Welcome to Luton’s Annual Dementia Conference
9th November 2016
Sponsored by
House-Keeping

- Presentation Slides
- Photo Disclaimer
- Mobile Phones
- Need a Break?
- Toilets & Fire Alarm

#dementialuton2016
Cllr. Aslam Khan
Portfolio Holder – Public Health, Commissioning & Procurement
Luton Borough Council

Welcome & Opening Address
'Friends with Voices'

A collaboration from across Luton.
Stephen Gunther
Service Director
Healthcare and Adults Commissioning
Luton Borough Council

The Luton Perspective
Age is the biggest risk factor for dementia

The ageing population is fuelling the growth in cases of dementia

11.4 million people in the UK

65+

This figure is projected to rise by over 40% in the next 17 years to over 16 million

By 2040

nearly 1 in 4 people in the UK (24.2%) will be aged 65 or over

1 in 688 people under 65 have dementia

1 in 14 people over 65 have dementia, and this rises to 1 in 6 for people over 80

1 in 688 people under 65 have dementia
<table>
<thead>
<tr>
<th>YEAR</th>
<th>0-4</th>
<th>5 to 15</th>
<th>16-17</th>
<th>18-64</th>
<th>65-89</th>
<th>90+</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>16,700</td>
<td>30,150</td>
<td>5,400</td>
<td>127,400</td>
<td>23,050</td>
<td>950</td>
<td>203,650</td>
</tr>
<tr>
<td>2021</td>
<td>18,050</td>
<td>36,050</td>
<td>5,650</td>
<td>142,600</td>
<td>27,150</td>
<td>1,450</td>
<td>231,000</td>
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<tr>
<td>2031</td>
<td>18,650</td>
<td>38,000</td>
<td>6,600</td>
<td>154,550</td>
<td>33,800</td>
<td>2,400</td>
<td>254,050</td>
</tr>
</tbody>
</table>

2011-21 Change
|          | 1,350 | 5,900  | 250   | 15,200 | 4,100  | 500    | 27,350 |

2011-31 % Change
|          | 8.1%  | 19.6%  | 4.6%  | 11.9%  | 17.8%  | 52.6%  | 13.4%  |

2011-31 Change
|          | 1,950 | 7,850  | 1,200 | 27,150 | 10,750 | 1,450  | 50,400 |

2011-31 % Change
|          | 11.7% | 26.0%  | 22.2% | 21.3%  | 46.6%  | 52.6%  | 24.7%  |

Proportions
<table>
<thead>
<tr>
<th>YEAR</th>
<th>0-4</th>
<th>5 to 15</th>
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</thead>
<tbody>
<tr>
<td>2011</td>
<td>8.2%</td>
<td>14.8%</td>
<td>2.7%</td>
<td>62.6%</td>
<td>11.3%</td>
<td>0.5%</td>
<td>100%</td>
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<tr>
<td>2021</td>
<td>7.8%</td>
<td>15.6%</td>
<td>2.5%</td>
<td>61.7%</td>
<td>11.8%</td>
<td>0.6%</td>
<td>100%</td>
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<tr>
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<td>15.0%</td>
<td>2.6%</td>
<td>60.8%</td>
<td>13.3%</td>
<td>0.9%</td>
<td>100%</td>
</tr>
</tbody>
</table>
4 Lifestyle Behaviours
- Smoking
- Drinking
- Inactivity
- Diet

4 Chronic Diseases
- Respiratory Disease
- Heart Disease
- Cancer
- Stroke

Lead to
Which cause

54% of Deaths

From Plymouth
Around a **third** of Alzheimer’s disease cases might be attributable to potentially modifiable risk factors.

A **20% reduction** in risk factors per decade could reduce UK prevalence by **16.2%** (300,000 cases) by 2050.

