# Agenda

<table>
<thead>
<tr>
<th>Agenda Item</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Arrival and Registration:</strong> (tea and coffee will be available)</td>
<td>9.30am</td>
</tr>
<tr>
<td>An opportunity to visit the stands and network</td>
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<tr>
<td><strong>Housekeeping:</strong> Chair – Maria Collins – Chair of LDAA</td>
<td>10.00am</td>
</tr>
<tr>
<td><strong>Welcome and Opening Address:</strong> Cllr Rachel Hopkins - Portfolio Holder Public Health, Commissioning &amp; Procurement - LBC</td>
<td>10.05am</td>
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<tr>
<td><strong>Luton Perspective:</strong> Gerry Taylor – Corporate Director Public Health, Commissioning &amp; Procurement - LBC</td>
<td>10.15am</td>
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<tr>
<td><strong>Integrated Personal Commissioning (IPC) for Luton:</strong></td>
<td>10.30am</td>
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<tr>
<td>IPC - Person Centred Support &amp; Living with Dementia</td>
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<tr>
<td>Ronald Ferguson, Steve Broome &amp; Sherone Phillips</td>
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<tr>
<td>IPC – What’s happening in Luton</td>
<td></td>
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<tr>
<td>Mary Bennis - CCG</td>
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<tr>
<td>IPC – People at the Heart of Change – Strategic Coproduction</td>
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<tr>
<td>IPC Lived Experience Advisor: NHSE – Keymn Whervin &amp; Sherone Phillips</td>
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<tr>
<td><strong>Tea &amp; Coffee Break</strong></td>
<td>11.20am</td>
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<tr>
<td><strong>Alzheimer’s Society: The New Deal on Research</strong></td>
<td>11.50am</td>
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<tr>
<td>Louise Walker – Alzheimer’s Society Research Communications Officer</td>
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<tr>
<td><strong>Bedfordshire Fire &amp; Rescue Service – ‘Safe &amp; Well’</strong></td>
<td>12.20pm</td>
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<tr>
<td>Thomas Warner - Prevention Support Manager</td>
<td></td>
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<tr>
<td>Robert Jones - Service Diversity Adviser</td>
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<tr>
<td><strong>Luton Dementia Action Alliance (LDAA)</strong></td>
<td>12.40pm</td>
</tr>
<tr>
<td>Maria Collins - Chair of LDAA &amp; Sian Gilleard – LDAA Coordinator</td>
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<tr>
<td><strong>Lunch Break &amp; Networking</strong></td>
<td>1.00pm</td>
</tr>
<tr>
<td><strong>‘Friends with Voices’</strong></td>
<td>2.00pm</td>
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<tr>
<td>A collaboration Choir from across Luton</td>
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<tr>
<td><strong>What the future holds for people with dementia and the impact on the BAME communities</strong></td>
<td>2.15pm</td>
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<tr>
<td>Dr Sen Kallumpuram - Consultant Psychiatrist</td>
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<tr>
<td><strong>“I just don’t know”</strong></td>
<td>2.45pm</td>
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<tr>
<td>(a legacy to Bert)</td>
<td></td>
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<tr>
<td>Jenny Moody MBE</td>
<td></td>
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<tr>
<td><strong>Decision Making with Dementia</strong></td>
<td>3.20pm</td>
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<tr>
<td>Siobhan Rooney – Partner at Pictons Solicitors</td>
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<tr>
<td><strong>Closing remarks</strong></td>
<td>3.50pm</td>
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<tr>
<td>Maria Collins – Chair of LDAA</td>
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</tbody>
</table>

**Agenda**

- **CCG** – (Luton) Clinical Commissioning Group
- **LDAA** – Luton Dementia Action Alliance
- **NHSE** – NHS England
- **LBC** – Luton Borough Council
- **IPC** – Integrated Personal Commissioning

**Luton Dementia Conference**

Wednesday 8th November 2017 9.30am to 4.00pm
Venue 360, Riverside Suite, 20 Gipsy Lane, Luton, LU1 3JH
Welcome to
Luton’s Annual Dementia Conference
8th November 2017

Sponsored By:

www.luton.gov.uk

#LDC2017
House-Keeping

#LDC2017

Photo Disclaimer

Mobile Phones

Need a Break?

Toilets & Fire Alarm

Wi-Fi

www.luton.gov.uk
Cllr. Rachel Hopkins

Portfolio Holder – Public Health, Commissioning & Procurement
Luton Council

Welcome & Opening Address
The Luton Perspective

Gerry Taylor

Corporate Director  Public Health, Commissioning and Procurement
Luton’s people

The future: 2037

- Expected whole population increase of 30,000 in next 20 years
- In 20 years there will be 37,000 more people in the 65-85 year age group.

