-diagnostic and/or rehabilitation strategies to enable them to live well with whatever cognitive difficulties they may face.

## Types of cognitive assessment

There is a hierarchy of assessments from short simple tests which can quickly identify marked cognitive impairment to long complex neuropsychological assessments which give the most comprehensive indication of a person's cognitive abilities [2, 4]. Every test needs specific training to administer and interpret.

All cognitive tests have strengths and limitations. Tests need to be selected to be good measures of the cognitive abilities affected by dementia; they should be given consistently and carefully, and scored and interpreted correctly. Poor quality assessments are costly for the person being assessed, services, and society.

All cognitive assessments should be carried out alongside other investigations such as medical screening and brain imaging in order to create an accurate formulation of a person's strengths and difficulties and, where applicable, a diagnosis. Detailed cognitive assessments describe a person's abilities, and contribute significantly to a holistic, accurate, and informative assessment process and outcome.

## Good quality basic cognitive assessment

Brief tests are often in the public domain and may be administered by staff from different disciplines following training (Alzheimer's Society, 2014; Ashford, 2008; Brodaty et al., 2002; Brooke & Bullock, 1999). Tests such as the Six Item Cognitive Impairment Test (6-CIT) can typically be carried out by health care professionals such as Practice Nurses or General Practitioners with small amounts of training.

Other tests such as the Montreal Cognitive Assessment (MoCA) or Addenbrooke's Cognitive Examination (ACE-III) are usually carried out as part of a more comprehensive assessment by specialist services<sup>1</sup>. They require higher levels of training and regular supervision and monitoring of standards.

Tests at this level are essential initial assessments, but have limited ability to distinguish between dementia and other causes of poor cognitive performance, or between different forms of dementia, particularly unusual initial presentations. Cognitive decline can be overestimated in people who have sensory impairments, a limited education, a learning disability, poor physical or mental health, or past or current substance misuse, or in those from a different culture or with a different language. Conversely, in a person of very high lifelong intellectual ability, change may be underestimated. Accurate classification can be particularly difficult in the early stages of dementia when pressure for a quick diagnosis can lead to error (Cullen et al., 2007; Stoppe et al., 2007; Varma et al., 1999; Wood et al., 2006). These cases should be referred to specialist services for an in-depth individual cognitive assessment by a Clinical Psychologist or equivalent specialist.

Avoidable errors in the use of these tasks can be reduced by regular training, supervision and audit from experienced Clinical Psychologists. Training should include the technical aspects of test administration, including scoring and interpretation, how to set up the test

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<sup>1</sup> Until recently, the Mini Mental State Examination (MMSE) was commonly used, falling somewhere between the most basic tests and more advanced individual tests such as the ACE-III in terms of length and domains covered. It has significant limitations with its psychometric properties and since it became subject to copyright it is less commonly used.

environment appropriately, how to introduce the test to the individual, and issues relating to informed consent, and the sensitive use of test results.

All users of cognitive tests should demonstrate competence in their use before assessing people for the first time. It is important that competence in administration is maintained, and as such, refresher training may be indicated on an annual basis.

In order to maintain best practice, it is desirable to have a specialised Clinical Psychologist or Neuropsychologist embedded within the Memory Assessment Team.

## **In-depth assessment**

When basic cognitive assessments are inconclusive, people will need an advanced, hypothesis-driven neuropsychological assessment (Cox, 2011; Dimcovic, 2003; Diniz et al., 2008; Lonie et al., 2010; Morris et al., 2000; Seo et al., 2010). Such in-depth assessments will use reliable estimates of life long levels of intellectual ability, and a range of up to date assessments of memory, attention, executive function, perception, and language in order to clarify clinical uncertainty. Advanced assessments integrate quantitative and qualitative cognitive information with history, background, and knowledge of physical and mental health to improve validity. Assessments may need to be repeated after a number of months dependent upon rate of change, but usually six months or more, to determine whether cognition is changing and to clarify any remaining uncertainties. The specific cognitive tools used need to be suitable for the characteristics of the population being assessed, and of demonstrable reliability and validity.

## **Choosing the correct assessment level**

Services must ensure that people do not undergo lengthy assessments unnecessarily. Protracted assessments with no justification are neither desirable for people using services or for services themselves. It is unlikely that an individual would start the assessment process with the highest (i.e. most advanced) level of assessment. More likely, people would progress from a more basic test to a more in-depth assessment once a need has been identified. Should specific needs be identified early on, it would be appropriate to instigate a full, hypothesis driven neuropsychological assessment.

Some services have attempted to operationalise guidelines indicating the level of assessment an individual may need, for example, by stating that people of very high or low premorbid levels of ability or those with complexities related to their mental health may need full neuropsychological assessment. However, whilst clinically helpful, there is no evidence base to support these decision making processes. A likely result may be more or less obvious at an early stage: ultimately, the level of assessment required should be dictated by sound clinical judgement informed by consideration of initial interview and test data.

The characteristics of various level of assessment are indicated in Table 1 below.

**Table 1.**

Name of Test	Potential Benefits	Potential Limitations
Test Your Memory	Good scores can rule out cognitive problems for most people.	Poor scores do not rule in cognitive problems.
Montreal Cognitive Assessment	Can distinguish between normality and dementia reasonably well in most people.	Cannot distinguish between normality and mild cognitive impairment or mild cognitive impairment and dementia.
Addenbrooke's Cognitive Examination	Can distinguish between normality, mild cognitive impairment, and dementia.	Can not reliably distinguish between these categories in the presence of poor health or mood disorders.
Neuropsychological Assessment	Can distinguish between categories in the presence of poor health and mood disorders, etc.	Takes time, training and specific expertise to administer and interpret.

## High quality services

High quality services providing cognitive assessment have the following characteristics.

- Good services will ensure that basic cognitive assessments are carried out accurately, reliably and validly through effective monitoring by experienced and qualified cognitive assessors.
- Good services will contain staff capable of conducting advanced cognitive assessments, and clear methods for accessing those assessments appropriately.
- All staff carrying out cognitive assessments will be aware of the uses and limitations of the tests they use, their own competence regarding which tests to use and when, and when to seek advice and support from experienced colleagues with specific qualifications in advanced neuropsychological assessment.
- Good quality services will ensure that assessments undertaken are person-centred and individualised to ensure that the appropriate level of assessment is carried out for each individual.
- Good quality services will ensure assessments are chosen and adapted where necessary to ensure that they are not unduly aversive for people, and provide the least experience of failure.
- Good services will be able to monitor the quality of cognitive assessments and make sure that poor quality practice does not result from pressures to increase the number of assessments carried out.
- Good services recognise the potential for error in assessing cognitive abilities and actively seek out and correct errors.