**What’s good for the heart is good for the brain**

[www.luton.gov.uk](http://www.luton.gov.uk)
How to protect against dementia

Volunteering
Meeting friends
Reading
Puzzles
Crosswords
Learning a second language
Social engagement
Education
Cognitive stimulation
Once diagnosed:

“the most effective therapies for mild-to-moderate dementia (and perhaps those with the least potential for adverse effects) seem to be exercise and helping the patient/caregivers provide the most useful interventions to improve the ADLs [Activities of Daily Living], provide meaningful activities for the patient, etc.”

Reduce the risk of dementia by:

- developing and implementing guidance and policies to reduce alcohol consumption across the population
- supporting people to eat healthily
- developing, delivering and enforcing comprehensive local tobacco control strategies, in line with current policy
- improving environments where people live and work to encourage and enable everyone to build physical activity into their daily lives
- addressing loneliness and encouraging people to be socially active and mentally stimulated

www.luton.gov.uk
Wellbeing and economic prosperity are intimately linked. The wellbeing of our population is a key asset for our economic prospects, but equally a thriving economy is essential for good health.
Strategic Priorities

- Building economic growth and prosperity
- Enhancing skills and education
- Improving health and wellbeing
- Developing quality homes and infrastructure
- Supporting safe, strong and cohesive communities
- *Integrated, efficient and digital service delivery – striving for a ‘one Luton’ approach*
People Plan

“We have great ambitions for Luton, but to turn them into reality we need the right people in the right jobs”

Sets out how we provide staff and managers with the skills and opportunities they need to fulfil their potential.

Help achieve the Council mission:

“Enabling Luton to be proud, vibrant, ambitious and innovative”
VISION WITHOUT EXECUTION IS HALLUCINATION.

-thomas a. edison
Pat Mooney

Living with Alzheimers
Hobbies
Luton Dementia Action Alliance – Working to make Luton a Dementia Friendly Community

http://www.luton_dementia_action_alliance

Luton DAA Chair – Maria Collins
Luton DAA Coordinator – Sian Gilleard
Contact via sian.gilleard@alzheimers.org.uk

Update 1/11/16  01582 470910
850,000 people live with dementia in the UK

...if we don’t take action this number is predicted to rise to over two million by 2051.

2,092,945

...more than the entire population of Liverpool, Manchester and Birmingham combined.

1,142,677

...more than the entire population of Birmingham, the UK’s second largest city.

850,000

2015

2025

2051
What is dementia?

Dementia is caused by diseases of the brain, the most common of which is Alzheimer’s. The chart shows the following percentages:

- Alzheimer’s disease: 62%
- Vascular dementia: 17%
- Mixed dementia: 10%
- Rarer causes of dementia: 5%
- Dementia with Lewy bodies: 4%
- Frontotemporal dementia: 2%
1. Dementia is not a natural part of ageing
2. Dementia is caused by diseases of the brain
3. It’s not just about losing your memory
4. It’s possible to live well with dementia
5. There’s more to a person than the dementia

The risk of dementia increases with age

1 in 688 people under 65 have dementia.
1 in 14 people over 65 have dementia.
1 in 6 people over 80 have dementia.
Why do we need **Dementia Friendly Communities**?

For the benefit of those living with dementia

Too many people with dementia aren’t living as well as they could

34% do not feel part of their community.

Too many people with dementia aren’t living as well as they could

40% felt lonely recently.

Why do we need Dementia Friendly Communities?

For the benefit of those caring for loved ones living with dementia

Unpaid carers: overworked, under supported

1,340,000,000 hours were spent caring for people with dementia in 2013. That’s more than 150,000 years.

43% of carers do not receive enough support.
Why we do need Dementia Friendly Communities?

To ensure our community meets the needs of those affected by dementia.

No two people with dementia are the same – services need to reflect the needs of individuals.

7 out of 10 people are living with another medical condition or disability as well as dementia.

1 out of 20 people living with dementia are under the age of 65.
Building dementia-friendly communities: A priority for everyone

Only 47% of survey respondents feel a part of their community.

When asked what they have had to stop doing, people said:

- 28% getting out of the house
- 22% exercise
- 16% transport
- 23% shopping
- 9% have had to give up everything
Building dementia-friendly communities: A priority for everyone

63% of people with dementia do not wish to try new things in their community.