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<table>
<thead>
<tr>
<th>All ages</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
<th>Luton % Population</th>
<th>UK % Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 – 4</td>
<td>9,300</td>
<td>8,800</td>
<td>18,100</td>
<td>8.3%</td>
<td>6.1%</td>
</tr>
<tr>
<td>5 – 9</td>
<td>8,700</td>
<td>8,000</td>
<td>16,700</td>
<td>7.7%</td>
<td>6.2%</td>
</tr>
<tr>
<td>10 – 14</td>
<td>7,300</td>
<td>6,800</td>
<td>14,200</td>
<td>6.5%</td>
<td>5.5%</td>
</tr>
<tr>
<td>15 – 19</td>
<td>6,600</td>
<td>6,600</td>
<td>13,200</td>
<td>6.1%</td>
<td>5.8%</td>
</tr>
<tr>
<td>20 – 24</td>
<td>7,500</td>
<td>7,200</td>
<td>14,700</td>
<td>6.8%</td>
<td>6.5%</td>
</tr>
<tr>
<td>25 – 29</td>
<td>9,600</td>
<td>8,700</td>
<td>18,300</td>
<td>8.4%</td>
<td>6.9%</td>
</tr>
<tr>
<td>30 – 34</td>
<td>10,000</td>
<td>9,200</td>
<td>19,200</td>
<td>8.9%</td>
<td>6.7%</td>
</tr>
<tr>
<td>35 – 39</td>
<td>8,300</td>
<td>7,800</td>
<td>16,100</td>
<td>7.4%</td>
<td>6.4%</td>
</tr>
<tr>
<td>40 – 44</td>
<td>7,100</td>
<td>6,700</td>
<td>13,800</td>
<td>6.4%</td>
<td>6.4%</td>
</tr>
<tr>
<td>45 – 49</td>
<td>6,800</td>
<td>6,600</td>
<td>13,400</td>
<td>6.2%</td>
<td>7.0%</td>
</tr>
<tr>
<td>50 – 54</td>
<td>6,500</td>
<td>6,700</td>
<td>13,200</td>
<td>6.1%</td>
<td>7.1%</td>
</tr>
<tr>
<td>55 – 59</td>
<td>5,500</td>
<td>5,300</td>
<td>10,800</td>
<td>5.0%</td>
<td>6.2%</td>
</tr>
<tr>
<td>60 – 64</td>
<td>4,400</td>
<td>4,400</td>
<td>8,800</td>
<td>4.1%</td>
<td>5.4%</td>
</tr>
<tr>
<td>65 – 69</td>
<td>3,700</td>
<td>3,900</td>
<td>7,600</td>
<td>3.5%</td>
<td>5.5%</td>
</tr>
<tr>
<td>70 – 74</td>
<td>2,700</td>
<td>3,100</td>
<td>5,800</td>
<td>2.7%</td>
<td>4.3%</td>
</tr>
<tr>
<td>75 – 79</td>
<td>2,500</td>
<td>2,800</td>
<td>5,200</td>
<td>2.4%</td>
<td>3.3%</td>
</tr>
<tr>
<td>80 – 84</td>
<td>1,800</td>
<td>2,200</td>
<td>4,000</td>
<td>1.8%</td>
<td>2.4%</td>
</tr>
<tr>
<td>85 – 89</td>
<td>900</td>
<td>1,400</td>
<td>2,300</td>
<td>1.1%</td>
<td>1.5%</td>
</tr>
<tr>
<td>90 and over</td>
<td>400</td>
<td>1,400</td>
<td>2,300</td>
<td>0.6%</td>
<td>0.9%</td>
</tr>
</tbody>
</table>

Total | 109,800 | 107,000 | 216,800 |
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.

www.luton.gov.uk
Prevalence of Dementia

- Currently over 750,000 people with dementia in the UK
- In Luton this is estimated at 1,900 people living with Dementia.

http://www.poppi.org.uk/index.php

<table>
<thead>
<tr>
<th>Age Group</th>
<th>2017</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
<th>2035</th>
</tr>
</thead>
<tbody>
<tr>
<td>People aged 65-69</td>
<td>94</td>
<td>96</td>
<td>110</td>
<td>129</td>
<td>131</td>
</tr>
<tr>
<td>People aged 70-74</td>
<td>169</td>
<td>183</td>
<td>189</td>
<td>219</td>
<td>255</td>
</tr>
<tr>
<td>People aged 75-79</td>
<td>298</td>
<td>293</td>
<td>351</td>
<td>362</td>
<td>414</td>
</tr>
<tr>
<td>People aged 80-84</td>
<td>500</td>
<td>523</td>
<td>500</td>
<td>607</td>
<td>641</td>
</tr>
<tr>
<td>People aged 85-89</td>
<td>500</td>
<td>539</td>
<td>633</td>
<td>633</td>
<td>772</td>
</tr>
</tbody>
</table>
Life Course of Dementia Risk.
Starting from childhood, modifiable risk factors add up to 35 percent of dementia cases, according to the report.

[Courtesy of Livingston et al., The Lancet 2017.]

www.luton.gov.uk
Loneliness and the elderly

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>51%</td>
<td>Live alone</td>
</tr>
<tr>
<td>800,000+</td>
<td>&quot;Chronically lonely&quot; in England</td>
</tr>
<tr>
<td>About 5m</td>
<td>Rely on TV for company</td>
</tr>
<tr>
<td>450,000</td>
<td>Alone for Christmas</td>
</tr>
</tbody>
</table>

Source: Campaign to End Loneliness and Age UK

www.luton.gov.uk
Reduce the risk of dementia by:

1. Developing and implementing guidance and policies to reduce alcohol consumption across the population.
2. Supporting people to eat healthily.
3. Developing, delivering, and enforcing comprehensive local tobacco control strategies, in line with current policy.
4. Improving environments where people live and work to encourage and enable everyone to build physical activity into their daily lives.
5. Addressing loneliness and encouraging people to be socially active and mentally stimulated.

