

# Communicating a diagnosis of dementia

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## **Briefing paper for Faculty for Psychology of Older People and Dementia Action Alliance**

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## **Introduction**

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The number of people with a formal diagnosis has increased since the launch of the National Dementia Strategy (DoH, 2009). However, approximately half of people living with a dementia have not been formally given a diagnosis (DoH, 2012). With clear targets to increase rates of early diagnosis, debate remains regarding whether the provision of early diagnosis is in the best interests of the individual living with the dementia. The case for timely as opposed to early diagnosis is identified as being of utmost importance, in order for the benefits to be balanced against the risks (Nuffield Council on Bioethics, 2009).

The consensus within current practice is that a timely disclosure is required, unless there is sufficient reason to withhold the information (Nuffield Council on Bioethics, 2009). However, the disclosure of a diagnosis is a difficult part of a clinician's practice (Bamford et al., 2004; Iliffe, Menthorpe, & Eden, 2003). More than 50% of clinicians reported 'always' giving the diagnosis as difficult (Iliffe, Eden, Downs and Rae, 1999). Giving a diagnosis has been identified as one of the five most difficult aspects of dementia care (Rae, McIntosh, & Colles, 2001).

In response to the increased volume of referrals from Primary Care seeking a memory assessment to Memory Clinics, and the increase in referrals for a neuropsychological assessment this is an exciting opportunity to embrace as Clinical Psychologists to invest our skills, knowledge and application in the process of giving a diagnosis. Clinical experiences informs us that Clinical Psychologists working into Memory Clinics who routinely write neuropsychological reports and identify diagnosable causes of individual memory problems are not routinely involved in the final process of the diagnostic process.

The argument put to the members of the Faculty of Psychologists working with Older Adults is that Clinical Psychologists are best placed following consultation with the Multi-Disciplinary Team (MDT) to complete the diagnostic process and communicate the diagnosis to the individual. The combination of Clinical Psychologists' neuropsychological and therapeutic skills allows us to have a significant wealth of experience and knowledge specifically relating to the sensitivity required for the diagnostic disclosure. However, these skills are under-utilised, resulting in longer waiting times for a diagnosis from the memory clinic and for a memory assessment appointment. With the inclusion of Clinical Psychologists making diagnoses, there will be a direct impact on waiting times between

assessment diagnosis, resulting in a reduction in waiting times for a memory clinic and/or neuropsychological assessment appointment.

For many Clinical Psychologists this will involve a revision of their current practices and an investment in clinical professional development to meet the task of communicating a diagnosis. It is therefore timely to consider how a diagnosis should be communicated, and the processes faced for the individual living with a dementia, their carer and the psychologist involved who delivers the diagnosis.

The following chapter focuses on the Current National Guidelines and recommendations informed by physical health services that deliver diagnoses. Attention is paid to the process of giving and receiving a diagnosis and the transitional process for the individual who is faced with having to adjust to living with a diagnosis of Dementia. After consideration of the national guidelines and recommendations, Dementia specific recommendations on how to give a diagnosis of Dementia are made through the use of a Stepped Care Model. The aim of the Stepped Care Model is to guide and signpost Clinical Psychologists through the diagnostic process, identifying the core considerations required when making a diagnosis. Service implications and improvements are further considered in light of the recommendations made.

## **Current national guidelines**

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In light of the DoH (2012) guidelines for increasing the provision of diagnoses it is important to meet patient's needs and maintain quality at the heart of the diagnostic process. In order to appreciate what makes a good diagnosis it is necessary to understand the recommendations so far. The current practice of dementia diagnosis disclosures of General Practitioner's (GPs) is reviewed alongside older age psychiatry. From here a number of non-dementia breaking bad news guidelines will be evaluated, leading to more dementia specific disclosure recommendations from current research.

The debate of who (for example GP versus memory service specialist) should make and disclose a diagnosis of dementia has been argued within the literature. Goodwin, Curry, Naylor, Ross and Duldig (2010) outlined that any diagnosis of dementia should be conveyed by a specialist or General Practitioner with Specialist Interest (GPwSI) to the individual and then communicated to the GP. This is supported by the Department of Health and Royal College of General Practitioner (2003) competency guidelines that state that a GPwSI must evidence the 'diagnosis and management of important clinical conditions in older age including...degenerative diseases' (p. 5). Connelly and Perera (2013) produced a working document of the ideal older age service from a psychiatry perspective, identifying 'benefits of a timely diagnosis' (p.8) however the quality of diagnosis disclosure skills was not addressed.

There are several published guidelines addressing how 'to break bad news', however they are general guidelines that are more fitting to physical health diagnoses rather than dementia. Buckman's (1992) guide for health-care professionals on how to break bad news puts forward a six stage process, the first 3 stages focusing on getting started, identifying how much the patient knows and what they do and do not want to know, highlighting the patient's right not to know (Nuffield Council on Bioethics, 2009). The remaining three stages focus on how the professional shares the diagnosis and are concerned with responding to the individual's feelings and questions, and planning

for the future. The author acknowledges that all professionals should be trained in these skills because 'increased confidence translates into increased competence' (Buckman, 1992, p.5).

Silverman, Kutz, and Draper (1998) created a framework on how to break bad news. It follows similar format of preparation, the interview, and after the interview to Buckman's (1992) model. However Silverman et al. (1998), emphasise the need for planning and support to be addressed separately to follow-up and close of interview, as opposed to being combined in Buckman (1992).

These frameworks were developed more specifically for oncology patients in the SPIKES model (Baile et al., 2000). SPIKES stands for setting, perception, invitation or information, knowledge, empathy and summarise or strategize. It was felt that within the SPIKES framework a clinician could meet the four aims of a bad news disclosure in oncology which were 'gathering information from the patient, transmitting the medical information, providing support to the patient, and eliciting the patient's collaboration in developing a strategy or treatment plan for the future' (Baile et al., 2000, p.302).