To do more in their local area, people with dementia want:

- 35% more care and support...
- 14% of which want more support to organise activities
- 14% better transport
- 10% improved health
Building dementia-friendly communities: A priority for everyone

When asked how often they left the house:
- 35% go out once a week or less
- 10% go out once a month or less
Building dementia-friendly communities: A priority for everyone

66% of people with dementia did not feel they could contribute to their community.

However when people thought they could, suggestions included:

- 10% socialising
- 8% volunteering
- 6% sharing skills
- 3% helping out at religious services
Building dementia-friendly communities:
A priority for everyone

People with dementia feel their biggest barriers to participating in their local area are:

- Lack of confidence: 69%
- Worried about becoming confused: 68%
- Getting lost: 60%
- Mobility difficulties: 59%
- Physical health: 59%
- Not wanting to be a burden: 44%
- Transport: 33%
- Lack of opportunity: 33%
Building dementia-friendly communities:
A priority for everyone

The opportunity for change:

- **33%** of people think that shops and local businesses would benefit in areas where people with dementia were supported to be more involved in their local community.
- **47%** think that dementia-friendly areas would be nicer places for everyone to live.
- **74%** think supporting people to be a part of the community would help reduce stigma.
- **40%** think everyone has a role to play to support people with dementia in their community.
- **3%** think that people with dementia don’t have anything to offer their communities.

Source: YouGov
Empowering people with dementia to have high aspirations, confidence and know they can contribute.

Becoming dementia friendly means:

- Shaping communities around the views of people with dementia and their carers
- Ensuring early diagnosis, personalised and integrated care is the norm
- Maintaining independence by delivering community-based solutions
- Appropriate transport
- Challenging stigma and building awareness
- Empowering people with dementia and recognising their contribution
- Businesses and services that respond to customers with dementia
- Ensuring that activities include people with dementia
- Easy to navigate physical environments
- Befrienders helping people with dementia engage in community life
The National Dementia Declaration – Seven “I” statements

• I have personal choice and control or influence over decision about me
• I know that services are designed around me and my needs
• I have support that helps me live my life
• I have knowledge and know-how to get what I need
• I live in an enabling and supportive environment where I feel valued and understood
• I have a sense of belonging and of being a valued part of my family, community and civic life
• I know there is research going on which delivers a better life for me now and hope for future
People in Luton living with dementia

Luton - Sept 2016 - 66.5% Diagnosis rate
Estimated prevalence 1,676
On Dementia Register 1,115

* Source HSCIC Sept '16
A Dementia Friend learns a little bit more about what it's like to live with dementia and then turns that understanding into action.

You don't need any previous experience or knowledge of dementia to be a Dementia Friend but you do need to want to know a little bit more about what it's like to live with dementia and then turn that understanding into something that could make a difference to people with dementia living in Luton.

Please join us. Because, together, we can create more dementia friendly communities.

To become a Dementia Friend you can attend a one hour information session or you can learn the key messages by registering online https://www.dementiافriends.org.uk/register-digital-friend
Luton DAA Members

Transport

- Centrebus
- Grant Palmer

Housing

Arts, culture, leisure and recreation

- active Luton
- Luton Town Football Club
- Luton Culture
Luton DAA Members

Health and social care

Luton DAA Members

East London NHS Foundation Trust

Cambridgeshire Community Services NHS Trust

NHS Leagrave Surgery

Bramingham Park Medical Centre

Generix Care

Quantum Care

Keech hospice care

Luton

Gardenia & Marsh Farm Practice Dr Z Ahmad & Partners

Larkside Practice

Clinical Commissioning Group

Bedsfordshire Local Pharmaceutical Committee

Community Dental Services

JADE

Bedfordshire Northamptonshire Cambridgeshire and Hertfordshire Probation Community Rehabilitation Company