Luton
How to protect against dementia

- Meeting friends
- Volunteering
- Reading
- Puzzles
- Crosswords
- Social engagement
- Cognitive stimulation
- Education
- Learning a second language
Strategic Priorities – Luton’s LIF

- Building economic growth and prosperity
- Enhancing skills and education
- Improving health and wellbeing
- Developing quality homes and infrastructure
- Supporting safe, strong and cohesive communities
Dementia Strategy

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.

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
What have we achieved?

- A well established Dementia Action Alliance with 60 organisations signed up as members
- The ELFT Memory Assessment Service had an ‘outstanding inspection’ in 2016
- We have produced our own local ‘Luton Dementia Guide’
- Appropriate level of training to people working with those living with Dementia and their Carers
- Awareness raising particularly with BAME community group
- Regular Dementia Friends training
- Increased post diagnostic support available to people living with dementia and their carers in Luton
- Bedfordshire Police Herbert protocol established and responding well.
- LBC Helpdesk have been trained specifically on available services, activities and support around Dementia and for Carers.
- Review of Extra Care Housing.
- Virtual Dementia Tour
The year ahead

- Area wide mapping of Dementia Services
- Opportunity for GP Led Diagnosis
- Increased awareness of rights and support given around end of life care.
- Further information raising sessions around Luton community groups.
- Public Health wellbeing awareness campaign on preventative measures.
- Further increase the Luton Dementia Action Alliance.
- Review Luton’s Respite Provision for people living with Dementia.
- Ensure carer friendly policies are in place in all services.
Ronald Amanze Ferguson is **Living** with Dementia

Sherone Phillips

The Disability Resource Centre
IPC Luton: A Dementia Capital Network Approach

Steve Broome, Director, Broome|Gekoski
Dementia Capital Networks: What is it?

- **a person-centred** approach – understand the lived experience of the individual and what is important to them through dialogue
- **a relational** approach – change is made through relationships with ourselves, with each other, within our community/environment
- **a system** approach – understanding the system of relationships around an individual, and the system of assets and support in a community
- So DCN works at the individual level (micro), the ‘core caring unit’ level (meso) and community/authority level (macro)
- **a coproductive** approach – developed in partnership in the local context, training local stakeholders
- **Why? Unseen, underused capacity** exists in communities to help address individual and local opportunities/problems: a network and asset based approach makes better use of what is already there
- **Visualising networks** encourages and help people and services to understand themselves and make change in new ways
- **Summary, DCN is a way of understanding the individual, the community, and the individual in their community**
Dementia Capital Networks: Definitions

- **Dementia Capital**: the set of internal and external resources that can be drawn upon to enable an individual with dementia to live the life they wish to live and are capable of living.

- **Personal DC**: includes personal assets (accommodation, money, transport etc), skills, health, mental wellbeing, aspirations, values.

- **Social DC**: impact, enablement and resources available through trusted relationships with family, friends, neighbours, colleagues.

- **Community DC**: impact, enablement and resources available through community assets including public services, community/voluntary organisations, parks, pubs, cafes, shops, faith institutions, ...

- **Cultural DC**: the individual’s perception and objective experience of social attitudes and norms in relation to dementia.

- **DCN (individual)**: the total set of resources available to an individual with dementia through direct and indirect relationships.

- **DCN (community)**: the total set of resources available in a community that are (or could be) available to an individual with dementia through direct and indirect relationships.
Dementia Capital Networks: Process

• Preparation and informed consent
• Open, person-centred start to DCN conversation
• Focus of dementia: how does this impact on belonging and connection to community?
• Eliciting Community Dementia Capital
• Qualities of connection: importance, medium, purpose, impact, what supports/enables/hinders connection?
• Identifying and prioritising community-focused goals and developing creative adjustments/solutions
• Reflection and agreeing actions
# Dementia Capital Networks: Example prompts

<table>
<thead>
<tr>
<th>1 What do you do in your community/local area?</th>
<th>12 Where do you like to go to eat or drink in the local area?</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 What would you like to do in your community/local area?</td>
<td>13 What outdoor places do you like to go to in the local area?</td>
</tr>
<tr>
<td>3 Which local organisations do you engage with?</td>
<td>14 What do you enjoy in the community that is creative or artistic in some way?</td>
</tr>
<tr>
<td>4 What local services do you use?</td>
<td>15 What places in the community do you wish you used or went to?</td>
</tr>
<tr>
<td>5 What local services would you like to use?</td>
<td>16 Do you volunteer in the community? If so, where</td>
</tr>
<tr>
<td>6 What local shops and businesses do you use?</td>
<td>17 Would you like to volunteer in the community? If so, where?</td>
</tr>
<tr>
<td>7 What local shops and businesses would you like to use?</td>
<td>18 What places in the community understand people with dementia best?</td>
</tr>
<tr>
<td>8 What do you do in the local area for fun?</td>
<td>19 What stops you taking part in your community in ways you would like?</td>
</tr>
<tr>
<td>9 Do you belong to any local groups or organisations?</td>
<td>20 What in the local area helps you to feel good about yourself?</td>
</tr>
<tr>
<td></td>
<td>21 What online or social media groups or spaces do you use regularly?</td>
</tr>
<tr>
<td></td>
<td>22 What places, facilities or organisations in the local area are important to you that we haven’t mentioned?</td>
</tr>
</tbody>
</table>
Dementia Capital Networks: Blank canvass
Dementia Capital Networks: Case study