Within the group of clinicians using the SPIKES framework, 95% felt it was helpful, however 52% felt the empathy and responding to patient's emotional responses was the most difficult task. Kaplan (2010) confirmed these findings in a singular case study using the SPIKES framework and concluded that 'breaking bad news is a complex communication task, but following the stepwise sequence of the SPIKES protocol can help ease the distress felt by both parties: the patient, who is receiving the news, and the healthcare professional, who is breaking the news' (p.515). This highlights the need for best practice guidelines in disclosing bad news as 'the manner in which you tell the truth may be even more important than the fine details of the information' (Buckman, 2005) p.139). In response to this Back, Arnold, Baile, Tulskey, & Fryer-Edward (2005) developed a separate protocol NURSE (Naming, Understanding, Respecting, Supporting and Exploring) which can be used to respond to difficult emotions triggered by the disclosure.

The Department of Health, Social Services & Public Safety (DHSSPS) (2003) further developed the preparation, interview and after interview format to create regional guidelines in Belfast. The authors split the preparation section into three components (yourself, setting and patient), renamed the interview to 'providing' which is in three parts (information, support and plan) and then a final element for after the interview. The equal split of preparation and providing highlights that each process is as important to each other. However these are general breaking bad new guidelines which are not specific to any condition or client group.

There are several reasons why such frameworks do not fully support the disclosure of a dementia diagnosis, which are similar to why they do not work for persons with intellectual disabilities. Tuffrey-Wijne (2013) adapted a model of how to break bad news to people with intellectual disabilities in response to the acknowledgement that Buckman's (1992) and Baile et al.'s (2000), SPIKES framework assume three factors which are not applicable to the needs of those with intellectual disabilities. This argument could be extended and applied to people living with dementia.

The breaking bad news models outlined above represents a 1 bearer and 1 recipient format, whereas for individuals living with intellectual disabilities and dementia, this is often not the case as there are many people involved in the process. Secondly, the previous models are developed around

one central piece of information where for those with intellectual disabilities and those living with dementia, there are many pieces of complex information to make sense of. Finally, the above models relate to a singular event of disclosing bad news whereas for individuals living with intellectual disabilities or a diagnosis of dementia, as a function of their cognitive impairment the individuals require additional time to make sense of the information.

Tuffrey-Wijne's (2013) model in figure 1 involves four inter-connected components which focus on the process of breaking bad news, rather than on the single interview. Component one, 'Building foundation knowledge' relates to building up pieces of complex information over time (eg. facts, practical skills and education). Component two, 'Understanding', addressed how a person gains understanding of an area that is difficult to operationalize (eg. from a piece of information, an experience or a feeling). Component three concerns the 'People' involved highlighting that no one person has the full picture reinforcing the need to include people from the various systems surrounding the person involved in the diagnostic process. The final component is about 'Support' identifying that everyone involved (including professionals at all levels) require support at some point during the diagnostic process.



**Figure 1:** Model of breaking bad news to persons with intellectual disabilities, taken from Tuffrey-Wijne (2013).

Tuffrey-Wijne (2012) created a tool to support the use of their model to help understand the additional pieces of information underlying the diagnostic process. The tool is split into background knowledge, what is happening right now and what will happen in the future. The following example taken from an case used by Tuffrey- Wijne (2013) specifically relating to an individual living with cancer has been adapted to help explore people's thoughts about living with dementia. For example, in relation to the situation of being told 'I have Dementia'. The background knowledge could be 'Dementia is bad', 'My Mum had Dementia' and 'I have always been independent'. Pieces of information for the present could be 'I don't seem to be the same', 'people seem worried about me', and 'my daughter comes round more often'. Pieces of information for the future may be 'I'm going into a home', 'I don't want to leave my house' and 'will I still be me?'

Fisk et al. (2007) support the progressive nature of a diagnosis, particularly for dementia. Fisk et al. (2007) conducted a review of the literature around dementia disclosures and provide a summary of recommendations for best practice in this area that were approved by the 3rd Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (CCCDTD) in 2007. The authors identify that the process starts when the individual notices when something has changed, which can be a long time before a diagnosis is given. There are also many components of information around the statement 'You have dementia' which means the full disclosure and understanding of the diagnosis will occur over many sessions, with different people and over a long period of time. The authors also support Tuffrey-Wijne (2013) recognition that everyone needs to be involved, including current and possible immediate future carers, family and professionals.

However, even though the statement 'You have dementia' is only one part of the framework of knowledge for an individual, this particular piece of information is the confirmation of what is happening and the gateway to treatment. Therefore the disclosure of this information needs to be given 'in a sensitive, compassionate way that instils realistic hope' (Lee & Weston, 2011, p.852). To do this takes great skill, as it crosses medical and social boundaries.

Looking at more specific dementia policies, the DoH (2009) 'National Dementia Strategy' refers to 'breaking the diagnosis sensitively well to the person with dementia and their family' (p.37). Additionally, the 'The Prime Minister's Challenge on Dementia' identifies that a 'timely' diagnosis should be made. Although these are recent and well recognised documents in dementia care, they do not address how and what the best practices are in disclosing a diagnosis.

Therefore there are no specific guidelines on how to disclose a diagnosis of dementia that incorporates the diagnostic interview and the transitional adjustment that progressively takes place post-diagnostically over a period of time.

## **The challenges of giving a diagnosis**

The following chapter of the Briefing paper reviews the literature around the attitudes and experiences of GPs and multi-disciplinary professionals, identifying the challenges and barriers to giving a diagnosis and the techniques adopted to avoid detailed discussions during the diagnosis disclosure (Karnieli-Miller, Werner, Aharon-Peretz, & Eidelman, 2007).

The chapter considers the experiences of disclosures for individuals with dementia and their carers identifying the information patients want to know and the challenges they experience in receiving a diagnosis. A number of models are considered to gain an understanding of the process for the individual receiving a diagnosis, including the psychosocial model (Pratt & Wilkinson, 2003), the transitional process of the full diagnostic procedure (Steeman, Casterlè, Godderis, & Grypolonck, 2006) and the transitional process for carers (Wald, Fahy, Walker, & Livingston, 2003).