Some services use stepped care models, in which the response systematically varies depending upon the level of cognitive impairment suspected. Such approaches need to take account of the differing base rates of dementia in different parts of the health care system, and how these interact with the results of cognitive assessment. Routine screening for dementia is not recommended, but changes in personality, behaviour, or ability to manage everyday activities, particularly in older people who are at risk of dementia, and particularly in the absence of low mood or poor health, can suggest a developing dementia.

Whilst some individuals with mild cognitive complaints can be appropriately reassured without the need for specialist assessment, it is important to recognise that in a small number of cases, assessment of relatively mild complaints may prove very challenging and require the highest level of assessment. There should be clear guidelines to help identify when more comprehensive assessments will add most value to the care of an individual. These guides should not become barriers to accessing services through overly rigid application.

## **Qualifications and training**

Differing types of assessment require varying levels of expertise as shown in Table 2 overleaf.

## **Conclusions and recommendations**

*‘Assessment should be collaborative. They should tell us what tests they’re doing and why they are doing these tests.’*

Assessing cognition is a key part of the experience of people receiving a diagnosis of dementia. Services should be mindful of the potential for benefit and harm when assessing cognition and should strive to maximise the positive outcomes for the people being assessed by the judicious selection of assessment tools, and their careful application by properly trained and supervised workers.

**Table 2.**

Level	Who can administer?	Level of training required	Training delivered by	Examples of tests
<b>Brief test</b>	GPs, Practice Nurses and equivalent professionally trained staff.	Instruction in the basics of test administration and scoring (1–2 hours).	Professionally qualified staff, currently working in Memory Assessment services, experienced in assessing cognition.	6-CIT
<b>Basic cognitive measure</b>	Professionally qualified staff experienced in assessing cognition, e.g. Mental Health Nurses, Occupational Therapists.	Specific training in all aspects of setting up, administering & scoring a cognitive assessment (half to full day). Ongoing supervision and annual refresher training. Ability to carry out assessments with sufficient regularity to ensure competence is developed & maintained.	Clinical Psychologist/ Neuropsychologist.	ACE-III, MoCA
<b>Hypothesis driven neuro-psychological assessment</b>	Clinical Psychologist/ Neuropsychologist experienced in Memory Assessment work. Testing can also be carried out by Assistant Psychologists working under the direct supervision of the above.	Clinical Psychology training. May also have additional training in neuropsychology (post-graduate diploma or Masters degree and/or professional Qualification in Clinical Neuropsychology).	Recognised University courses in Clinical Psychology (doctorate) and Clinical Neuropsychology (postgraduate diploma or MSc).	Variety of tests including those assessing general ability, attention, memory and executive functioning as required (e.g. Wechsler tests of intellectual ability and memory).

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# Communicating a diagnosis of dementia

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Developing evidence from research, and surveys of people with dementia and their families, show that sharing a dementia diagnosis can be immensely useful, when this is done well, but that significant numbers of people are reporting problems with how this is currently undertaken. This has been underlined by findings from the Alzheimer's Society, the Dementia Engagement and Empowerment Project, and the Dementia Service User consultation undertaken by FPOP alongside the development of these papers. A subsequent BPS/FPOP paper, 'Communicating a diagnosis of dementia' is in preparation and will appear in early 2015.

This paper will address:

- the complex nature of the ethical issues arising from dementia diagnosis and disclosure; the 'right to know' and the 'right to not know';
- the problem of uncertainty in dementia diagnosis;
- potential benefits and disadvantages of sharing the diagnosis;
- psychosocial models integrating the meaning of diagnosis for the individual and family, their wishes and capacity to know and understand the diagnosis, and their wider social context; these models can help professionals understand and work with the emotional responses arising throughout the process of assessment and diagnosis sharing;
- the importance of separating issues around neurological impairments from quality of life and placing an emphasis on hope in the face of a difficult diagnosis;
- the need to manage positive and negative expectations about treatment options;
- where appropriate the use of progressive disclosure to allow the person (and caregivers) time to prepare and adjust;
- practical considerations about dementia disclosure, including skills, training and supervision needed for memory clinic staff;
- the contribution psychologists can make to support this work.



# Post-diagnostic support for people living with dementia

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*‘When they told me [the dementia diagnosis] it felt hopeless. [The advice] just seemed to be about getting your affairs in order... I could hardly talk afterwards! I locked myself away for a while, I was withdrawn...’*

*‘... they shouldn’t be focused on what pills to give us; they should be focused on feelings! They should ask, ‘Are you coping?’’*

## Key messages

1. Currently, the policy across NHS Services is to make diagnoses of dementia earlier, and for more people, to maximise opportunities for adjustment and to deliver savings to the health and social care economy.
2. This policy focus has not been matched by attention to the need for adequate post-diagnostic support. Available support services are variable in content and frequently limited to a small percentage of the people accessing services.
3. In the absence of more effective preventative or curative treatments, concerns about the limitations of post diagnostic support will impact on referrals from general practitioners, and on participants’ engagement with services.
4. There are particular implications for people with dementia for whom pharmacological intervention is not an option. In the absence of psychosocial support, diagnosis may be experienced particularly negatively.
5. Adjustment to diagnosis is complex and an important stage in offering help to live well with the condition. While many people are able to adjust, the impact of the diagnosis is often profound and underestimated, but with good clinical practice, a diagnosis of dementia should not be experienced as coming ‘out of the blue’.
6. Adjustment to dementia diagnosis is an emerging area of research. However, the available evidence has also contributed to the international consensus, that timely dementia diagnosis is beneficial.

7. Psychosocial interventions promote psychological well-being by minimising and alleviating psychological distress and facilitating adjustment. Interventions can also enable people with dementia and families to improve self-management. Currently, the evidence base indicates the effectiveness of, and demand for, a range of interventions which address:
  - Adjustment to diagnosis and therapies for the person with dementia;
  - Rehabilitation work;
  - Help for families to adjust.
8. In order to balance the need for individualised interventions with the finite resources available, services should develop pathways to enable individuals and families to be directed to appropriate options and to choose between them.
9. It is essential that this Psychosocial Intervention Gap is addressed. Services should identify and deliver practical ways of ensuring that people who are living with dementia and their families receive adequate psychosocial support.