Overview: rich and diverse

Dementia Capital – local support and service organisations trusted friends, PA, family. Creativity and entrepreneurialism are very important. London roots and networks are also a strong part of his identity. Ability to remember agreed actions, handle frustrations, ‘fit’ with services, service expectations are all ‘negative’ DC. Not a high degree of density in this network: DC is not very interconnected so coordination of DC is down to him. Possibility of connecting up different aspects of network to help achieve his goals is aided through the visualisation of his Dementia Capital.
Dementia Capital Networks: Case study

**Goal:** Plan and carry out a small pilot in [___] in London that will engage 15 ‘hard to reach people’ in health awareness raising activity. Activity will include the use of therapeutic journaling, art, and poetry.
Dementia Capital Networks: Next steps

- Complete pilot stage DCN conversations
- Analyse data at individual and aggregated levels
- Adjust DCN tools and guidance as necessary
- Use intelligence to inform individual person-centred care planning and support, workforce development, organisational change, service design, and wider strategy
Dementia Capital Networks: Next steps
Dementia Capital Networks: Next steps

- Housing association
- Community centre
- Library
- Local newspaper
- Facebook

Broome | Gekoski
Topline reflections: Dementia Capital Networks

• through reflective dialogue, identity the current and potential resources a person has available to them
• identity problems, opportunities and goals
• visualise the network of resources as a way to organise and reflect on a complex, dynamic situation
• co-design creative adjustments in the individual’s network
• aggregate individual networks, then visualise and analyse combined community dementia capital
• co-design ways to grow and make use of community dementia capital
Dementia Capital Networks: wider reflections

• ‘services’ can be considered not just as things provided by the state but also as influencing wider social attitudes and support
• services should be socially productive, not thin, transactional relationships
• blur boundaries between the state and civil society - well designed public services can encourage and support, rather than crowd out, efforts of families and communities to help vulnerable people
• make more of the unseen, untapped capacity in communities – isolated/vulnerable citizens have personal / social assets that are unrecognised, un-utilised
• develop capability to map and realise local assets and resources across multiple domains
Any questions...?

Contact
Steve Broome, Director, Broome|Gekoski
Email: steve@broomegekoski.co.uk
Twitter: @smbroome
Luton: The story so far
Vision - person-centred integrated Community Services -
Meeting physical, mental & social needs

- Transforming primary, community and social care together so that it becomes central to the delivery and co-ordination of healthcare and wellbeing across Luton

- A move from the current system (often reactive, organisation driven and paternalistic) to pro-active population health management that puts the needs of the individual central to the purpose of the system

- Shared decision making with patients, carers, and families to support self care and increase confidence levels
What is Integrated Personal Commissioning (IPC)?

IPC is aimed at improving the experience of care for people with complex on-going physical, social and mental health needs and those who are at high risk of crises leading to unplanned or institutional care.

- IPC blends funding from health, social care and other services at individual level for people with complex needs, enabling them to direct how the combined resources are used.

- IPC requires a different approach to planning and commissioning community, social care and other services to deliver person-centred, coordinated care at scale for target populations.

- IPC explicitly harnesses community and VCSE sector capacity to support self-management.
Individual level experience of IPC

- A different conversation with the people involved in your care focussed on what's important to you
- A shift in control over the resources available to you, your carers and family
- A wider range of care and support options tailored to your needs and preferences
- A community and peer focus to build your knowledge, confidence, and connections
- A proactive approach to improving your experience of care and preventing crises
## NHSE 5 key shifts and Luton