Luton DAA Members

To us, it’s personal

healthwatch Luton

POhWER

advocacy, making your voice heard

Clincal Excellence, Quality & Safety
Luton DAA Members

Community, voluntary, faith groups and organizations

- Stroke Association
- Alzheimer's Society
- Disability Resource Centre
- The Stopsley Tent Project
- MEANINGFUL EDUCATION
- MUSIC 24
- Luton Irish Forum
- Roman Catholic Parish of The Holy Family and St John the Apostle
- The Gospel Pentecostal Reconciliation & Restoration Centre
- Age Concern Luton
- Citizens Advice Luton
Our Future Ambitions
Back by 12.00 noon please.
Luton’s New Dementia Strategy

Kimberly Radford
Commissioning Manager

Kimberly.radford@luton.gov.uk
The old strategy expired last year – it needed a complete re-write, to incorporate the 2020 Challenge on Dementia and to ensure we are fit for purpose moving forward.

There has been a huge amount successfully achieved over the last 4 years in Luton and much of this is due to the commitment of individual organisations and the very strong partnership working that has grown from: -

• The original Dementia Strategy Working Groups
• The Luton Dementia Action Alliance

It was time to take stock and begin planning for the next four years – in light of this we have coproduced Luton’s new Dementia Strategy.

www.luton.gov.uk
Who has been involved?

People Living with Dementia & their Carers
What have we already achieved?

- A well established LLDAA with over 40 organisations signed up as members
- Luton met the national dementia diagnosis target in July 2016.
- The ELFT (East London Foundation Trust) Memory Assessment Service had an ‘outstanding inspection’ in 2016 and have kept their MSNAP (Memory Services National Accreditation Programme) Accreditation over the last four years
- Keech Hospice are working towards becoming a dementia friendly hospice and have begun working with people living with dementia and their families
- We delivered a coproduction project looking at the reasons and solutions for Carer stress and break down, which has been fed into this strategy
- We have produced our own local ‘Luton Dementia Guide’, a guide written for carers by carers – hugely welcomed by all
- We have increased the amount of post diagnostic support available to people living with dementia and their carers in Luton – demonstrated by ‘Friends with Voices’
What does it do?

This strategy sets out our vision for the development and commissioning of services and support for people living with dementia and their carers over the next four years.

Inputs
Actions from work plan (p.26)

Outputs
Themes (p.18)

Outcomes
‘I’ Statements (p.9)
The ‘I’ statements

People with dementia have told us what is important to them – they want a society where they are able to say: -

• I have personal choice and control over the decisions that affect me.
• I know that services are designed around me, my needs and my carers' needs.
• I have support that helps me live my life.
• I have the knowledge to get what I need.
• I live in an enabling and supportive environment where I feel valued and understood.
• I have a sense of belonging and of being a valued part of family, community and civic life.
• I am confident my end of life wishes will be respected.
• I can expect a good death.
• I know that there is research going on which will deliver a better life for people with dementia, and I know how I can contribute to it.
Key themes:

The Strategy covers 7 theme areas:

1. Enabling equal, timely access to diagnosis and support.
2. Promoting health and wellbeing.
3. Developing a dementia friendly town
4. Supporting carers of people with dementia
5. Ensuring Excellent Quality of Care
6. Preventing & Responding to Crisis