## Aims

The aim of this document is to provide an overview of the range of psychosocial interventions available and good clinical practice in supporting people with dementia, their families and carers, commencing as soon as possible after diagnosis.

The focus is on the needs of people who are still at home, and in a relatively early stage of dementia. This excludes the specific needs of people with late diagnoses, and as such, this document does not address needs relating to significant levels of challenging behavior, which have been addressed by the Faculty's Dementia Workstream in an earlier document (Brechin et al., 2013). However, because the paper focuses on facilitating adjustment to the diagnosis of dementia, it is likely that such interventions will prevent or reduce the possible development of challenging behaviour in the future.

## Introduction

Nationally a broad range of consumer groups, voluntary and statutory organisations and a cross-party consensus all support a drive towards 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 potential savings to the health and social care economy arising from early diagnosis (Banerjee & Wittenberg, 2009).

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 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. This is despite the fact that adjustment to diagnosis is a process – as recognised by the Payment by Results Cluster 18 pathway (Department of Health Payment by Results team, 2013) – that may take up to two years.

*'My GP misdiagnosed me. They took me off my medication... There was no support. My only support was from Alzheimer's Scotland. There was no counselling or anything.'*

*'Once I'd accepted it, life became much easier. I didn't have to be super-efficient any longer.'*

The original research projects which inspired the movement towards early diagnosis included a broad range of post-diagnostic support for people with dementia and their carers, together with the prescription of medication for people with Alzheimer's disease. Banerjee and Wittenberg (2009) analysed this information and, in addition to the more immediate clinical benefits of early diagnosis, identified significant scope for economic savings to the wider health and social care system, as a result of delayed admission to institutional care. The failure to offer the comprehensive packages of care offered in the original research and service trials may limit the calculated economic benefits. This not only represents a missed opportunity to provide support for people living with dementia and their families, but also has potential economic costs. Thus the Commissioning Guidance neither incorporates 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 is 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 the perceived benefits of pharmacological treatment. However, with only limited time available and a restricted range of support options, there is little scope for such services to be tailored to the needs of individuals and their families. This situation has led to recent concerns being raised (Illiffe & Manthorpe, 2010; Manthorpe et al., 2011) that diagnosis without adequate support may not be beneficial, and in some respects be detrimental.

*'It felt hopeless. It just seemed about getting your affairs in order. Then, after some time, I was offered peer support. That worked for me. It changed my life.'*

## **Good quality psychosocial support**

This term reflects a broad range of individual and group approaches with diverse therapeutic style and focus, and covers different aspects of memory service provision. Interventions 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:

- sharing the diagnosis with the family in a sensitive and thoughtful manner;
- providing opportunities for rehabilitation and adjustment, possibly through the provision of psychotherapy or peer support groups;
- working with the person who is living with dementia, and his/her carer.

Initially, after being given a diagnosis, many people with dementia often describe moving from frustration and embarrassment, through feelings of shock and grief, and then to 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. 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. 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 & Bouman, 2003; Jha, Tabet & Orrell, 2001), although a minority are clear that they don't want to know. A fundamental part of this wish to know is that gaining this understanding helps enable people to prepare for the future. For some people, the process of receiving a diagnosis, although difficult, can lead to significant changes in their lives. Thus, James McKillop, quoted in Mountain (2006), 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.'*

The importance of skilled communication between people with dementia, carers and professionals is a unifying theme throughout the process of receiving a dementia diagnosis and the series of transitions that follow. Talking to people effectively about what is happening from assessment, through diagnosis and into the future is crucial. However, effective communication about such sensitive issues is often difficult.

At present the limited range of post-diagnostic support that is available is fragmented and provided by multiple organisations. There is no national standard or mapping of this. The National Service Framework for Dementia (2001) recognised the need for an individual who knows the family and their circumstances to provide continuity of support and to assist people in making choices about the appropriate services for their needs at the right time.

*'After diagnosis I was put in touch with a dementia advisor. I don't remember who referred me, or what happened before, but I remember her.'*

There is an evolving literature describing effective psychosocial interventions for the early stages of dementia. Moniz-Cook and Manthorpe (2009) provide a comprehensive overview 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. The FPOP *A Guide to Psychosocial Interventions in Early Stages of Dementia* (2014), produced in conjunction with this document, provides descriptions of what these involve and summarises the current evidence supporting each one. Table 1 summarises the main types of intervention and key references.

Although Table 1 indicates that there are many potential examples of good practice, there is evidence that this support is not consistently available across the country. Every family and every person with dementia is unique in their experience, preferences and needs, and therefore a menu of intervention choices can help to empower people to engage with their treatment process.

**Table 1: Examples of good practice.**

Type of intervention	Summary of good practice	Selected references
Guidelines for sharing the diagnosis.	Good practice for sharing the diagnosis, includes preparing for this throughout the assessment, considering family involvement, exploring the patient's perspective and responding to their reactions.	Lecouturier et al., 2008.
Mild Cognitive Impairment (MCI) interventions.	Although people affected by MCI do not have a diagnosis, they live with cognitive disabilities, and can benefit from monitoring and help with adjustment to these difficulties.	Tuokko & Hultsch, 2006; Cantegreil-Kallen et al., 2009.
Therapeutic interventions, to help the person with dementia adjust to their diagnosis and forthcoming life changes, including use of peer support groups.	Therapeutic groups combine practical information with an opportunity to share experiences of dementia in a safe, emotionally-containing environment.	Logsdon et al., 2010; Marshall et al, 2014; Sorensen, Waldorff & Waldemar, 2008; Sadek et al., 2011.
Education about the symptoms of dementia and coping strategies.		Moniz-Cook et al, 2006, 2008.
Specific psychological therapies for distress, depression and anxiety in the person with dementia (e.g. Cognitive Behaviour Therapy (CBT) in the early stages of dementia).	A range of psychological and counselling therapies can be used to work individually with the person with dementia. For example, CBT addresses the interaction between thoughts feelings and behaviour, based on the needs of the individual.	Spector et al., 2014; Lipinska, 2009; Miller & Reynolds, 2006.
Life Story and Reminiscence.	Using personal history and long term memories in a range of approaches and activities, designed to increase social engagement and well-being.	Young, Howard & Keetch, 2013. Cochrane Collaboration Review: Woods et al., 2009. <a href="http://www.lifestorynetwork.org.uk">www.lifestorynetwork.org.uk</a>
Dementia cafés.	Open events for people with dementia and their families to meet in informal settings, to exchange information and social support.	Jones, 2010.
Group and individual adjustment work with carers.	May use a variety of psychological techniques, including CBT and cognitive reframing. For example, in dementia care, cognitive reframing interventions focus on family carers' possible maladaptive, self-defeating or distressing thoughts about their relatives' behaviours and their own caring role.	Cochrane Collaboration Review: Vernooij Dassen et al., 2011; Charlesworth et al., 2009; Selwood et al., 2007.
Coping strategies and stress management for carers.	These interventions involve working with carers to identify individual difficulties and implement strategies to overcome these.	Cooper et al., 2012; Sommerlad et al., 2014.
Cognitive Stimulation Therapy (CST), individual CST (iCST), Maintenance CST.	CST is an intervention for people with dementia which offers a range of enjoyable activities providing general stimulation for thinking, concentration and memory usually in a social setting, such as a small group. Individual approaches are also being developed.	Cochrane Collaboration Review: Woods et al., 2012; Orrell et al., 2012, 2014.
Cognitive rehabilitation in early dementia.	Cognitive training and cognitive rehabilitation are specific approaches designed to address difficulties with memory and other aspects of cognitive functioning.	Clare et al., 2010, 2013; Bahar-Fuchs, Clare & Woods, 2013; Clare, 2008.
Interventions to support maintenance of activities of daily living/lifestyle e.g. Occupational Therapy.	Aim to improve patients' ability to perform activities of daily living, promote independence and participation in social activities. Also reduce the burden on the care giver by increasing their sense of competence and ability to handle problems.	Graff et al., 2006, 2008.