<table>
<thead>
<tr>
<th>NHS 5 Key Shifts</th>
<th>Luton’s Delivery</th>
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</thead>
</table>
| **A proactive approach to improving your experience of care and preventing crises** | • Dementia pathway - Identify people who have complex needs which include dementia, through the risk stratification.  
• People have been offered integrated intensive case management by **At Home First teams** aligned to GP surgeries.  
• The NHS recognised a need to proactively identify people who have symptoms of dementia. Dementia or symptoms are cross checked by the CCG, GP and memory assessment service to ensure all diagnosis is registered on the Quality Outcome Framework national database.  
• 13 September 2017 in Luton there are 1,148 people on the register  
• Luton have exceeded the national target of 66.7%. reaching 69.5%  
• There may still be 30% of people in Luton with dementia who have not received a diagnosis. |
<table>
<thead>
<tr>
<th>NHS 5 Key Shifts</th>
<th>Luton’s Delivery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Capacity and peer support</td>
<td>• <strong>Mapping of all community service</strong>  Mapping helped highlight service gaps, overlaps and helped shape commissioning intentions for both LCCG and LBC.</td>
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<tr>
<td></td>
<td>• <strong>The Local Authority and NHS choices 111 Directories</strong> has been updated</td>
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<tr>
<td></td>
<td>• <strong>Voluntary and charitable organisations are commissioned</strong></td>
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<tr>
<td></td>
<td>• <strong>Individual asset map with the support and expertise of NHSE VCSE partners</strong></td>
</tr>
<tr>
<td></td>
<td>• <strong>A local peer support group</strong></td>
</tr>
<tr>
<td>Service</td>
<td>Provider</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Enhancing Lives</td>
<td>Age Concern</td>
</tr>
<tr>
<td>Help in your home</td>
<td>Age Concern</td>
</tr>
<tr>
<td>Home Support</td>
<td>Age Concern</td>
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<tr>
<td>Meet and Greet</td>
<td>Age Concern</td>
</tr>
<tr>
<td>Podiatry</td>
<td>Age Concern</td>
</tr>
<tr>
<td>Lunch clubs</td>
<td>Age Concern</td>
</tr>
<tr>
<td>Befriending Service</td>
<td>Age Concern</td>
</tr>
<tr>
<td>Surgery Dementia Support Point and CriSP L+D Support Service</td>
<td>Alzheimer’s Society</td>
</tr>
<tr>
<td>Carers Peer Support</td>
<td>Alzheimer’s Society</td>
</tr>
<tr>
<td>Singing for the Brain</td>
<td>Alzheimer’s Society</td>
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<tr>
<td>Cognitive Stimulation</td>
<td>Alzheimer’s Society</td>
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<td>Dementia Café</td>
<td>Alzheimer’s Society</td>
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<td>Activity Group</td>
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<tr>
<td>MAS</td>
<td>Alzheimer’s Society</td>
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<tr>
<td>Day Centres</td>
<td>LBC</td>
</tr>
<tr>
<td>Carer Assessment</td>
<td>LBC</td>
</tr>
<tr>
<td>Carer Grant</td>
<td>LBC</td>
</tr>
<tr>
<td>Carers Short Break</td>
<td>LBC</td>
</tr>
<tr>
<td>Home Care</td>
<td>LBC</td>
</tr>
<tr>
<td>Personalised care and support planning</td>
<td>Luton’s Delivery</td>
</tr>
<tr>
<td>--------------------------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>• We have coproduced a single integrated plan for primary care. IPC partners have also worked with continuing healthcare, the mental health provider and local authority teams to offer personalisation using the same IPC framework.</td>
<td></td>
</tr>
<tr>
<td>• An integrated electronically shared personal care and support plan that includes prevention and anticipatory crisis avoidance approaches and emergency contact details.</td>
<td></td>
</tr>
<tr>
<td>• Helps to identify specific services where we can offer choice</td>
<td></td>
</tr>
<tr>
<td>• The person and family will be given advice to self care by the primary multi disciplinary teams</td>
<td></td>
</tr>
<tr>
<td>NHS 5 Key Shifts</td>
<td>Luton’s Delivery</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>---------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Personal Budgets:</strong></td>
<td>• Developed a bespoke IT platform and <strong>My Care Bank</strong> to select from an electronic directory /market place to meet your needs in your approved care plan and make payments.</td>
</tr>
<tr>
<td>A shift in control over the resources</td>
<td>• Seamless view of integrated health and social care <strong>personal budget</strong></td>
</tr>
<tr>
<td>available to you, your carers and family</td>
<td>• It enables people, carers and families to blend and control the resources available to them across the system in order to ‘commission’ their own care through personalised care planning and personal budgets.</td>
</tr>
</tbody>
</table>
Nestor Primecare Services

With over 40 years experience, we can be relied on to deliver care that helps our customers live the life they want, where they want.

Our home care service is entirely bespoke - we consider our customers needs and what they would like to achieve from our assistance, and then work with them to ...

See More

Nestor Primecare Services
Langham House, Mill Street, Luton
T: 01582 459023
Email
supplier@carebanking.co.uk
Website
ttt.com

Carer
£22.50 per hour

repositioning
£120.50 per day

FNC
£22.32 per day

Caremark
Our friendly service enables you to remain in the familiar surroundings and comfort of your own home, receiving regular social care visits and services to suit your personal needs. Every day, we meet and exceed the personal care requirements and wishes of thousands of customers throughout the...

See More

Caremark
Plaza 668 Suite 101 Hitchin Road
T: 01462 550443

CQC Rating
Outstanding
• “Sam” can search for services by provider name, type of service or even by proximity to his house, for example within 5 miles of his postcode.
• The services listed show CQC rating. “Sam” can filter services by CQC rating if he wishes.
Co-production – My Care Bank

• Met with service users to discuss how they would like the system to look and function – ensure maximum usability.

