Evidence briefing: Making and sharing a diagnosis of dementia

The aim of this briefing paper is to provide an overview of the psychological dimensions of the process of assessing a person with a suspected dementia, diagnosing dementia if present, and sharing the outcome with the person and their family. The document aims to summarise research and best practice in this area to aid commissioners and other stakeholders in shaping the service landscape. It is not intended to be read as a set of recommendations for practitioners.

Key messages

- The rights and wishes of the person with suspected dementia should be paramount in engaging with the assessment process used to achieve a diagnosis. While progress in increasing the numbers of people receiving a diagnosis of dementia is welcomed, the risk of prioritising quantity over quality of experience remains. The wide variation in the needs and preferences of people who may be developing dementia requires choices in the type and intensity of interaction with services.

- A diagnosis may be made at any age and any point during a person’s journey with dementia. The research literature recommends access to diagnosis at a time when people are able to use this information to make sense of what is happening to them, make lifestyle changes and plan for the future. However, for many people a diagnosis is made not at the onset of cognitive decline but at a much later point in their experience of dementia. Diagnosis needs to be available at every stage of the dementia journey and the content and rigor of the assessment process adjusted in the best interests of the person with dementia, taking into account the needs of their family or carers.

- The diagnostic process should involve an assessment of cognition (alongside behaviour, emotion, motor and perceptual function). Choosing the optimum level of cognitive assessment and selecting the most appropriate cognitive assessment tools from the range available requires sound clinical judgement. Memory assessment services need dedicated sessional time from clinical psychologists and neuropsychologists who have the highest levels of expertise in conducting such assessments.

- Giving and receiving a diagnosis of dementia is a key intervention in the complex adjustment process to living with dementia. Before the formal diagnostic assessment takes place, the person and (with permission) family members/significant others should be provided with appropriate information and given an opportunity to discuss their expectations, experiences, hopes and fears. Good practice in pre-assessment counselling and establishing informed consent lays the foundation for future engagement with services and maximises the advantages of early diagnosis. Sharing the diagnosis is one aspect of a communication strategy which needs to span the
entire process. Skills training, an understanding of the psychological impact of diagnosis and supportive supervision are required for staff undertaking this task³.

- All diagnoses should be followed by information, emotional and practical support (if required) and signposting to other services. Successful adjustment to a diagnosis of dementia is key to the envisaged health and economic benefits of receiving a diagnosis early. However, the process of adjustment is dependent on the availability of postdiagnostic support, including psychosocial interventions, particularly for those who do not benefit from currently available medication².

Examples of good practice

- **Memory Assessment Service, Birmingham and Solihull Mental Health NHS Trust**

  - **Pre-assessment counselling.** All senior practitioners (generally mental health nurses and occupational therapists) working in the service have received specialist training and supervision in preparing people for the assessment process and ensuring that, if at all possible, they give informed consent to proceed. This pre-assessment counselling is offered to everyone referred to the service (including, with their permission, family members), irrespective of the severity of their cognitive impairment, before formal assessment commences. In addition to explaining the components of the assessment process itself, discussions cover the person’s understanding of their cognitive changes, the possible implications of receiving a diagnosis, ascertaining their choice about how and where the outcome of the assessment will be communicated and who else (if anyone at all) they would like to be present. This is a structured process supported by formal recording of the discussions and outcomes.

- **Early Intervention Dementia Service, Worcestershire Health and Care NHS Trust**

  - **Continuity of Person-Centred Care.** Following referral to the team, the first appointment usually takes place in the person’s home with the nurse for their locality and focuses on pre-assessment counselling. If someone then makes an informed choice to pursue an assessment, the same nurse continues to coordinate the person’s care during their time with the service and will usually be present when a diagnosis of dementia is confirmed. Seeing diagnosis as a process (rather than a single event) allows members of the team (the named nurse in particular) to build a relationship with the person and their family, and therefore tailor the process to meet their needs. Following diagnosis, everyone is offered a personalised letter which aims to confirm and explain the diagnosis in a way that is helpful to them. Understanding the person and those around them and building quality relationships allows postdiagnostic support to be tailored to their needs and facilitates adjustment to the diagnosis of dementia.

Calls to action

- Clear pathways for assessment and diagnosis at every stage of the dementia journey need to be developed and disseminated.
- Pre-assessment counselling is an essential standard for services making dementia diagnoses, involving sufficient discussion to enable informed decision making by the person with suspected dementia.
-Diagnostic services should be underpinned by a communication strategy which meets the need of all sectors of the community they serve.
- Services making dementia diagnoses require access to high levels of neuropsychological expertise to undertake comprehensive cognitive assessments where these are indicated.
- A clear structure of supportive supervision is required for staff involved in the process.

The future development of the diagnostic process should be shaped by the views of experts by experience.

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Key references