*‘Everyone’s diagnosis is different, there’s got to be something that suits everyone.’*

*‘There is a lot going on that I just don’t know about... Why isn’t something being done to bring it all together and raise people’s awareness of what is out there?’*

Perhaps the most basic form of advice involves telling people about their diagnosis. While the manner and sensitivity with which their diagnosis is shared is important, unfortunately people with dementia and their family carers give a mixed picture about how well this is done (Lecouturier et al., 2008). Often health professionals either ignore or underestimate the emotional impact of the diagnosis. Connell et al. (2004) carried out focus groups with both care givers and doctors. The caregivers 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 the quality and amount of information with which they are subsequently provided. The National Audit Office Report of 2007 found that roughly half of the community services they surveyed had no policies regarding discussion 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 being a low priority for support, and yet many may remain for some years in a state of uncertainty as to whether their condition will convert to dementia. At the same time they are still living with the consequences of changed memory and thinking abilities. Between 10 and 15 per cent of people with MCI will progress to a diagnosis of dementia within a twelve month period (Ward et al., 2012). The National Service Framework (2001) recommended monitoring people with MCI. This would help these people adjust to their cognitive changes and to cope with the uncertainty over diagnosis.

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 have a particular impact on younger people, including those with a diagnosis of fronto-temporal dementia, or people with a learning disability. Similarly, the limited services for people from Black and Ethnic minorities may be less likely to meet their needs.

When adequate support is provided, this not only improves quality of life, but also enables people to make choices about their lives, reduces stress for their families, and means that people are less likely to require long term residential or hospital care (Brodaty et al., 2003; Spijker et al., 2008).

### **Matched Care Model for post-diagnostic support**

In meeting the needs and preferences of people with dementia and their families there has to be a balance of evidence-based clinical good practice and cost-effectiveness. It is not only a question of what is offered by Memory Services but also the pacing and timing of what is offered. Services need 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.

In order to meet the dilemma of how best to meet individual need within limited resources, Moniz-Cook and Manthorpe (2009) suggested a model of intervention spread across four tiers. More recent work in this area has proposed the development of pattern recognition to help match individual need and intervention. Within this matched care model, people would benefit from individualised (and/or family-centred) psychosocial profiling, leading to patterns of care interventions or ‘prescriptions’. Moniz-Cook describes up to eight groups of prescriptions to address psychological and social needs in the person and the family carer. These could be delivered within a planned pathway (Rewston & Moniz-Cook, 2013: personal communication).

## **Essential standards for supporting 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 MSNAP Psychosocial Interventions Module provides a first attempt at a set of quality standards to address the current gap in commissioning guidance (MSNAP, 2012). These 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.

Consideration should be given to the provision of access to dedicated care workers to support the psychosocial interventions pathway. Such workers would enable people affected by dementia and their families to understand and make choices between the post-diagnostic support options available to them. Dedicated dementia care workers will need to know the person with dementia well, and to understand the family, its circumstances and the progress made with adjustment for this to work effectively. They will also need to develop the practical and emotional support skills to encourage people to choose and take up these interventions.

The end result of post-diagnostic adjustment should be to help people reach a point at which they feel that having a diagnosis has been helpful. That is to say, if the process works effectively, they should be able to see a way forward in their lives once again, towards living well with dementia.

## Recommendations

FPOP recommends that all services which are involved with the person with dementia and their family should:

1. Provide equal access to post-diagnostic psychosocial support for all, regardless of age, ethnicity or diagnosis.
2. Provide a detailed assessment process which enables the clinician and the person involved to understand preferences around receiving a diagnosis and their needs for subsequent information and support afterwards.
3. Provide access to a dedicated care worker who will enable people affected by dementia and their families to understand and make choices between the post-diagnostic support options available to them.
4. Commission and provide psychosocial interventions, including individual and group therapeutic approaches which are informed by evidence-based practice and will support people throughout the process of adjustment.
  - Base rehabilitation work around psychological principles and understanding of cognitive processes: Research consistently indicates both that people affected by dementia can learn to use more effective ways of remembering information and that use of these strategies reduces distress and improves quality of life.
  - Provide help for families to adjust through interventions which combine education, problem-solving and enhance the coping skills of family carers to aid adjustment and reduce the likelihood that the care they provide will break down.
  - Provide a choice of interventions: Models of post-diagnostic support need to move away from ‘one model fits all’ approaches as research suggests that people with dementia and families need to be provided with an opportunity to choose from a menu of options.
  - Ensure that psychosocial support is timely and provided at a pace that is acceptable for the person living with dementia.
5. Provide staff with training, supervision and support to develop the skilled communication which is essential throughout the post-diagnostic process to support negotiations about changing needs and possible interventions over time.

## The psychologist’s contribution

A complex interaction of cognitive changes, psychological distress, and social and family circumstances determines how each individual who is affected by dementia responds to the illness. Clinical psychologists’ general and neuropsychological expertise and skills place them in a unique position to support people following a diagnosis of dementia, through:

- sensitive assessment of the person’s emotional reaction to the diagnosis;
- neuropsychological assessment that identifies areas of preserved ability;
- formulation of specific individualised communication and treatment plans;
- direct provision of therapy;
- development of communication skills within teams;

- training and supervision of family care workers and other staff;
- training for, and ongoing supervision of, the delivery of specific psychosocial interventions;
- further development of interventions;
- identification of gaps in the evidence base, and contribution to research.