• Sat with Sam’s advocate and went through the process of spending Sam’s PHB via Mycarebank – we learnt lots! For example:
  – Would be easier for client to be able to pay tax directly to HMRC for pay through Mycarebank. This is now possible, using specific tax reference numbers
  – Using the system to pay insurance costs directly
  – Function where PAs can submit timesheets directly onto MyCareBank
The Vision: Patient and Carer’s Choice of Care

JOINING UP HEALTH AND SOCIAL CARE

My care, My choice, My care budget
Integrated Personal Commissioning

People at the Heart of Change – Strategic Co-production

Sherone Phillips
IPC Community and coproduction Lead
The Disability Resource Centre
A common approach to co-production for IPC

1. Commitment & Leadership
2. Contact & Connect
3. Identify Collective Ambition
4. Build Knowledge, confidence and skills
5. Co-produce IPC
6. Review Impact

Facilitate the process
Achievements – Co-producing the programme nationally

- Interviewing sites to become part of the IPC programme
- Creating key features of a personal health budgets and IPC
- Presenting at national events including Voluntary Sector events and Rolling out Personal Health Budgets
- Contributing to the national Direct Payments Guideline for personal health budgets
Co-producing the programme locally

- Developing IPC Peer Network; people with lived experience from Nyabingi, people living with dementia and their carer’s, people with complex needs – and more....

- Work streams;
  - Community assets; Working together to build the conversation tool.
  - New ones to be aligned to the key shifts; Choice and Control, Proactive Co-ordination of care

- Going forward;
  - More people skilled up to be involved in other work streams.
  - Developing people with lived experience to be part of the IPC Steering Board
  - Further future- Broadening out IPC coproduction across Bedfordshire and MK.
Thank you

- Ronald Amanze Ferguson
- Steve Broome
- Mary Bennis
- Sherone Phillips

Happy to talk to you in the break
Back by 11.50am please.
ALZHEIMER’S SOCIETY RESEARCH

What research do we fund?
<table>
<thead>
<tr>
<th>Care, Services and Public Health Research</th>
<th>Biomedical Research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding clinical and economic impact of dementia</td>
<td>Developing and testing diagnostic methods</td>
</tr>
<tr>
<td>Understanding the contribution of modifiable risk factors</td>
<td>Developing and testing effective treatments</td>
</tr>
<tr>
<td>Developing and evaluating new services and support</td>
<td>Improved diagnosis, treatment, services, support and prevention</td>
</tr>
</tbody>
</table>

Care for today, cure for tomorrow.
Breakdown of our research portfolio

- Improving our understanding of the causes of dementia
- Finding better ways to diagnose the condition
- Accelerating progress towards a cure
- Driving forward advances in dementia care
- Risk reduction and prevention of dementia

150 grants
£30 million
Our unique approach to funding research

- A partnership between researchers, practitioners and people affected by dementia
- Allows us to fund high quality and relevant research
- Allows us to maximise our impact

Research Network
270+ dedicated volunteers
Dementia Research Leaders

- Attracting and retaining the best talent to dementia
- Supported 160 early career researchers since 2014
- Research funding: Undergraduates, PhDs, Fellows
- Training and mentorship with dementia experts

For every £2m of disease costs, there are:

- 1 dementia researcher
- 10 cancer researchers
- 5 heart disease researchers
Doctoral Training Centres

- £3.2 million from AS
  leveraged £1.6 million from universities
- Supporting 53 PhD researchers
- Biomedical and care research
IMPLEMENTING RESEARCH

Putting findings into practice
Support with dissemination of findings to the right audiences

Innovation Fund
Projects like Meeting Centres
Implementation grant funding

Links with policy and public affairs team
Namaste care

- Run by Dawn Brooker, University of Worcester
- Holistic approach to care in care homes
- Based on a successful US initiative
- What aspects would work in the UK?
- Identify and overcome barriers
Life through a lens

- Run by Karen Watchman, University of Stirling
- Helping people with dementia and learning difficulties
- Based on resource ‘Jenny’s Diary’
- What changes can help to provide better care?
STrAtegies for RelaTives (START)

- Developed an intervention to teaching coping strategies
- Psychology graduates met one on one with carers over 8 weeks
- After two years, carers were 7 times less like to have clinical depression
- Intervention is deemed cost-effective for NHS
STrAtegies for RelaTives (START)

- Alzheimer’s Society funded a dissemination grant – ‘train the trainers’
- Now funding an implementation grant
- How can we get START to be used in charity sector?
- Also focus on minority communities
GREAT into practice

- Run by Linda Clare at the University of Exeter
- Cognitive rehabilitation
- Maintain independence
- Positive results from trial
- Adapt method for use in real-life settings
- NHS memory services, social care providers
INNOVATIONS IN CARE RESEARCH

Centres of Excellence
Identifying priorities

– Areas of need in care research
– Consulted with people affected by dementia, staff and volunteers
– Four priority areas:
  • Independence at home
  • Improving quality of life
  • Support after a diagnosis
  • Care in advanced dementia
– Three projects awarded
– More to come!
NIDUS

- Run by Claudia Cooper, UCL
- Area addressed: Independence at home
- Deliver training for family carers and care professionals
- Co-develop and test protocols and strategies
Pri-DEM

- Run by Louise Robinson, University of Newcastle
- Area addressed: Support after a diagnosis
- Can care be delivered through GPs and community services?
- Examine examples in other countries and for other conditions
- Reduce the ‘postcode lottery’
IDEAL-2

- Run by Linda Clare, University of Exeter
- Area addressed: Quality of life, advanced dementia
- Extension of existing IDEAL study
- How can people with dementia have a good quality of life?
- Add experiences of people from BAME backgrounds and advanced dementia
HOW CLOSE ARE WE TO A CURE?
What does dementia do to the brain?