7. Evidence based commissioning - Supporting theme
How will we get there?

Work plan - Live document

<table>
<thead>
<tr>
<th>1. Enabling equal, timely access to diagnosis and support.</th>
<th>Action</th>
<th>How</th>
<th>Who</th>
<th>When</th>
<th>‘I’ Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>a</td>
<td>Ensure Luton continues to meet the national target for dementia diagnosis of 66.9% registered on QOF register - Luton currently meets this target - September 2016</td>
<td>A plan to be devised to ensure that all people living in nursing/care homes or in a high risk group to be assessed for cognitive functioning/dementia using DOH recognised tools e.g. GP’s to check all residents on prescribed Antipsychotic medication or high number of falls etc.</td>
<td>CCG</td>
<td>March 2017</td>
<td>B,C,E</td>
</tr>
<tr>
<td></td>
<td></td>
<td>A Quality Improvement project focussed on Memory Clinic review processes and systems is currently underway, working with service users To detail and implement outcomes from project.</td>
<td>ELFT</td>
<td>March 2017</td>
<td>B,E</td>
</tr>
<tr>
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<td>ELFT</td>
<td>TBA</td>
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<td></td>
<td></td>
<td>Explore to evaluate that cognitive function is assessed at annual health checks and that hospital or nursing home recommendation to check dementia diagnosis query are being followed up</td>
<td>CCG</td>
<td>December 2016</td>
<td>B,C,E</td>
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<tr>
<td></td>
<td></td>
<td>Clinical leads from CCG to offer support to GP’s to diagnose people with dementia where needed</td>
<td>CCG Clinical Leads</td>
<td>December 2017</td>
<td>B</td>
</tr>
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</table>
Luton leading the way.........

Alzheimer's Society - Dementia-friendly personal budgets charter..

• We have developed a set of principles that we believe will ensure personal budgets work effectively and improve the lives of people affected by dementia.

• We want every local authority to sign up to these principles and demonstrate their commitment to dementia-friendly personal budgets.

We want every person with dementia to have choice and control over their lives through their personal budget.

www.luton.gov.uk
Supporting people living with dementia

Presented by Chief Inspector Jaki Whittred and Sergeant Phil Boyd
Policing and Mental Health

- Beds Police attend over 3000 mental health related incidents per year which includes
  - People suspected of committing criminal offences or ASB
  - People who are victims of crime or ASB
  - Vast majority are people who are presenting with a perceived mental health problem which may put themselves or others in immediate risk of harm
We have a duty to protect people and keep them safe

But we are not mental health professionals!

The police response therefore often relies on the application of legal powers under the Mental Health Act or the Mental Capacity Act

This is not always the most appropriate response to an individuals needs and we are not the professionals that people want to see when experiencing a crisis.
Are police the right response to crisis?
Mental Health Street Triage?
Who are we?

- **Bedfordshire Police**
- **NHS Bedfordshire Clinical Commissioning Group**
- **NHS Bedfordshire & Luton**
  - Mental health and wellbeing services provided by ELFT
- **NHS Luton Clinical Commissioning Group**
- **SAMARITANS**
- **Mind**
  - For better mental health
Early outcomes

- Positive feedback from service users
- Positive feedback from professionals using the service
- Significant reduction in use of powers under the MHA
- Reduction in police and ambulance callouts
- More appropriate pathways identified for individuals
- Better signposting to Mind and Samaritans
Current projects

Support in the Community Working Group

Missing Persons Project
Community Safety Project
Assistive Technology Project
Herbert Protocol

Keep People with Dementia Safe & Found

Do you care for someone with Dementia and worry they may go missing? If you do, the Herbert Protocol is here to help you find your loved ones, friends and neighbours if they go missing.

Safe & Found

"These new measures will really help the police to act quickly to find someone who has gone missing and hopefully minimise the stress that this can result in both for the individual and their family."

Alzheimer’s Society Operations Manager for Yorkshire and the Humber, Joanne Gregory.

Download the form to submit family members, friends and neighbours with an up-to-date photograph if your loved one goes missing and the information is handed to a Police Officer. The photograph can be linked to all Police officers and PCSOs on the front line as their Smart phone.
Police Dementia Champions

1. Improve Community Engagement - personally attend groups organised by Alzheimer's Society (4874)

2. Force - encourage virtual Dementia Tour attendance - somehow incorporate this.

Kevin Broom
I would like to complete the dementia champion training and help in any way I can, maybe by delivering? (I) delivering friend training.

Kevin Broom
Happy to deliver Dementia Friends Training.

Support cadets to get involved too.
Police Dementia Champions

MARK PUGH (DS5598)

0 will become dementia Champion. Deliver to crime (Community) ESGU officers to be a dementia champion too. They deal with cyber fraud so deal with dementia victims.

Sincerely,
for the Police
- with the Police
- brief all frontline officers
- with dementia champions.