## The challenge for the professional giving the diagnosis

General practitioner's (GP's) attitudes and experiences of disclosing diagnoses of dementia have been widely documented around the world. There are similar patterns across these studies which evidence how challenging GP's find making and disclosing a diagnosis.

In Australia, Hansen, Hughes, Routely and Robinson (2008) outlined that in a group of GPs (N=24) from rural, city and urban practices felt a lack of confidence in diagnosis and that early diagnosis is not always helpful. Downs, Clibbens, Rae, Cook and Woods (2002) in Scotland, found that in 99% of cases the family were disclosed the diagnosis but only 55% of the individuals living with dementia were told by GPs. Holroyd, Turnbull and Wolf (2002) found slightly lower percentages in the USA as 93% of cases the family members were told compared to 49% of the individuals. However, only 22% of individuals living with dementia compared with 77% family members were informed of the types of symptoms to expect in the future. Turner et al., (2004), looked at a group of English and Scottish GPs (N=127) identifying that lack of confidence and/or knowledge about dementia reduced the likelihood of talking openly with the individual or their carer during the diagnostic process.

A survey of psychiatrists (N=259; Rice and Warner, 1994) reported that 98% of carers were told of the Dementia diagnosis, however the severity of the dementia influenced the clinician's decision to inform the individual living with the dementia. Up to 80% of clinician's nearly always or sometimes disclosed the diagnosis of mild dementia to the person, however 55% of clinicians rarely told the individual if they were living with 'moderate' dementia. For those living with severe dementia 89% of clinicians reported withholding the diagnosis.

In Scotland, Szymczynska, Imes, Marson, and Stark (2011) identified that geographical location presents further challenges to clinicians. In rural areas, there is limited access to specialist services, consequently primary care has more involvement in more complex conditions. Cahill et al. (2008) identified that only 43% of Irish GPs (N=300) had access to older age psychiatry within 12 months and 76% had to wait for longer than 12 months for a specialised neuropsychology assessment for dementia. Cahill et al.'s (2008) findings 'provide compelling evidence that training and access to diagnostic services are only two of several different obstacles that GPs encounter when attempting to diagnose dementia' (p.667).

Werner, Karnieli-Miller and Eidelman (2013) identified the need for further exploring specialist clinicians' experiences of giving a diagnosis. This is evidenced in the current body of literature exploring specialist clinicians (Karnieli-Miller et al., 2007 (Rice & Warner, 1994), (Kaduszkiewicz, Bachmann, & van den Busscle, 2008) (Milby & Murphy, unpublished thesis, 2013).

Milby and Murphy (unpublished qualitative thesis, 2013) interviewed multi-disciplinary professionals involved in the giving of a diagnosis (nurses, psychologists and psychiatrists) and identified three general themes: 'finding ways to help', 'the struggle with barriers to helping' and 'the reactions we have to contain and manage'. Clinician's communicated wanting to do the best for their patients whilst facing personal and professional challenges. The clinician's diagnosis disclosures were experienced as emotionally challenging whilst the barriers to helping were the lengthy diagnostic assessments and the constraints of waiting lists. The third theme ('the reactions we have to contain

and manage’) highlighted the impact of the diagnosis on the psychological wellbeing of the clinician and individual receiving the diagnosis.

In Germany, Kaduszkiewicz et al. (2008) compared the disclosure practices of GPs (N=389) and specialists (neurologists and psychiatrists, N=239). Approximately a third of the specialist group and over 50% of the GPs avoided using ‘Dementia’ and ‘Alzheimer’s disease’ preferring euphemisms such as ‘memory problems’ or ‘normal aging’. Karneili-Miller et al. (2007) recorded neurologists (N=3) delivering a dementia diagnosis. The authors found that the length of time of the disclosure appointments averaged between 4.4 to 13.5 minutes with a mean time of 0.4-5.4 minutes discussing diagnosis specific information, reflecting the clinician’s avoidance of discussing the diagnosis.

The challenges identified highlight the difficulty of disclosing a diagnosis of dementia for clinicians. One theme linking the literature is that professionals experience the disclosure of dementia as a single event. However, as discussed below the diagnostic process is not experienced as a single event by the individual receiving the diagnosis. (Steeman et al., 2006; Fisk, et al., 2007).

## **The challenge for the individual and carer receiving the diagnosis**

### **Individuals receiving the diagnosis**

To understand the needs of individuals receiving a diagnosis it is important that clinicians are aware of the growing body of evidence exploring the reactions to receiving a diagnosis of dementia (Connell, Boise, Stucky, Holmes, & Hudson, 2004; Lackkonen et al., 2008; Steeman et al., 2006).

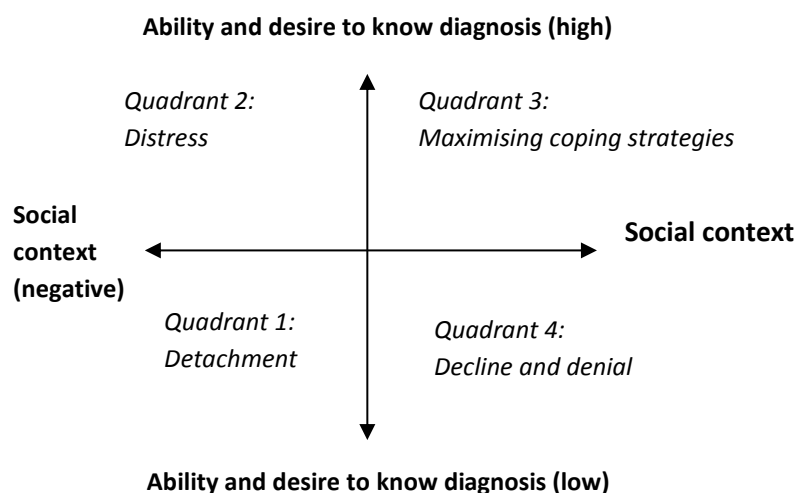
Elson (2006) found that 86% of individuals (N=36) prior to receiving a diagnosis wanted to know the cause of their memory issue and a further 69% wanted to know if the cause was specifically Alzheimer’s Disease. Jha, Tabet, & Orrell, (2001) compared a cohort of individuals receiving a diagnosis of either dementia or depression. In response to the diagnosis, only 25% of the dementia group felt optimistic compared to 75% of those in the depression group. Smith and Beattie (2001) further explored the impact of the diagnosis for the individual. Those individuals who were given a firm diagnosis of Alzheimer’s disease experienced relief and confirmation, whilst those informed of having probable Alzheimer’s disease or no dementia felt confused and frustrated.

