

# The Facts about...

# **Dementia Diagnosis**

In the UK it is estimated that 800,000 individuals are living with dementia, yet fewer than 50% of that number are ever formally diagnosed.

There is a belief that dementia is part of normal ageing and that nothing can be done to contribute to the low diagnosis rate.

The Department of Health has tried to raise awareness and to encourage people to come forward for investigation and treatment.

Attempts have been made to counter stigma and to increase awareness of dementia and its early symptoms.

### Why is Diagnosis Important?

Diagnosis empowers the person living with dementia to make decisions and plan for the future.

Diagnosis allows family discussion and planning - such as putting in place Power of Attorney, long term care planning.

# Why Worry About a Formal Diagnosis?

The goal of diagnosis is to eliminate any other possible condition that could be creating dementia-like symptoms.

It is important to distinguish between dementia and depression. Both conditions are associated with impairment of thinking and a diminished interest in activities. Both in dementia and depression, the symptoms can be disruptive to daily activity.

Depression is more common than dementia in older people. Ruling out depression is an important step in diagnosing dementia. Distinguishing dementia from the mild normal cognitive decline of advanced age is critical.

# How is Dementia Diagnosed?

The first port of call for people who are concerned that they, or a relative, may have undiagnosed dementia is their GP.

The GP will ask about the symptoms and other aspects of the patient's health.

They will do a physical examination.

They will organise blood tests and establish what medication the patient is taking, as these can sometimes cause symptoms similar to dementia.

They will ask questions or give the patient some memory exercises to measure any problems with memory or the ability to think clearly.

Dementia can be difficult to diagnose, especially if symptoms are mild.

If the GP is unsure about the diagnosis, they will refer the patient to a specialist such as a neurologist (an expert in treating conditions that affect the brain and nervous system), an elderly care specialist or a psychiatrist with experience of treating dementia.

The specialist may be based in a memory clinic alongside other professionals who are experts in diagnosing, caring for and advising people with dementia and their families.

Further tests that may assist in diagnosis include brain scans such as a computerised tomography (CT) scan, or preferably a magnetic resonance imaging (MRI) scan.

If there is still uncertainty about the diagnosis further, more complex, tests may be required.

### What Happens After Diagnosis?

Once the necessary tests have been completed, the doctor will ask the patient if they want to know their diagnosis. They will explain what having dementia might mean for them. They will give the patient the opportunity to ask any questions they may have.

The doctor or a member of their team should explain to the patient and to their family:

- ✓ the type of dementia the patient has or, if it is not clear, what the plan to investigate
  further will entail. Sometimes, despite investigations, a diagnosis may not be clear, in
  which case the doctors will review the patient again after a period of time to reassess
- ✓ details about symptoms and how the illness might develop
- ✓ appropriate treatments that might be offered
- ✓ care and support services in the local area, including support groups and voluntary organisations for people with dementia and their families and carers
- ✓ where to find financial and legal advice

# Linking Diagnosis to Support

Carers or families should be involved in the assessment process.

Outcomes are better for everyone when diagnosis and support is in place.

Ethical issues around patient confidentiality need to be considered but weighed against the impact of diagnosis on the family.

Diagnosis must lead to person-centred care, including treatment of physical conditions which may also be present.

Wider networks, such as support groups, specialist organisations and local resources must be signposted to the patient, family and/or carer.

### **Support services**

#### Helpline:

 Call Dementia UK's Helpline on 0800 888 6678 or send an email to helpline@dementiauk.org

#### **Online Communities:**

- Alzheimer's Society has an online community called Talking Point Forum. https://forum.alzheimers.org.uk/
- Dementia Awareness has a Facebook support group 'Dementia Awareness. Every Day'.

#### Support groups:

- Find a support group in your area through Young Dementia UK https://www.youngdementiauk.org/support-across-uk
- Dementia Awareness support group (Facebook)
- Dementia Alliance International; a weekly online peer-to-peer support group. For more information email <a href="mailto:info@infodai.org">info@infodai.org</a>
- Dementia support group for under 21's (Facebook) https://www.facebook.com/dementiasupportu21?fref=ts
- Dementia Mentors offer virtual memory cafes. This is a virtual social gathering for those living with dementia. dementiamentors@gmail.com

### Diagnosis should be "more than diagnosis"

#### To contact Share and Care Homeshare:

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This fact sheet should only be used as a guideline and we recommend you seek professional advice.