## Closing comment

Dementia is one of the most widely feared aspects of growing old – and evidence suggests that the older we are, the more likely we are to be worried about developing dementia. The National Health Service is prioritising early or timely diagnosis of dementia, however, all too often people affected by dementia and their families tell us about the gap in services for them after diagnosis. While medication is available for some people with dementia, many are left to cope on their own with the emotional and psychological impact of the diagnosis.

At the same time, there is growing evidence that the right psychological interventions have an important role to play in easing distress, providing support, aiding adaptation and reducing the need for long term care. The time seems right, therefore, 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, through structured pathways which give access to a choice between a range of evidence-based interventions.

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# FPOP consultation with people living with dementia in the UK: A position paper

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*‘Perhaps at one stage, we don’t just want to understand... What we want is to live a normal life.’*

## Introduction

This document has been created in conjunction with several groups of people with dementia: The Forget Me Nots, based in East Kent, Al’s Café and Friends Together, based in Redditch, the Scottish Dementia Working Group, based in Glasgow, and EDUCATE, based in Stockport. Workshops and focus groups of this consultation were co-facilitated by the Dementia Engagement and Empowerment Project (DEEP) and the Dementia Workstream of the Faculty.

This document summarises the consultation with people living with dementia and informs the FPOP suite of papers on the early dementia care pathway.

It includes comments on each section of the FPOP suite of papers (pre-diagnostic counselling, cognitive assessment, communicating diagnosis and post-diagnostic support) gathered from involvement groups of people with dementia from across the UK. It also contains comments on *A Guide to Psychosocial Interventions in Early Stages of Dementia*, which was researched and compiled as a direct result of the early stages of this consultation.

This document is for:

- Members of FPOP and the wider BPS with an interest in the views of people living with dementia.
- People living with dementia, and their families and friends.
- GPs, commissioners and other professionals who are planning and providing dementia services.

## Section 1: Pre-diagnostic Counselling and Informed Consent

### 1.1 First contact with clinicians

*‘You go to the GP when you’re ill or injured... you only bring up your memory as an afterthought.’*

Several points highlighted in discussions concern how people were first referred to memory or diagnostic services, in most cases being referred by a GP:

- Many felt that GPs needed training in dementia, as some seemed to lack knowledge on the subject. *‘We need specialist GPs in dementia... And all staff need training really, including receptionists!’*

- Some felt that many clinicians were behind an impenetrable wall of professionalism. Empathy was highlighted as an important factor in positive experiences with health care professionals. *'It's important that professionals are good at just being human... it makes a difference being a human being.'*
- Some GPs were praised for their knowledge and understanding. *'My GP was fantastic. He said he knew exactly what was wrong with me and would pass me onto people who could help me even more.'*
- It helps to stay with the same clinician throughout the process, rather than being transferred repeatedly. *'I didn't always have the same GP every time I visited, so I didn't really have any time to build up a relationship with anyone.'*

***'I think everybody's different. I think there needs to be an understanding by the GPs that people are different.'***

## 1.2 Pre-diagnostic information and consent

***'We had no information given to us before testing. We just went and they asked us questions. They didn't mention dementia.'***

Informed consent was highlighted as ethically imperative as it allows people to assess whether or not they wish to continue, and whether or not they would wish to know that they have a dementia. The following points are important in allowing informed consent:

- Provide time and space to absorb pre-diagnostic information. It is important not only that information is provided, but also that it is made easy to absorb and that time is given to do so. *'Because of the dementia, there was trouble absorbing verbal information. You need written information to take away.'*
- Give information about types of dementia other than dementia in Alzheimer's disease, including the possibility that memory may not initially be the most pressing issue. *'...all professionals seem to just emphasise memory! I was doing my own research. In the end I was informing my GP about dementia!'*
- Consent must be given at every diagnostic and pre-diagnostic appointment. *'[The psychologist] was constantly giving me a 'get out of jail free card'. I think that's very important.'*
- Ensure that the diagnostic process is collaborative and clients know what the purpose of each test is, and what the final diagnosis might be. *[Carer] 'We went through the GP who referred us. He [husband] was sent for a brain scan. I never saw this and the consultant never explained the scan or the process, but just diagnosed Alzheimer's.'*
- Highlight the possibility of diagnostic uncertainty. *'The consultant warned me. That helped me because when the scans came back not showing anything wrong, I was prepared for the possibility it was still dementia.'*

***'The sooner you use the word [dementia], the better. If a medical person avoids using the word, it puts it way up there.'***

## Section 2: Cognitive assessment

### 2.1 The assessment itself

*'When you have a test you automatically think, 'Well I want to pass this test!'... You're constantly thinking, 'Am I passing this test or am I failing?'... I thought about what they asked me last time... so I revised and practised!'*

- Transient emotional and cognitive states can play a huge role in determining cognitive performance. *'Assessments are very tiring. Psychologists need to be aware of this.'* *'My psychiatrist noticed this, how stressful the tests were to me... they talked to me and conveyed that they wanted me to be relaxed.'*
- The environment needs to be appropriate. *'Hospitals aren't suitable because you go there for so many other things. You also need time. You should be offered the chance to ask questions later, perhaps even two hours after your meeting.'*
- Some highlighted that, before the appointment, they knew what was likely to come up in the test and so were able to prepare, thus giving inaccurate data. *'I think it's important to have different versions of cognitive tests, to make sure questions are different. Because I did learn the answers.'*
- It is important to think about which test would be appropriate: too easy, and difficulties might go undetected; too difficult, and self-esteem is needlessly damaged. *'Some tests are so easy that someone with early dementia could pass them and then not necessarily be referred, because there was no problem, as it were.'*

*'Not seeing the same person every time was a problem. It probably stopped me knowing earlier about my dementia.'*

### 2.2 Information

*'I thought of recruitment selection psychometric testing. It wasn't until I started doing the tests that I realised it wasn't like that. But they did explain a bit.'*