Milby and Murphy (unpublished qualitative thesis, 2013) highlighted three major themes describing the patient’s experience of receiving a diagnosis; 1) ‘I’m finding a way to cope’, Patients reported adopting helpful and unhelpful strategies in an effort to cope with the diagnosis; 2) ‘things are not what they used to be’, patients acknowledged their increasing awareness of the impact of the Dementia on their ability to recount the past, and their diagnosis, reinforcing that the disclosure of the diagnosis is not a single event as the individual continues to make sense of their symptoms (Fisk et al., 2007). The final theme ‘the social environment: help or hindrance?’ identifies how an individual’s social context can facilitate or limit the opportunities to seek help.

The impact of the social context above is considered by Pratt and Wilkinson’s (2003) psychosocial model as shown in figure 2. The model identifies two axes that influence how a person may respond to a diagnosis; 1) the desire and ability to know the diagnosis and 2) the social context. There are four quadrants which a person can move around during the diagnostic process (detachment,

distressed, maximising coping strategies and, denial and decline) highlighting the progressive nature of a diagnosis disclosure, as opposed to the process being a single event (Lecouturier et al., 2008).

**Figure 2:** Psychosocial model of receiving a diagnosis of dementia, taken from Pratt and Wilkinson (2003).



Extending Pratt and Wilkinson's (2003) psychosocial model, Steeman et al. (2006) developed a transitional process that includes the pre-diagnostic and post-diagnostic phase. Steeman et al. (2006) identified that the process starts when the individual first notices a problem with their cognition and this awareness becomes heightened by incidents that happen day to day. The diagnosis is the final step in the Diagnostic phase, and is only the start of accepting the diagnosis. Milby and Murphy (unpublished thesis, 2013) interpreted the patient's experience of the diagnosis in relation to the psychosocial model. Integrating the psychosocial model with the transitional process outlined by Steeman et al. (2006), would enable a clinician to tailor and individualise a disclosure (Nuffield Council on Bioethics, 2009).

### **Carer's receiving the diagnosis**

Connell et al., (2004) reported that caregivers (N=52) experienced mixed feelings after a diagnosis was given ranging from shock, anger, and devastation to a sense of relief and ability to plan for the future. The provision of a diagnosis increased carer's understanding of the symptoms and influenced whether the caregiver attributed blame towards the person living with the dementia. In situations where the diagnosis was unexpected, the disclosure was experienced as more threatening and shocking, highlighting the need to prepare the patient and the carer on the possible outcomes of the assessment Derksen, Vernooik- Dassen, Gillissen, Olde Rikkert, and Schelten (2006).

Individuals with dementia and caregivers face a transition during the diagnosis process where the diagnosis disclosure is experienced as a significant cross-road (Steeman et al., 2006). Aminzadeh, Byszewski, Molnar, and Eisner (2007) suggested that individuals with dementia and caregivers



experience three stages of emotional responses to the diagnosis: denial/lack of insight, grief reactions culminating in positive coping strategies. However a person can move around these stages in response to changing circumstances and the degenerative nature of dementia.

Ducharme, Lèvesque, Lachance, Kergoat, and Coulombe (2011) assessed caregivers (N=122) of relatives who had received a diagnosis of Alzheimer's disease in the last nine months. Caregivers reported receiving little to no informal support and only 57% had low level knowledge of support services. Consequently, 86% of caregivers reported low level psychological distress, increased family conflicts and more intrusive negative thoughts about individual following the diagnosis. A number of caregivers highlighted that even when the diagnosis was expected, they still felt unprepared. Wald et al., (2003) reported variation between caregivers (N=100) wanting to know as much as possible all in one go, to be 'forewarned and therefore forearmed' (Wald et al., 2003, p.315) whilst some caregivers wanted information when the need arose as they felt it was all too overwhelming.

In summary, individuals with dementia and caregivers want to know the diagnosis but it is important to remember as a clinician that both recipients will have gone through a different journey to get to the disclosure stage (Steeman et al., 2006; Wald et al., 2003).

## **Overlapping challenges for individuals living with dementia, caregivers and professionals**

Kaduszkiewicz et al. (2008) reported that GPs and specialists (neurologists and psychiatrists) identified 'double taboos' during a dementia disclosure session. Double taboos were defined as 'things that patient's don't want to discuss and what professionals don't want to discuss' (p.222). Lecouturier et al. (2008) observed a significant overlap between individuals with dementia, carers and multi-disciplinary professionals who prioritised organising a private space, having ample time to talk and break the bad news over a series of contacts. Despite the overlap, contradictions were observed highlighting the mismatch between what the individual with dementia, the carers and clinicians feel are best practice disclosure behaviours.

Milby and Murphy (unpublished thesis, 2013) observed that clinicians and individuals living with dementia both experienced denial and avoidance, emotional distress and acceptance following the diagnosis. With the right diagnostic environment and pathways, clinicians can have a good awareness of the patient's experience and respond accordingly. The clinicians acknowledged that working within a multi-disciplinary team helped reduce uncertainty about the diagnosis, reducing the emotional burden, reinforcing the need for the professional environment to facilitate rather than impede the diagnostic process (Fisk et al., 2007; Pratt & Wilkinson, 2003; Steeman et al., 2006).