DAW

Have talk on dementia delivered to all specials. For understanding, deliver to crime bureau colleagues.
Singing for the brain…

“I wanted to get involved because I wanted to learn more about dementia, and also because this is something I can do to give back to the community. However small it is, I am contributing to something and hopefully I can encourage more people to do the same.”
Sword
Sgt. Phil Boyd Singing
Raising awareness…
Raising awareness…
Raising awareness...
Thank you for listening!

Jacqueline.whittred@bedfordshire.pnn.police.uk
Integrated Personalised Commissioning in Luton

Pam Garraway
Programme Director - LBC
Integrated Personalised Commissioning (IPC)

- Help people manage their own health by giving them more choice and control about the personal care they receive
- Improving, integrating and personalising services
- Builds on learning from personal budgets in social care and progress with personal health budgets.
JOINING UP HEALTH AND SOCIAL CARE

My care, My choice, My care budget

LUTON DEMONSTRATOR SITE

www.luton.gov.uk
NHS ENGLAND - 5 STEPS

1. **Proactive coordination of care:**
   A proactive approach to integrating care at individual level around adults, children and young people with complex needs.

2. **Community capacity and peer support:**
   A community and peer focus to build knowledge, skills and confidence for self-management.

3. **Personalised care and support planning:**
   A different conversation about health and care focused on what is important to each person, through personalised care and support planning.

4. **Choice and control:**
   A shift in control over the resources available to people, carers and families, through personal budgets.

5. **Personalised commissioning and payment:**
   A wider range of care and support options tailored to individual needs and preferences, through personalised commissioning, contracting and payment.
IPC IN ACTION

A Luton Patient Story

‘MY CARE BUDGETS’
I have vascular dementia. In the last year I went into hospital 3 times as I got a chest infection and had to stay in hospital 3 weeks each time. The doctor told me that my swallowing is now affected by the dementia.

I have a direct payment from my council for care but I don’t have the same option for my health services.

If I had a regular conversation about my needs this may have stopped me going into hospital. I would have liked to be able to have more control over who gives me my care. My family could have been taught how to carry out the same tasks as what the district nurse is currently monitoring for my swallowing, skin and breathing.
What might it look like?

• Multi disciplinary team identify a lead coordinator from all of the health and social care services involved with the family.

• The coordinator, a community matron, met with the family in their home.

• Full health check was completed including blood tests, reviews of medication and equipment. All areas of daily living were discussed with the patient, carers and family.

• Plan was completed starting with what matters to the family.

• Advice and signposting including the Disability Resource Centre, Alzheimer's Society and Age Concern
• Today I sat down with my family and selected the services we need following a conversation with the nurse at home. I understand that I am having more trouble with my breathing and swallowing but she said I could choose how I wanted to manage this.

• So we chose to have more support planned in advance and a care worker is going to come more often to help me.

• We could see what services were available and we selected what works for us as a family.

• Hopefully I don’t have to go to hospital again.
nothing worth having was ever achieved without effort

theodore roosevelt
Back by 2.25pm please.
“Lift your foot up Bert.”

Jenny Moody MBE
Early Diagnosis of Dementia

Dr Johan Schoeman
Clinical Lead for Luton Memory Clinic

18th June 2016
Let us eavesdrop!
Age Related Cognitive Impairment

- *Forgetfulness* - common complaint
- Longer to learn and recall
- Frustrating
- *NOT* - warning sign for onset of dementia
Why – Age Related Cognitive Impairment?

I suggest:

• Hippocampus deteriorates with age
• Protecting hormones and proteins decline with age
• Decreased blood flow to brain
• Under-stimulation of brain
Primary difference between age-related memory loss and dementia is that age-related cognitive impairment isn’t disabling.

Key is *early* Diagnosis Of dementia.

- GP → Memory Assessment Service
What is required from the Memory Assessment Service and what we deliver

Objective 2 of the National Dementia Strategy (2009) requires a Memory Assessment Service to provide the patient with a ‘good-quality early diagnosis and intervention.