- It is important to consider how much information is appropriate for/desired by each individual. *'You can't have one rule for everyone – you're going to have to talk to people about what they want to know.'*
- Explanations about tests are important to many people. *'If you know in advance, if you are told, you are more prepared for the testing – but you don't want to prepare for it.'*
- Reports from cognitive testing need to be accurate. *'The report produced was inaccurate on two accounts; (the) medication I'd previously had was incorrect. Driving – it said my wife was not happy to drive with me. But she actually said that this was due to my cataracts, not my cognitive skills.'*
- Assessment should be collaborative. Information should be given to the person on the purpose of the tests, the results from each test, and how these results inform a possible diagnosis, if this information is desired by the person. *'There should be a better transition from assessment to the point of diagnosis. The professionals should communicate with us better; they should share what they're thinking during the process. Assessment should be collaborative. They should tell us what tests they're doing and why they are doing these tests. They should tell us if they are leaning towards one diagnosis or another.'*

*'I fought it to the end because I didn't believe it. No one pressured me into doing the tests though, and I came to terms with it.'*



## Section 3: Communicating a diagnosis of dementia

### 3.1 Who shares the diagnosis?

*‘Staff knew I was going to be told by a doctor I had never met before. They didn’t seem to realise how serious this was. It was horrific.’*

The person most people would like to give the diagnosis is someone with whom they have built up a relationship. Ideally this would be the person who did the majority of the assessment.

- Sometimes the psychologist was identified. *‘The biggest relationship you build is actually with the psychologist.’*
- It was often the community psychiatric nurse who was identified. *‘My doctor could have explained the illness and its symptoms, the different types and what that means for me... I also would have preferred my community psychiatric nurse to give the diagnosis...’*
- Sometimes the person had a good relationship with the GP. *‘My GP texts me. We have a good relationship. He respects me.’*
- Others were happy with a psychiatrist sharing the diagnosis. *‘The psychiatrist was the central person who brings it all together, so it didn’t seem wrong to me.’*
- If the diagnosis is communicated by a lead clinician only, some identified that they would still like the clinician with whom they had the best relationship to be present at the appointment. *‘I had a good relationship with my community psychiatric nurse, but they weren’t allowed to be there. I would have liked him to be part of the process. My doctor’s first words were, ‘it’s dementia, it’s progressive, you can’t drive now’. I asked him ‘what kind of dementia?’ he said ‘does it matter?’ I went into denial after that... I think it was because of the way it was conveyed...’*

*‘I got a long letter from my psychologist. It was very personal and human. This is what I needed.’*

### 3.2 How the diagnosis is shared

*‘There is no single answer.’*

Many people stated that they would prefer whoever communicates a diagnosis to take time in doing so in order to do it in a sensitive manner.

- An abrupt diagnostic appointment can be distressing. *‘You have an incurable brain disease... Didn’t even say sorry. I was in the room for two minutes.’*
- The build up to the diagnosis affects how the diagnosis is received. *‘The delivery wasn’t a problem as we’d built up to it. Where I was let down was that there was no immediate follow-up. There was all this support up to this – it felt like ‘Go away and live with dementia’. It was like a vacuum, a cliff-edge.’*
- The diagnosis should be collaborative, with not just the diagnosis itself shared, but how clinicians came to this conclusion. *‘The psychiatrist gave a rationale for why he came to his conclusion.’*
- The diagnosis needs to be communicated sensitively and with empathy. *‘He didn’t introduce himself. He turned half way round in his seat. No name, he didn’t call me by my name. ‘I’ve been looking at your notes and you have got Alzheimer’s disease and you will never work again.’ He still didn’t look at me. I thought, ‘should I say something or should you?’ He just showed us the door, there was no one else waiting, no information.’*



- The importance of how a diagnosis is communicated was emphasised, as it has an effect on how people come to terms with it later. *'If you [Health Care Professional] communicate this wrong, and the person goes on a downward spiral, resources are more to get them back to the surface. The cost would be greater to the individual and to society.'*

*'It was very neutral, not bad or positive. Many people would like positiveness, but not false positiveness.'*

### 3.3 Language and terminology

*'Language should be challenged in the field of dementia care. There's currently no challenge to the language that people still use. I still hear 'demented', 'sufferers', 'pre-senile dementia'. We find it offensive!'*

- Many of the terms that are sometimes used in the field of dementia care, including in diagnosis, people find unhelpful. *'Don't like the word 'journey' because the destination isn't somewhere I want to get to. 'Experience of dementia' might be better.'* *'Words are really important! We hate the word 'sufferer'. It's really important people know that.'*
- The language used around diagnosis is important. Many feel that the diagnostic process should be collaborative, and that the language should reflect this. *'Disclosure' feels like someone is hiding something from you.'* *'Sharing' is a better word. We [client and clinicians] have been through this process together.'*
- At the point of diagnosis, language use needs to be considerate and sensitive. *'Be sensitive. Never be dramatic. For example, do not use terms like 'I am afraid to tell you...''*

*'Think: How would you tell your mother?'*

## Section 4: Post-diagnostic support

### 4.1 Signposting and how post-diagnostic support is offered

*'We need a list of what is available, how to get hold of this kind of treatment, who it is suitable for and who I ask for advice.'*

There is wide variation in the quality of signposting and the availability of post-diagnostic work.

- Some people were asked what they would like in terms of post-diagnostic work by clinicians. *'They asked me what I was interested in. I joined service users – I've never had such a good social life.'*
- Post-diagnostic signposting, like the diagnosis itself, should be done with someone with whom the person has a good relationship. *'The doctor asked me to come back after a visit and the Community Psychiatric Nurse was introduced to me soon after. The community psychiatric nurse then went on and talked to my wife rather than me! I kicked her out after that! It should have been a person who knew us that talked to us.'*

*'What is there? How are you supposed to find out about them?'*

*'...they shouldn't be focussed on what pills to give us; they should be focussed on feelings! They should ask, 'Are you coping?''*

## 4.2 Post-diagnostic groups and courses

*'Loneliness is your biggest enemy.'*

- Post-diagnostic courses are often praised for the practical, emotional and social benefits that they provide. *'When I found I got dementia I didn't know what that meant. I didn't know anything about it... The post-diagnostic course was very helpful in getting all the information for my wife as a carer and myself. Very helpful.'*
- It was said that some individuals are put off by the idea of a group, and needed encouragement to go. *'My wife didn't tell me about the course, she just said 'we're going down to [local town]. I wouldn't have gone if I'd known it was a group. I wouldn't have been here otherwise.'*
- Some argued that groups have a downside. *'There is a downside to groups. You see someone sitting round a table, and you see someone who is obviously worse than you and you think oh God, that is yet to come. And I think that would put me off a bit.'*
- Others disagreed. *'No, I think it's good to have people at different stages because everyone has different problems and you adapt to that.'*
- While post-diagnostic support should be offered to families and carers, it is important to also offer support to the person living with dementia. *'Not everyone has a spouse or someone with them, they can often get forgotten.'*