## **Summary of challenges**

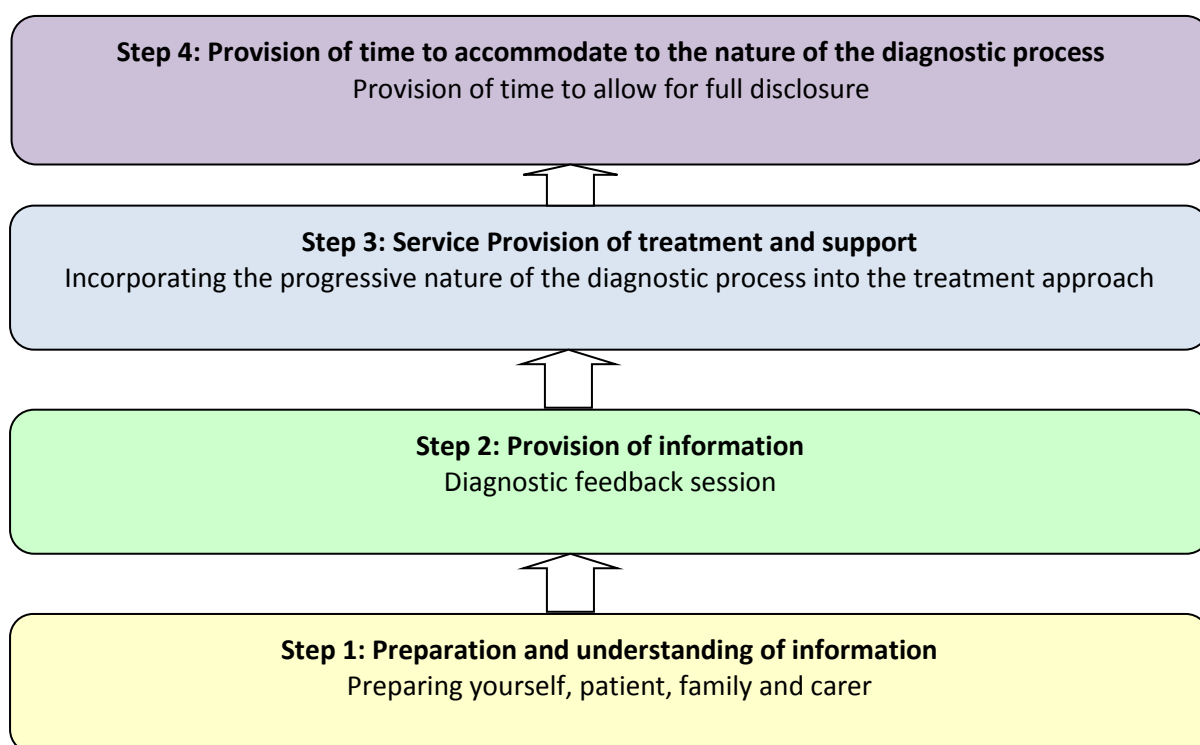
There are many challenges for the professional giving the diagnosis, and the individual living with the dementia and their caregiver receiving the diagnosis. Some challenges are unique to all three parties but there are many overlapping difficulties (Milby & Murphy, unpublished thesis, 2013), taking place during a diagnostic procedure in addition to the organisational and service level challenges.

## Making a good diagnosis

### A Stepped care model of assessment diagnosis and intervention

Stepped care approaches in healthcare provide the framework to organise healthcare delivery informed by evidence based practice and applied knowledge. The following stepped model incorporates the above findings from the current national guidelines, research into making and living with a diagnosis and is informed by good clinical practice currently taking place.

The 4 steps describe the level of assessment and actions required when preparing and making a diagnosis of Dementia. The stages range from the Preparation and understanding of the information where the focus is on preparing your patient, family and carers and preparing yourself as the clinician to give the diagnosis (Step 1), the Provision of the diagnostic information (Step 2), Provision of treatment and support incorporating the progressive nature of the diagnostic process into the treatment approach (Step 3), and the Provision of time to accommodate the nature of the diagnostic process, recognising the need to provide the time to allow for full disclosure and an understanding of the progressive nature and impact of receiving a diagnosis over a period of time (Step 4).



**Figure 1:** The Assessment and Diagnosis Stepped care model

The aim of the model is that Step 1 is undertaken first. After this, it is pragmatic to undertake the following steps in order. The model provides sign posts to draw the clinician's attention to the required actions, with focusing on providing the patient with the best possible diagnostic process with the aim of preventing further increase in distress for the individual and the carer.

## Step 1: Preparation and understanding of information

This step is focused on signposting the clinician to appropriately prepare for the process of giving a diagnosis and to understand the information and the implications for the individual receiving the diagnosis their family and carers. The focus is on preparing the patient through the process of pre-diagnostic counselling and prompting the clinician to prepare them-selves for the process of giving the diagnosis.

### Step 1: Preparation and understanding of information Preparing yourself, individual, family and carer

#### Assessing

- Neuroimaging – CT, MRI, SPECT
- Comprehensive neuropsychological diagnostic assessment (Ian James' chapter)

Assess risk issues for client and carer(s).

#### Actions

##### **Preparing the patient and carer - Pre-Diagnostic Counselling** (Jenny LaFontaine's chapter)

- Sharing the facts: What are we assessing for?
- How much does the patient understand? Judge the patient's level of insight
- Does the individual consent to being assessed?
- Does the individual want family or carers to be involved?
- How do they want to receive the diagnostic information?
- Answer the patients and family/carer's questions with honesty
- Allocate enough protected time for the feedback session (approximately 1 hour)
- Identify appropriate setting (where does the patient want to receive the information?)
- The level of support that the carer is currently receiving
- If risks identified, identify treatment and support package required at time of diagnosis

##### **Preparing yourself**

- Specifically understand the content of the information you are about to share
- Consider and reflect on the potential impact the diagnosis may have on the individual
- Plan a follow-up appointment with a named clinician to give to the patient at the diagnostic feedback session
- Arrange planned supervision/peer support/debrief time to discuss the diagnostic process with another clinician

## Actions

### Preparing the patient, family and carer

Step 1 reinforces the importance of Pre-Diagnostic counselling to introduce and clarify the individual's understanding of the process that they are entering. Sharing the facts is important to explain why the individual is meeting with you. It is therefore necessary to share the results from the brain scan and identify what the purpose of the neuropsychological assessment is and the potential findings that could be identified from the assessment. This involves naming the potential Dementia diagnoses that this process could identify. It is important at this early stage that the

clinician does not avoid naming the possibilities and implications. The clearer the information the more prepared the individual is for the diagnostic feedback session.