Memory Services National Accreditation Programme (Royal College of Psychiatrists) is voluntary participation. **Luton received accreditation in 2013 and 2015.** We are one of more than 180 clinics with accreditation in England and Northern Ireland.
My understanding of dementia

• Dementia is a common condition.
• Risk increases as you get older.
• Usually occurs over age of 65 years.
• Group of related symptoms associated with on-going decline of brain and its abilities.
• Death of brain cells causes ‘shrinkage of the brain’.

Around 800,000 persons in the UK

My understanding of dementia

Brain decline:
• memory loss
• attention and concentration
• mental agility
• language
• understanding
• judgement
• visuo-spatial difficulties

‘Draw me a clock face, put in the numbers and put in the hands to read 10 past 11’

lacken, clock, pencil
Subtract 7 from 100
Name as many words starting with the letter A. Name me as many animals as you can
Read the following words: sew, pint, soot, dough, height
‘I would like you to follow my instructions in the following task’
‘Tell me how you would cross a busy road safely?’

We care  We respect  We are inclusive
My understanding of dementia

Patients with dementia can become:
• apathetic or disinterested in usual activities.
• problems controlling their emotions.
• find social situations challenging.
• decline visits outside the home.
• may be personality changes.
• difficulties planning, organising and doing everyday tasks
Awkward behaviours

• loss of sleep normal pattern
• more irritable/losing temper more often
• more anxious
• more suspicious
• becoming low in mood
• having visual hallucinations
• living in the past
• having false beliefs
• losing awareness of social situations (disinhibited)
• losing awareness of own physical appearances (less pride in personal appearance)
Early diagnosis is key! Why?

1. Symptoms might be reversible
e.g. depression, anxiety, stress

2. It may be treatable
causes are not reversible but might be treatable

3. Diagnoses more accurate early in disease process

4. It's empowering.
own decisions on e.g. driving, will, property, finances, social care, health care

We care  We respect  We are inclusive
Early diagnosis is key! Why?

5. Focus on what's important
   opportunity to reprioritize how time is spent and what matters most

6. Consider research

7. Use resources available

8. It helps loved ones
   learn about the illness, develop realistic expectations, plan the future

9. It helps the person with dementia
   illness is about the PERSON and not the diagnosis, not personal failings,
   helps to preserve person’s identity, reduces stigma
My concern about early diagnosis in Luton

Memory Clinic Study and Census 2011

<table>
<thead>
<tr>
<th>BME Group</th>
<th>Number in Census</th>
<th>% in Study</th>
<th>Number in Census</th>
<th>% in Census</th>
</tr>
</thead>
<tbody>
<tr>
<td>White: British</td>
<td>69</td>
<td>69%</td>
<td>90,530</td>
<td>44.6%</td>
</tr>
<tr>
<td>White: Irish</td>
<td>6</td>
<td>6%</td>
<td>6,126</td>
<td>3%</td>
</tr>
<tr>
<td>White: Other</td>
<td>3</td>
<td>3%</td>
<td>14,225</td>
<td>7%</td>
</tr>
<tr>
<td>Black: Caribbean</td>
<td>11</td>
<td>11%</td>
<td>8,177</td>
<td>7%</td>
</tr>
<tr>
<td>Black: African</td>
<td>2</td>
<td>2%</td>
<td>9,169</td>
<td>4.5%</td>
</tr>
<tr>
<td>Asian: British Pakistani</td>
<td>6</td>
<td>6%</td>
<td>29,353</td>
<td>14.4%</td>
</tr>
<tr>
<td>Asian: British Bangladeshi</td>
<td>1</td>
<td>1%</td>
<td>13,606</td>
<td>6.7%</td>
</tr>
<tr>
<td>Asian: British Indian</td>
<td>2</td>
<td>2%</td>
<td>10,625</td>
<td>5.2%</td>
</tr>
</tbody>
</table>

Our Asian and Black African Community Groups are underrepresented in our Memory Clinic