*'We did different things each week and there was plenty of information and leaflets there on how to get help. At the time it was quite new, I hope it's still going on.'*

## 4.3 Good post-diagnostic support services are key to living well with dementia

*'Families need support and time to adjust – these are big life changes for them as well.'*

- Many people feel alone, confused and frightened after getting a diagnosis. Post-diagnostic support services can help people to adjust to living with dementia. *'I locked myself away for a while, I was withdrawn. Then, after some time, I was offered peer support. That worked for me. It changed my life.'*
- Post-diagnostic support should be available equally to everyone, regardless of time since diagnosis. *'Yes, everyone should have equal access to services and there should be no timescale on when they receive these.'*
- Support should be given according to the person's individual needs and circumstances. People offering services should recognise this. *'Our individual needs, they do change. Do we know what we need and when?'*
- Information on what is being offered should be communicated effectively to people. *'Services should think about communications systems so this information gets through and back to us.'*

*'It felt hopeless. It just seemed to be about getting your affairs in order. I could hardly talk afterwards! Then I thought about giving something back. I thought I should do something positive. Giving support to other people gave me hope!'*

#### 4.4 There are barriers to getting post-diagnostic support

*'If you are injured, then you go to a minor injuries unit. Where do you go if you've got dementia?'*

- Many people with dementia and their families do not know what is available or how to access it. *'Where are these things happening? What about local information on local support?'*
- People with dementia and their families may be reluctant to seek support. *'We also need someone to encourage us to attend. This is really important. I didn't want to go to any of the groups or activities offered to me. Only with encouragement from my family did I end up going at all, and then I found it really good!'*
- Lack of accessibility is often a barrier to people getting the support that they need. *'How do you get there? If you are old and cannot drive and have no money or family nearby, how do you get to support groups, courses, etc.?''*

*'We should be given support with transport and information... how can people get to any of these groups if there isn't someone to look out for them?'*

#### 4.5 Information about post-diagnostic support is vital

People with dementia need access to good quality, clear information about different types of post-diagnostic support.

GPs and other professionals who work with people with dementia need to know what support is available after their diagnosis.

Local information about what services are available, where they are available and how to access them is vital.

*'There should be a leaflet or booklet out there that tells us – 'where do I go next'.' 'There is a lot going on that I just don't know about. There's a lot going on and why isn't something being done to bring it all together and raise people's awareness of what is out there.'*

## Section 5: The guide to psychosocial interventions

### 5.1 General comments and layout

*'Will the guide be developed in simple terms, something everyone will understand?'*

- Originally, the title was 'Compendium of Psychosocial Interventions', however, this consistently drew criticism due to its complex nature. *'The title [Compendium of Psychosocial Interventions] needs changing. It's too academic sounding.'* Other suggestions included 'Next Steps', 'Guide' and 'Catalogue'.
- Use of a signposting system within the guide that identifies specific needs and matches interventions to them (the 'What is My Need' section) was praised. *'The What is My Need section makes you think about things you might need but hadn't really thought about before.'*
- Comments were made regarding the general formatting of the document. *'Headings should be bigger, with more space in between sections.'* *'References should be put at the bottom of the same page, or if not, 'See appendix X for details of the full paper'.'*
- General wording was commented on. *'What are the possible downsides' could be changed to 'Are there any downsides?' A bit less pessimistic.'*

- Who is the guide addressed to? Some felt that directly addressing the reader was too direct. *'In a way it's better if it's more detached. 'You', 'you' all the time feels like you're singling me out.'*
- Comments were made on the general grammar of the document. *'Needs as many prompts and reminders as possible, so avoid using pronouns (it, they) and instead use the noun proper.'*

*'Any guides that we have would need pictures.'*

*'If this is produced, it should be useable by professionals so that we can work together.'*

## 5.2 Cognitive Behaviour Therapy (CBT) section

*'Stress and anxiety is a big thing. It's very important to have a therapist every week.*

*We don't have this.'*

- Some of the terminology was difficult to understand. *'Not sure what 'cognitive' means.'*
- Comments were made on specific wordings and phrases. *'Take out the phrase 'help you' and replace it with 'it aims to replace unhelpful...'. 'The phrase 'the severity of' is frightening.'*
- Use of technical abbreviations was criticised. *'Don't be so technical. Don't use abbreviations like 'CBT'. It's hard to distinguish all of these apart when you use abbreviations.'*

## 5.3 Cognitive Stimulation Therapy (CST) section

*'It looks interesting. I would go for that.'*

- People commented that the description of the intervention was clear and provided all the necessary information.
- Some commented that it was unhelpful to have information on CST and MCST simultaneously as this was confusing. *'Include MCST towards the end, in the 'How long does it take' section.'*
- Bullet points, where possible, would be useful. This also applies to other sections of the document.
- The 'What is the evidence' section (for all interventions) should be more accessible and summarised. While knowing if an intervention is evidence-based is useful, simply providing a list of references is inadequate in terms of information and accessibility.

*'Make it more friendly and accessible sounding.'*

## 5.4 Comments on other sections

*'Is it possible that you need different things at different times?'*

- Many felt that the Advanced Care Planning section was not accessible enough. *'This is awfully complicated.'* *'This was written for someone with brains!'*
- It was felt that the Stress and Anxiety management section was clearly distinguished from other similar interventions. *'This gives you examples about what it is.'* *'When your anxiety is higher, stress and anxiety management. When it is not serious, group.'*
- The downsides section in Counselling and Psychotherapy is useful. *'The downside in counselling and psychotherapy is big. It helps you decide between this and CST.'*

- It was felt that Life Review Therapy was clearly distinguished from CBT.
- The Assistive Technology section, while linguistically clear, needs to clarify what counts as assistive technology, for example, things like handrails which are not what one usually thinks of when thinking about technology. Also, the word ‘technology’ might put some people off.
- Pet Therapy needs a new ‘Possible Downside’. *‘Under ‘Possible Downsides’, note that hygiene is important in relation to pets.’*
- Many comments were made concerning the style of the Cognitive Training section. *‘This page is too wordy, it needs to be pruned, or broken up in some way.’ ‘Under ‘What does it do’, the second paragraph feels a bit like you’re talking down. Be careful not to become patronising!’*
- It needed clarifying that Music Therapy was a specific intervention using a specifically trained therapist to directly confront psychological difficulties.
- It was felt that the Life Story Work section, while well written, lacked ‘spark’ and sounded dull. *‘The section needs to express that sharing life stories can be an enjoyable and rewarding experience, and can have benefits for families later on.’*
- Wording of Personally Tailored Occupational Therapy needed rethinking. *‘This involves individualised goal setting – can put people off. It sounds as though you are being pushed, or forced to do things.’*
- There needs to be more direct reference to the appendix, as it contains useful information but was almost missed. *‘Perhaps have the information in the appendix in a fold-out sheet at the front so that people can refer to it while simultaneously reading the intervention entries.’*