It is vital that Clinicians consider the impact of the diagnostic process on the individual, family and carer and make sense of what having dementia may mean for the individual and the family. Clarifying the current level of support that the carer receives to ascertain how they are managing will also help to identify how aware the carer is of the current difficulties. Judging the individual and the carer's level of insight and how much the individual understands is necessary in helping to prepare the individual for the potential diagnosis. It is important to clarify the format the individual wants the feedback to be given. For example, do they want a written summary and copy of the report? It is important to clarify whether they are interested in knowing the statistical findings such as the percentile ranges or whether they require a more direct upfront approach.

It is essential that sufficient time (approximately 1 hour) is allocated to meet and feedback the findings to the individual. This time should be planned in advance and protected so that the time can be used to meet the needs of the individual receiving the diagnostic information. Allowing for sufficient time further allows the clinician to go at the individual's pace as opposed to experiencing a tension to deliver all of the information in a short period of time.

It is important to determine the environment chosen to feedback the diagnostic information at the pre-diagnostic meeting. The individual may have a preference to meet at their own home, or a relative's home, or in an outpatient setting. It is important that the setting identified allows for the patient's needs to be heard, listened and responded to.

If risks identified, such as a past history of suicidal ideation, suicidal attempts, history of low mood/anxiety it is necessary to discuss with the MDT and review the treatment plan, anticipating and planning for the support package that needs to be in place at the time of the diagnosis.

Clinical experience demonstrates the need for clear and transparent processes to take place. Therefore documenting in the patient records the above pre-diagnostic information will provide other member of the MDT a good understanding of what has been discussed with the patient.

### **Preparing yourself**

In preparation for the diagnostic feedback session the key areas for the clinician to address include:

- Specifically understanding the content of the information to be shared with the individual. If it is too complicated to make sense of it will be challenging for the individual, family and carers to understand. Rehearse the content and anticipated discussions/questions likely to be asked by the individual. Consider how you can explain what the findings mean at the patient's level of vocabulary, comprehension, and speed of processing in easy to understand terms.
- Consider and reflect on the potential impact the diagnosis may have on the individual specifically recognising their protective factors, living accommodation, current responsibilities including financial, and child-care responsibilities (in light of Older Adults providing the majority of out-of-school childcare).

- Plan a follow-up appointment with a named clinician to give to the patient at the diagnostic feedback session to ensure continuity and an interface with the service. The diagnostic session is only the start of the transition to living with a diagnosis of Dementia (Tuffrey-Wijne, 2013).
- Arrange planned supervision/peer-support/debrief time to discuss the diagnostic process with another clinician to enable the time to reflect on the impact and the challenge involved with giving a diagnosis. Informed by the individual's response to the diagnostic information the time to reflect will further enable the opportunity to identify further treatment interventions that the individual would benefit from as they adjust to living with the diagnosis.

## Step 2: Provision of Information: Diagnostic Feedback session

Step 2 is focused on prompting the clinician to appropriately provide the diagnostic information to the individual being assessed, their family and carer. The focus is on assessing and reviewing the information covered previously with the aim of going at the pace required for the individual receiving the feedback. The step identifies the actions that the clinician needs to address during the feedback session with the aim of maintaining transparency and being as clear as possible to prevent confusion and misunderstanding about the information received.

### Step 2: Provision of information Diagnostic feedback session

#### Assessing and review

Assess:

- Impact of waiting for the feedback
- Any additional significant life events since assessment

Review:

- Material from pre-diagnostic session: How they wanted to receive the results?
- Identify the protected time available for the diagnostic disclosure
- Encourage any questions

#### Actions

- Adapt to the patient's level of vocabulary, comprehension, and processing speed
- Acknowledge the individual's emotion during the session
- Allow opportunities for the individual/carer to ask questions 'Do you understand?'
- Maintain eye contact, avoid speaking solely to the carer
- Name the Dementia diagnosis. Do not avoid saying the diagnosis.
- Allow time for the patient and carer to express their feelings after receiving the information
- Share your recommendations
- Follow-up appointment

### Assessing and review

It is important that the individual awaiting a diagnosis is not kept waiting for long period of time following the assessment. Therefore the waiting time between the assessment and the provision of a diagnosis should be kept to a minimum, between 2-4 weeks. At the start of the diagnostic session it is important to set the scene and assess how the individual has been managing in the time that they have been waiting for the diagnosis session. It is important to clarify if there have been any

additional significant life events since the assessment phase completed that may impact on the process of receiving the feedback. At this point it may be necessary to reassess the individual's mood and level of risk.

It is important to summarise the previous assessment meeting with the aim of signposting the individual to the information discussed in the pre-diagnostic discussion reminding the individual that the purpose of the meeting is to receive the diagnostic feedback. It is important to be clear and transparent throughout the process, as it cannot be assumed that the individual has remembered all of the content of the pre-diagnostic session.

It is useful to acknowledge the protected time available for the feedback and to clarify that the time is for the patient and/or carer to use how they want to. This is their time to make sense of the information they are receiving. It is therefore important to make clear to the individual that the meeting will go at their pace, with the focus on encouraging the individual and family/carer to ask questions at any point during the process.

### **Actions**

Whilst giving the individual the feedback it is important to adapt to the patient's use of vocabulary, comprehension, and processing speed. It is therefore necessary to give the information in small easy to understand pieces, without using convoluted language whilst judging the pace that the individual wants to hear the information. It may be appropriate for the individual to have a written copy of the findings that they can refer to. During the feedback the findings it is important to gauge how the person, carer and family are feeling and whether they require time out or a break between the discussions. It can be difficult for the individual to make sense of what they are being told, it is therefore important to determine if they understand the information shared with them and that they are prompted if they want the information to be repeated.

