Dementia

Introduction
Dementia describes a set of symptoms that may include memory loss and difficulties with thinking; problem solving or language and is caused when the brain is damaged, most commonly by diseases such as Alzheimer’s disease (the most common cause) or a series of strokes. The specific symptoms that someone with dementia experiences will depend on the parts of the brain that are damaged and the disease that is causing the dementia.

There are around 800,000 people with dementia in the UK, and the disease costs the economy £23 billion a year. By 2040, the number of people affected is expected to double - and the costs are likely to treble.

Risk factors and vulnerable groups
The causes of dementia are not fully understood. Dementia can affect anyone whatever their gender, ethnic group or class; however, the risk of developing dementia increases as one gets older (the condition usually occurs in people over the age of 65). There are modifiable and non-modifiable risk factors of dementia as shown in Table 39. Actions to change the modifiable risk factors are described in other sections of the JSNA.

Table 39: Risk factors for dementia

<table>
<thead>
<tr>
<th>Non-modifiable risk factors</th>
<th>Modifiable risk factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (the greatest risk factor)</td>
<td>Diabetes (see section 10.2)</td>
</tr>
<tr>
<td>Genes</td>
<td>Harmful drinking (see section 9.6; 10.5.3)</td>
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<tr>
<td>Family history</td>
<td>High cholesterol (see section 10.3.2)</td>
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<tr>
<td>Down’s syndrome</td>
<td>History of depression (see section 9.2)</td>
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<td></td>
<td>Hypertension (see section 10.3)</td>
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<tr>
<td></td>
<td>Low educational attainment or cognitive inactivity (see section 11.5.4;11.5.5;11.7.1;11.7.2)</td>
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<td></td>
<td>Obesity (see section 7.2.3;9.4)</td>
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<tr>
<td></td>
<td>Physical inactivity (see section 9.3;11.8.2;12.2.3)</td>
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<tr>
<td></td>
<td>Smoking (see section 4.3;5.2;9.7)</td>
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Source: Alzheimer’s disease International

Once a person has dementia they will get progressively worse over time until the end of their life. Although most types of dementia cannot be cured, if it is detected early there are ways it can be
slowed down and mental function maintained for a period of time. Treating the symptoms of dementia and offering appropriate support services can make a significant difference to the lives of people with dementia, their families and carers.\(^\text{v}\)

The numbers of young people with dementia are small. However, there are certain types of dementia inherited as a single gene that can cause the disease amongst those under 65 (known as early-onset dementia).\(^\text{vi}\)

There is an association with learning disabilities, as the incidence of dementia for those with Down’s syndrome is about twelve times higher than general population.\(^\text{vii}\)

There is a growing body of evidence suggesting prevalence of dementia is greater among African-Caribbean and South Asian UK populations. African-Caribbean communities may also experience a lower age of onset due to the increased presence of risk factors for vascular dementia, such as hypertension.\(^\text{viii}\)

**What is the evidence base?**

The National Dementia Strategy contained 17 key objectives covering three main areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care.\(^\text{ix}\) This was followed by an outcome focused implementation plan covering four priority objectives:\(^\text{x}\)

- Good quality early diagnosis and intervention for all.
- Improved quality of care in general hospitals.
- Living well with dementia in care homes.
- Reduced use of anti-psychotic medication.

A good practice compendium was also developed to support local delivery.\(^\text{xi}\)

NICE also provides a range of guidance\(^\text{xii}\) and other materials on dementia including:

- Quality standards for supporting people to live well with dementia.\(^\text{xiii}\)
- Guidance with recommendations for the identification, treatment and care of people with dementia and the support of carers as well as best practice advice emphasising the principles of a person-centred approach.\(^\text{xiv}\)
- Support for commissioning dementia care – summarising key commissioning issues and the resource impact of NICE recommendations.\(^\text{xv}\)

**Local picture**

It is estimated that 1,759 people in Luton aged 65 and above will have dementia in 2015\(^\text{xvi}\) whereas those recorded on the dementia GP register as of 2013/14 was only 924\(^\text{xvii}\) suggesting more than 50% of patients with dementia could be unknown to their GPs. The prevalence of dementia in Luton is estimated to be 0.42% of the population (Figure 103).\(^\text{493}\)