- A healthy human brain has 100 billion nerve cells
- These cells make 100 trillion connections
- They need oxygen, nutrients and communication with other cells to survive

Cell death and brain shrinkage
Damage seen in Alzheimer’s disease

Amyloid plaques
- Form around brain cells

Tau tangles
- Form within brain cells

Immune system
- Activated by damaged cells
Why hasn’t there been a dementia drug in 15 years?

Potential disease-modifying treatments for Alzheimer’s disease in clinical trials

www.luton.gov.uk
Why hasn’t there been a dementia drug in 15 years?

Potential disease-modifying treatments for Alzheimer’s disease in clinical trials

www.luton.gov.uk
Removing amyloid plaques from the brain

Sevigny J et al. (Nature 537, 50–56; 2016)

Aducanumab antibody in people with mild-moderate Alzheimer’s

Phase II results from 2016
Is there another way?

– Alzheimer’s Society Drug Discovery programme

– Can drugs developed for other conditions help in dementia?

– Testing drugs for diabetes, rheumatoid arthritis, stroke and heart disease, erectile dysfunction, depression

– Bring drugs to the people who need them in half the time
Treatments for other forms of dementia

- Many fewer drugs in testing, nothing in Phase III

- Frontotemporal dementia - tau antibody in Phase II

- Vascular dementia – trials of Alzheimer’s drugs have failed. Some novel drugs in Phase II testing in China

- Dementia with Lewy bodies – Alzheimer’s drugs can be given. New drug in Phase II trial
UK Dementia Research Institute

- £250m total investment
- £50m from Alzheimer’s Society over 8 years
- Six UK centres
- Care research to be added in 2018
Thomas Warner
Prevention Support Manager
What is Safe & Well?

CFOA – Safe & Well Video
Risk of Fire Fatality - Office for National Statistics

Assessing personal risk; Index score by age / gender – risk of fire fatality

Source: Accidental exposure to fire or flame - External causes of morbidity and mortality, Office for National Statistics (2009)
Fire Safety

• A Check of every room
• Advice based on the risks in the home
• Advice on escape routes/safe zones
• Check of existing alarms and installation of new alarms if required
Crime Prevention

- Doors
- Door chains
- Windows
- Gardens
- Garden tools
- Unexpected callers

Don’t give your car keys away on a plate

Always keep car keys and other valuables stored in a safe place, out of view. Keep your car in the garage if you have one.

www.luton.gov.uk
Smoking Cessation

Protect your family. Make your home and car smokefree.

Stop smoking today with free proven support.

www.luton.gov.uk
# Falls

**Bedfordshire Fire and Rescue Service Falls Service Referral Form**

<table>
<thead>
<tr>
<th>Name:</th>
<th>Date of Birth:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address:</td>
<td>Contact Number:</td>
</tr>
<tr>
<td></td>
<td>GP Details:</td>
</tr>
<tr>
<td></td>
<td>(if known)</td>
</tr>
</tbody>
</table>

## Falls Risk Assessment Tool – FRAT*

1. Have you fallen in the last year?  
2. Are you taking 4 or more different medications per day?  
3. Do you have problems with your balance?  
4. Are you **unable** to rise from a chair of knee height?  
5. Do you have a diagnosis of a stroke or Parkinson’s?  

*Designed by Queen Mary College, London*

If there is a positive response to **three or more** of the questions, then the person should be considered as being at high risk of falling in the future.
Alcohol Consumption
Fire Safety & Dementia

• A person centred approach to Safe & Well Visits.
• It is important to educate all members of the household.
Fire Safety & Dementia

• Fire’s have occurred when an electric kettle has been put on the hob.
• Remove clutter
• Turn cooker off at the wall
• Don’t’ leave meals for microwaving in metal containers
• Consider meals on wheels
Fire Safety & Dementia

- Smoking Aprons.
- Plan your escape and practice it.
- Test smoke alarms weekly.
- Remove Matches and candles that are there for show.
Dementia affects all our Communities

Robert Jones
Diversity Advisor
Fire Safety & Dementia

• More than half of all people that die in fires in the UK are over 60

• People with dementia may find it more difficult to escape or understand the situation if there is a fire.

• Preventative work outlined earlier enables our staff to spot early signs of dementia in people who may be averse to seeking the help of medical professionals.
Engaging Communities

• We need to ensure that Fire Safety messages are targeted appropriately

• That all communities benefit from Safe and Well visits

• That Information and guidance is given in the appropriate languages
Fire risks in the homes of people with dementia

• Related to a person’s past role or actions
• Using appliances inappropriately
• Related to memory impairment or stress
• Person’s home environment and situation
Reducing risks

- A person-centred/Individual approach
- Improve the safety of peoples homes
- Work with other agencies to identify vulnerable households and provide support to people with dementia
- Raise awareness of fire safety
Approach to Dementia

• Raising awareness of Dementia amongst our staff

• Helping to ensure that families and carers are aware of the fire risks associated with the care and protection of people with dementia

• Helping to ensure that people with dementia are referred to the appropriate agencies
Approach to Dementia

• We work in partnership with other emergency services i.e. the Police ‘Herbert Protocol’

• We take an active role in building developments so that people can stay independent and safe in their own homes for as long as possible
In Case of Fire

• Once the person is known to us we can work with them and our partners to put safety measures in place.