Although it may be challenging to do when giving the diagnosis, it is important to maintain eye contact with the individual who is receiving the diagnosis and to avoid speaking solely to the carer. It is necessary to name the Dementia as opposed to avoiding naming the Dementia, as this may add further confusion and affect the process of adjusting to living with the consequences of the illness.

After the diagnosis has been named it is important that time is protected to enable/allow the individual living with the dementia and carer to express their feelings. Although relief may be experienced from naming the diagnosis, this is just the start of understanding the diagnosis and the diagnosis giving. The individual will require time in the session to try to make sense of and understand the implications. It is therefore important that in responding to their questions honest answers are given.

After sharing the recommendation eg referrals to clinicians within/outside the MDT, neuro-rehabilitative techniques/strategies that can be adopted to help the individual manage specific difficulties they are experiencing it is important to be clear on what the individual has to do next. For example, in relation to driving the individual will be required to inform the DVLA and the Driving Insurance Company.

Prior to ending the diagnostic meeting the individual should have an appointment arranged to meet with a named clinician who will be the individual's named nurse or care co-ordinator. In some

services the care co-ordinator could be waiting outside to meet with the individual after receiving the diagnosis or can attend the diagnostic meeting with the individual's permission.

Following the end of the diagnostic meeting it is important to document clearly in the patient records the detail of the feedback session so that the MDT clinicians know the language that has been used and are aware of the impact of the diagnosis on the individual and the carer.

### Step 3: Provision of treatment and support

Step 3 focuses on the treatment approach that is required and essential to following the individual living with dementia on their journey through the transitions that they face. It is important that memory clinic services continue to offer individuals living with dementia a service that goes beyond assessing the progressive nature of the illness.

#### Step 3: Service Provision of treatment and support

Incorporating the progressive nature of the diagnostic process into the treatment

##### Assess

- Utilise screening tools to measure progression (eg. Ace-R, Mioshi et al ,2006)
- Well-being and risk
- The needs of the individual living with the dementia and the carer

##### Actions

For the individual living with dementia and the carer

- Provide information for the individual and carer
- To maintain focus on the progressive nature of adjusting to a diagnosis
- Utilise service user feedback to review and inform service provision

For the clinician

- Peer support forums and continuous training regarding giving a diagnosis

The diagnostic process does not stop once the individual receives the diagnosis (Tuffrey-Wijne, 2013), the individual and their family are continuously adjusting to the process of accommodating the dementia into their life (Steeman et al, 2006). Therefore it is important that the individual is not left without interventions following receipt of the information. Memory clinic services are faced with a balancing act to maintain observation and assessment procedures to determine the progression of the illness whilst also reflecting the journey that the individual is facing. With this understanding it is important that the individual living with the dementia does not feel unsupported or left following receipt of the diagnosis.

#### **Assess**

In order to assess the individual's physical and emotional well-being and prevent the potential of the individual being placed at risk it is important to continue to assess the progressive nature of the illness through the use of screening tools such as the Addenbrooke's Cognitive Examination-Revised

(ACE-R) and regular specialist reviews. However at the early stage of receiving a diagnosis it is important to continuously reappraise the needs of the individual living with the dementia as they continue to find a way to incorporate living with dementia into their life. Continuous reappraisal of how the individual is managing should be built into the assessment process in the post-diagnostic phase.

### **Actions**

#### **For Individuals and carers**

The purpose of a memory clinic is to assess and help the individual living with the dementia to manage their experiences through medical and psychologically underpinned interventions. With emphasis paid to reaching diagnosis targets it is important to continue to raise the profile of the individual's needs after receiving the diagnosis. Following receipt of the diagnosis the individual may be confronted with confusion, shock, relief, despair, grief and loss among many other experiences. Consequently they will go through a period of reappraisal of their life, past, present and future (Steeman et al 2006).

Therefore the provision of information, about local community services, social, occupational and psychological interventions and support groups available is necessary to reinforce that the individual and the carer can access services during their journey of living with Dementia.

Whilst paying attention to the progressive nature of the dementia it is important not to lose focus of the progressive nature of the diagnostic process. Although the individual may be experiencing mild symptoms of dementia they will be continuing to adjust to the diagnosis and accommodate it into their lifestyle. It is therefore important not to assume that the individual understands, or remembers receiving the diagnosis. The individual and their carer will continue to experience questions, confusion and uncertainty. Consequently they will experience a need for further understanding during their journey of living with the illness. It cannot be underestimated the need for the individual and their family to have the opportunity to readdress and revisit the diagnosis and the impact that it has for them.

The opportunity to reflect on the diagnosis can be provided throughout all clinical, social, occupational and psychological contacts with the individual and the carer however it is beneficial for the individual living with the dementia and the carer to have a forum to communicate those feelings in. In recognition of the transitional process of adjusting to living with a dementia, the introduction of post-diagnostic transition groups has been highlighted as a beneficial experience for both the individual living with the dementia and the carer (Murphy; unpublished, 2013). This forum facilitated by a clinical psychologist prompts the individual and the carer to think, consider and voice their experiences to other members of the group who have also recently received a diagnosis. The process enables open honest communication, and the additional time to consider and ask questions to one another about their shared experiences so far. This is an excellent opportunity for the psychologist involved and the wider service to gain a greater understanding of the live processes that are taking place for the individual's living dementia.



### For the clinician

With the awareness of the challenge experienced by clinician's when providing a diagnosis (Fisk et al., 2007; Pratt & Wilkinson, 2003; Steeman et al., 2006), it is necessary to develop cross speciality peer support forums specifically focusing on the challenge of giving a diagnosis to enable shared experiences and examples of good practice. In recognition of the observed emotionally challenging process (Milby and Murphy 2013) that can be experienced by clinician's, there is a requirement for services to invest in providing additional support structures. There is further role for educational institutions offering Clinical Psychology Doctorate training to provide training psychologists greater training in the provision of a diagnosis to match the provision of training offered to psychiatrists.