We care  We respect  We are inclusive
What are we and what should we be doing to rectify this situation

• QI (Quality Improvement) Project for 2017
• Advanced stage: Survey and Audit of BME Groups
• Planning agenda for GP Surgery visits in 2016/7
• Multidisciplinary approach required.
• Key: BME Group representative participation
• Important that we act
Waiting Times

• ELFT – robust culture of Quality Improvement
• Luton Memory Clinic QI Project – reduction of waiting times to Diagnosis
• Project Team - patient, carers, members from voluntary orgs.
• Surprise finding – thus far meet the MSNAP and CCG target for Referral to Diagnosis.
How to have an Early Diagnosis of Dementia and start of Treatment

- GP is always first port of call

- From the GP Surgery we need:
  - blood screen results
  - names and contact details of a relative/carer

- From the Patient we need:
  - attend CT scan head at L&D Hospital

- From the Memory Clinic we need:
  - early Diagnosis
  - prescription of a Cognitive Enhancing Drug
  - referral for Support, Therapies and Research
• Dementia is a common condition with important consequences
• Realistic and achievable reasons for an Early Diagnosis
• The PERSON with dementia important, not the diagnosis
• MSNAP accredited Memory Service
• Luton Memory Clinic not complacent – we are QI dedicated
• Critical awareness of increasing BME Group residents to Clinic

We care    We respect    We are inclusive
Thank you for your attention

We care  We respect  We are inclusive
WHO CAN HELP RESEARCHERS TO BEAT DEMENTIA?

YOU
‘Join dementia research’

…a place for people to register their interest in taking part in dementia studies.

www.joindementiaresearch.nihr.ac.uk
Why is it important?

- One of the biggest difficulties researchers face today is **finding** people to take part in their studies.

- At the same time, many people are **looking for studies** to participate in, but don't know where to find out about them.

- ‘**Join dementia research**’ is a new national service where people can **register their interest in participating** in dementia research and be matched to suitable research studies.
How is Alzheimer’s Society involved?

- Provide a **telephone helpline service** to register those who need support to complete the **online registration**.

- The **helpline** is, in the most part, provided by **volunteers**.

- The service is delivered within the Society’s wider **National Dementia Helpline service**
  Telephone **0300 222 1122**
Growth of JDR

- **July 2014** - pilot commenced in North Thames region
- **October 2014** - studies across England start to be added to JDR
- **February 2015** - national launch across England, Scotland and Wales
- **April 2015** – more than 6000 people registered and around 40 studies recruiting through JDR
- **September 2015** – launch in Northern Ireland
- **September 2016** – more than 23,000 volunteers, 5,500 enrolled into studies, over 70 studies recruiting
Who can register?

- People **with or without dementia** and memory problems.
- People who **care for someone** or have a **family member** with dementia.
- **Anyone** with an interest in taking part in dementia research – researchers need **healthy controls**.
- A carer or next of kin can **sign up on behalf of someone else**, providing they have their consent.
What are the benefits of registering?

- **Find** the studies that match the individual, or the person they are registering for.
- **Connect** with researchers letting them know who may be interested in taking part in their studies.
- **Discover** exciting new studies, and be a part of research.
- **Help** those who plan for and provide services to improve dementia care and treatment.
Is there anything else I should know?

- Current research studies range from **clinical trials of new treatments to surveys** identifying what works in improving the quality of life of people with dementia.

- If matched to a study, there is **no obligation** to participate. It is always **the individual’s choice** whether to take part or not.

- Deciding not to register or not to participate in a study will not affect the level of support and care received.
How to sign up?

- Just provide some **demographic and health information** which will enable the service to match potential participants to suitable studies.

  - This can be done:
    - Online at [www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk)
    - By calling the National Dementia Helpline on **0300 222 11 22**

To find out more visit: [www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk)
Call the National Dementia Helpline on **0300 222 11 22**
Email: catherine.james@alzheimers.org.uk
Gerry Taylor
Corporate Director
Public Health, Commissioning & Procurement
Luton Borough Council

Closing Remarks