*‘Perhaps have a section on ‘How to use this compendium’ at the front.’*

### **Authors’ Note**

This consultation was an ongoing process throughout the period of compiling the suite of FPOP papers. Comments from service users were fed back to authors throughout the writing process and influenced the language used and informed the content. Comments also initiated *A Guide to Psychosocial Interventions in Early Stages of Dementia* and shaped the structure and presentation of the document.

We are very grateful to the service user groups and the organisations supporting them for sharing their expertise and enabling this collaboration between contributors.



# Glossary of terms

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**Accuracy:** In the context of cognitive assessment, accuracy refers to the likelihood of the findings of the assessment being correct.

**Alzheimer's disease:** A form of dementia associated with tangles and plaques in the brain. As the disease progresses, cognitive ability gradually declines.

**Capacity:** Mental capacity refers to an individual's ability to make an informed decision on a specific question.

**Carer:** One who cares for the needs of a person who is less able to manage independently.

**Clinical Psychology:** An area of psychology which uses psychological knowledge and research to promote psychological well-being.

**Clinical Supervision:** A space in which a health care professional discusses their clinical work with a supervisor with a view to improving quality.

**Cognitive:** To do with mental abilities and processes. Typically understood as thoughts, knowledge, language production, judgement and problem solving, among other thinking skills.

**Commissioning:** The act of buying services. In the United Kingdom, commissioners are responsible for deciding what services are provided in a specific area and how much funding these services receive.

**Counselling:** A type of talking therapy in which an individual discusses problems confidentially with a professional.

**Dementia:** A term which encompasses a range of medical conditions which cause ongoing decline in various thinking skills and abilities, for example, memory, planning, inhibition and being able to orient oneself to time and place.

**Diagnostic uncertainty:** It is sometimes difficult for people carrying out assessments to be certain that a dementia is present, or to distinguish between types of dementia. Diagnostic uncertainty refers to the possibility that the results of the assessment are inconclusive.

**Discharge:** Term used to describe the stage at which a client leaves a specific service, when the service is no longer deemed to be appropriate for the client.

**Euphemism:** A term that is used instead of another that might be considered offensive or distressing. An example would be the use of the phrase 'memory problems' instead of the word 'dementia'.

**Frontotemporal dementia:** A form of dementia which particularly involves the frontal and side regions of the outer brain. It is often associated with behavioural or personality change and/or difficulties with language.

**Good practice:** A term used to describe actions taken in health care that are seen as ideal for the well-being of the recipient of said care.

**Holistic:** Taking into account all aspects of a particular situation.

**Hypothesis:** A suggestion of fact made on limited evidence. Further testing is used to either support or disprove the hypothesis. In the context of cognitive assessment, for example, a psychologist might interpret existing evidence as suggesting a particular type of dementia before using in-depth tests to find evidence for or against this supposition.

**Informed consent:** According to best practice guidelines, no assessment or treatment should be undertaken unless the person receiving this is made fully aware of the processes and implications involved. In cognitive assessment, this means that the possibility of a diagnosis of dementia should be made clear before assessment is undertaken so that individuals can decide whether or not they would want to receive this information.

**Intervention:** A clinical term used to describe any treatment which aims to help people to adjust to changing circumstances or to improve quality of life.

**Memory Clinic:** A service which specialises in the diagnosis of neurological illnesses such as dementia, as well as early support for those with cognitive impairment and those closest to them.

**Memory Services National Accreditation Programme (MSNAP):** A programme which aims to evaluate services with the goal of improving their performance.

**Mild Cognitive Impairment (MCI):** A condition in which an individual's thinking skills are slightly but noticeably lessened, but not enough to impair day to day functioning. MCI may or may not indicate very early stage dementia.

**Neuroimaging:** The use of technology such as scans to provide an image of the brain.

**Neurology:** The study of the structure and function of the nervous system and the brain.

**Neuropsychology:** The study of the structure and function of the brain and how this relates to thinking and behaviour. Neuropsychological assessment involves testing specific thinking skills and using the results to gain an understanding of what might be physically happening in the brain.

**Peer review:** A process by which a piece of work is evaluated by a number of people knowledgeable on the subject matter of the work.

**Person-centred:** A style of health care which places the needs of the individual receiving said care as central to the process.

**Pharmacology:** The use of the active chemicals in medication to treat illness.

**Prophylactic:** A preventative measure.

**Psychology:** The academic study of the brain and how it relates to behaviour. In the context of clinical work with dementia, psychology focusses on the thinking skills which become more difficult to use and how one might compensate for these, as well as how individuals adjust to the life changes brought about by dementia.

**Psychosocial:** Relating to psychological (to do with the mind) as well as relating to social situations.

**Psychotherapy:** A form of therapy which aims to use psychological techniques and research to reduce psychological distress in an individual and promote good mental health.

**Rehabilitation:** The process of returning as much as possible to previous levels of functioning.

**Referral:** Term used to describe the allocation of a client to a service. For example, if an individual is referred by a GP to a memory clinic, the services of the memory clinic become available to the individual.

**Qualitative research:** Research that focusses on non-statistical data such as interviews. It is often used to study individuals in depth.

**Quantitative research:** Research that uses statistics to find general patterns in a population.

**Stepped Care Model:** An approach which seeks to treat service users at the lowest level required for their need, with intensity of care increasing with need.

**Stigma:** Negative views that are held by a large number of people about a specific subject or group of people. These views often come from inaccurate or exaggerated descriptions of real life.

**Systematic review:** The identification and analysis of all high quality research on a specific subject. Findings from systematic reviews carry great weight in terms of evidence.

**Timely diagnosis:** A term used to refer to a diagnosis given at a time most suitable for the service user receiving the diagnosis.

**Vascular dementia:** A form of dementia associated with repeated small strokes in the brain. As the disease progresses, cognitive ability gradually declines.

## Notes

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