In summary the focus of step 3 is to continue to reappraise and discuss the diagnosis with the individual diagnosed with dementia as opposed to perceiving that because the diagnosis session has ended that the diagnostic process has ended for the individual and their carer.

## Step 4: Provision of time to accommodate the nature of the diagnostic process

Step 4 recognises the individual's and carer's need to further explore psychologically the meaning of the diagnosis and the impact of the diagnosis on their life, relationships and family in individual psychological therapy. Following a period of time to consider and reflect on the diagnosis it may be more challenging for some individuals and carer's living with dementia to accommodate the impact and meaning of the diagnosis into their life. At this point it is important that the time to consider and reflect on the nature of the diagnostic process is offered to the individual and/or the carer so that they can find a way to work towards making sense of the loss and grief that can be experienced.

### Step 4: Provision of time to accommodate the nature of the diagnostic process

Specialised individually tailored one-to-one psychological therapeutic intervention focused on adjusting to and living with the dementia

#### Assess

- Biopsychosocial formulation
- Risk

#### Actions

- Psychological interventions
- Social and occupational interventions
- Medication
- Regular specialist reviews

At step 4 individualised assessments and interventions adopting specific psychological frameworks to focus on exploring the experiences and needs of the individual and the carer. At this level, psychological therapists with specialist training in family therapy, group therapy, CBT, CAT and

psychodynamic approaches and skills are required to therapeutically work with the individual and/or the carer in their adjustment to living with dementia.

### **Assessing**

At this step Clinical Psychologists specifically trained to deliver idiographic formulations should take the lead at developing individually tailored interventions. Specialist practitioners may do this from a range of formulation models (the Roseberry Park model, Dexter-Smith, 2010; Newcastle Columbo model, James, 2011) or psychological therapeutic perspectives. The formulation models referenced above have structural frameworks and protocols on how they should be utilised. The end product of the formulation process, would be an individually focused intervention specific to the person with dementia, and the carer.

At the point of formulation and intervention planning it is necessary to review the individual's care including assessment of risk psychological interventions; social and occupational interventions; medication and regular specialist reviews.

### **Action**

Compared with the previous steps the actions to address appears less, however as a direct result of the individualised formulation process there will be more clinicians involved applying specialist clinical knowledge and skill in the individualised intervention planning to address the individual's and carer's needs.

Further psychological, occupational and social interventions will support the individual in exploring their experience of living with dementia with the aim of helping the individual and the carer to explore ways to communicate and understand that experience.

## **Summary**

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1. The number of people with a formal diagnosis has increased since the launch of the National Dementia Strategy (DoH, 2009). With clear targets to increase rates of early diagnosis, approximately half of people living with a dementia have not been formally given a diagnosis (DoH, 2012).
2. In response to the increased volume of referrals from Primary Care seeking a memory assessment to Memory Clinics, and the increase in referrals for a neuropsychological assessment this is an exciting opportunity to embrace as Clinical Psychologists to invest our skills, knowledge and application in the process of giving a diagnosis. Clinical experiences informs us that Clinical Psychologists working into Memory Clinics who routinely write neuropsychological reports and identify diagnosable causes of individual memory problems are not routinely involved in the final process of the diagnostic process.
3. The argument put to the members of the Faculty of Psychologists working with Older Adults is that Clinical Psychologists are best placed following consultation with the Multi-Disciplinary Team (MDT) to complete the diagnostic process and communicate the diagnosis to the individual. The combination of Clinical Psychologists' neuropsychological and therapeutic skills allows us to have a significant wealth of experience and knowledge specifically relating to the sensitivity required for the diagnostic disclosure. However, these skills are under-utilised, resulting in longer waiting times for a diagnosis from the memory clinic and for a memory assessment appointment. With the inclusion of Clinical Psychologists

making diagnoses, there will be a direct impact on waiting times between assessment diagnosis, resulting in a reduction in waiting times for a memory clinic and/or neuropsychological assessment appointment.

4. However, the disclosure of a diagnosis is a difficult part of a clinician's practice (Bamford et al., 2004; Iliffe, Menthorpe, & Eden, 2003). More than 50% of clinicians reported 'always' giving the diagnosis as difficult (Iliffe, Eden, Downs and Rae, 1999). Giving a diagnosis has been identified as one of the five most difficult aspects of dementia care (Rae, McIntosh, & Colles, 2001).
5. Looking at more specific dementia policies, the DoH (2009) 'National Dementia Strategy' refers to 'breaking the diagnosis sensitively well to the person with dementia and their family' (p.37). Additionally, the 'The Prime Minister's Challenge on Dementia' identifies that a 'timely' diagnosis should be made. Although these are recent and well recognised documents in dementia care, they do not address how and what the best practices are in disclosing a diagnosis. Therefore there are no specific guidelines on how to disclose a diagnosis of dementia that incorporates the diagnostic interview and the transitional adjustment that progressively takes place post-diagnostically over a period of time.
6. There are many challenges for the professional giving the diagnosis, and the individual living with the dementia and their caregiver receiving the diagnosis. Some challenges are unique to all three parties but there are many overlapping difficulties (Milby & Murphy, unpublished thesis, 2013), taking place during a diagnostic procedure in addition to the organisational and service level challenges.
7. The 4 steps describe the level of assessment and actions required when preparing and making a diagnosis of Dementia. The stages range from the Preparation and understanding of the information where the focus is on preparing your patient, family and carers and preparing yourself as the clinician to give the diagnosis (Step 1), the Provision of the diagnostic information (Step 2), Provision of treatment and support incorporating the progressive nature of the diagnostic process into the treatment approach (Step 3), and the Provision of time to accommodate the nature of the diagnostic process, recognising the need to provide the time to allow for full disclosure and an understanding of the progressive nature and impact of receiving a diagnosis over a period of time (Step 4).

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