The Mental Health Observatory briefing projected in 2008 that 2,256 people in Luton would have dementia in 2015, an increase of 22% from the estimated figure of 1,756 people in 2008. The projection predicts that more women (1,320) will have dementia than men (935).\(^\text{xviii}\)
The percentage of patients diagnosed with dementia whose care has been reviewed in a face-to-face review in the preceding 12 months was 75.3% during 2013/14. This was lower when compared with Luton comparator areas as shown in Figure 104. Source: CQRS and GPES database - 2013/14 data as at end of June 2014, Health and Social Care Information Centre.

The percentage of patients with a new diagnosis of dementia recorded in 2013/14 with a record of full blood count, calcium, glucose, renal and liver function, thyroid function tests, serum vitamin B12 and folate levels recorded between 6 months before or after entering on to the register is the lowest compared with Luton’s comparator areas and among the lowest nationally (Figure 105). This is an indicator used to identify whether reversible dementia screen has been carried out to rule out other causes of cognitive impairment.
Figure 105: Patient with a new diagnosis of dementia.

Early on-set dementia (aged 30-64 years)

People diagnosed with dementia under the age of 65 are often described as younger people with dementia by health and social care professionals. Other terms used include early onset dementia, young-onset dementia, and working age dementia. The symptoms of dementia may be similar regardless of a person's age, but younger people may have different needs and require some different types of support. Currently, there are approximately 40-50 people with early onset dementia in Luton. There is a recognition that more needs to be done to decide how best to support these individuals and discussions with the Alzheimer’s Society are taking place on how best to provide this.

What is being done locally?

A multi-agency Dementia Strategy Group has been operating since 2010 supported by three work stream groups which have implemented the objectives of a Joint Commissioning Strategy for Dementia Services in Luton. An overarching care pathway for dementia services was established and this has been refined in the last two years with the development of a number of more detailed, subsidiary pathways (for example GP involvement and specialist diagnosis). The strategy has two main areas of focus:

1. Ensure better knowledge about dementia and remove the stigma
   a. Removing stigma - by becoming a dementia-friendly community.
   b. Raising awareness – through an annual dementia conference for both professionals and the general public.
   c. Training of staff and public- education and training for all public-facing organisations (26 local organisations and businesses have signed up) and there are over 40 dementia champions and over 3,000 dementia friends trained.
2. Ensure early diagnosis, support and treatment for people with dementia and their family and carers.
   a. Early Diagnosis - ensuring GPs have adequate training to recognise the signs and symptoms of the early stages of dementia and then refer to the Memory Assessment Service, where support services are available at the point of diagnosis.
   b. Provision of support services for people living with dementia, including: cognitive stimulation, activity groups, peer support networks, singing for the brain, music therapy and dementia cafés.
   c. Support for families and carers - Carers Information and Support Programme (CrISP) and Information Programme for South East Asian Families (IPSAF) which provide training to families and carers of people living with dementia at different stages of the disease.
   d. Services to meet changing needs – Luton & Dunstable hospital has a nurse dementia specialist to ensure people have a good experience when they are at the hospital and Hospital to home supports people living on their own when they return home following a stay from hospital.

**Perspective of public/service users**

There has been a range of views collected from the public and professionals through training and dementia conferences held in Luton. Many carers, family and friends and those living with dementia reported a range of materials locally and nationally to support them and they could find support when needed. It is recognised locally that Luton is providing a range of services not available in other areas, and that support is available but people are not always aware of it.

**Priorities**

1. Review and refresh the Dementia Strategy for Luton connecting preventative actions on modifiable-risks to reduce dementia – this will be done in line with the New National Strategy.

2. Increase number of people identified and treated for dementia within primary care.

3. Increase the number of professional staff and community members trained as Dementia Friends.

4. Co-produce a response to the issue of carer breakdown/crisis and how to reduce this.
References