• Every person is unique and therefore has different needs. Each visit we carry out is specific to that person's needs and wishes.

• We can put a note on the system if someone's vulnerable that will come up if there's a callout to their home
What else can be done?

• Ensure that fire safety messages reach all communities

• Build on the training we provide to ensure that all of our firefighters receive training and not just community safety team

• Work with others, agencies, carers and families across all communities

• Spread the message at events such as these
What else can be done?

Scientists at Staffordshire University are pioneering a project that will train fire officers by providing guideline to assess and detect cognitive decline and give them the tools to escalate cases if they are concerned about a person’s welfare.

If the project is successful, it could be rolled out nationwide, saving hundreds of lives every year.
Any Questions?
Luton Dementia Action Alliance
Working to make Luton a Dementia Friendly Community

http://www.luton_dementia_action_alliance

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

01582 470910
Maria Collins – Chair of Luton Dementia Action Alliance
People in the UK living with dementia

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

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
Luton DAA Members

**Children, young people & students**
- Luton Adult Learning
- Youth Space
- Stopsley High School

**Emergency services**
- Bedfordshire Police
- Bedfordshire Fire and Rescue Service

**Businesses and shops**
- The Mall
- Picton's Solicitors LLP
- Carlisle Support Services
- Post Office
- Argos
- Boots
Health and social care

- Gardenia & Marsh Farm Practice
- Dr Z Ahmad & Partners
- Larkside Practice
- Leagrave Surgery
- Bramingham Park Medical Centre
- Luton Clinical Commissioning Group
- Bedfordshire Local Pharmaceutical Committee
- Bedfordshire Community Rehabilitation Company
- POhWER
- Healthwatch Luton
Health and social care

Luton DAA Members

Home Instead Senior Care
Quantum Care
Castletroy
GenerixCare
Alicia Nursing Home
The Edwardian Care Home
The Georgiana Care Home
Care as YOU Like it Ltd
Mulberry Court
The Victorian Care Home
ST. ANNE'S CARE HOME
Luton DAA Members

Community, voluntary, faith groups and organizations

- Luton DAA Action Alliance
- Music 24: Making Music Matter
- Stroke Association
- Alzheimer's Society
- The Disability Resource Centre
- Community Works 4U
- AGE Concern
- Stopsley Tent Project
- Art Trend
- Meaningful Education
- Relate: The Relationship People
- Citizens Advice
- Liferoots: Therapeutic Horsemanship Centre
- Horses Helping People
- Luton Irish Forum
- Roman Catholic Parish of The Holy Family and St John the Apostle
- The Gospel Pentecostal Reconciliation & Restoration Centre
Dementia choir sings for Luton Airport passengers

Passengers arriving back at Luton Airport were greeted by a choir made up of people with dementia and their carers.

The group, called Friends with Voices, sang 'Hey! Baby' for travellers in arrivals as part of Dementia Awareness Week.

A spokesman for the airport said: "It's safe to say our passengers loved them. They were stopping and filming them."

© 22 May 2017 | Beds, Herts & Bucks
Successes
Successes

Dementia Friendly Organisation of the Year - Large

British Gas
Bedfordshire Police
Kingston Hospital NHS Foundation Trust

Welcome to Dementia Friends
Here's some helpful information & guidance on what to do next

“Alzheimer’s Society is delighted to be working with Bedfordshire Police on this initiative. The Herbert Protocol will benefit from the professional support of one of our Dementia Support Workers, to assist officers when a person with dementia, Alzheimer’s Disease or memory problems is reported missing.”

Tina Kerman,
Operations Manager at Alzheimer’s Society for Bedfordshire and Cambridgeshire

Safe & Found

For more information or to sign up to the Herbert Protocol in Bedfordshire; please contact 101 or email: dementia@bedfordshire.police.uk

THE HERBERT PROTOCOL
Safe & Found

Do you care for someone with Dementia, Alzheimer’s Disease or memory problems and worry they may go missing?
We're here to help.

www.luton.gov.uk
Successes

Music24 @music24_uk · Jun 16
The Music24 team is set to climb Snowdon on 8th July! Please support us!
jjustgiving.com/crowdfunding/m... #dementia #luton #fundraising #challenge

Donate to help Music24’s work supporting people living with Dementia...
We’re raising money to help Music24’s work supporting people living with Dementia in Luton & Hertfordshire. Support this JustGiving Crowdfunding

Based in or around Luton? @physieast is hosting a free Dementia in Practice event 17/6 grab a ticket while you can!

Eventbrite

Dementia in Practice Study Day
The CSP East of England Regional Network is pleased to present their next free event which will offer all CSP members an insight into dementia wh...

The University of Bedfordshire, Faculty of Health and Social Science offers:

Promoting Excellence in Dementia Care
Study Days, choose either:
6th December 2016 or 18th January 2017

Aim:
The University of Bedfordshire is hosting a series of study days, providing you with the opportunity to explore and reflect on your role in promoting excellence in dementia care in your clinical area and network with other practitioners.
Successes

Alzheimer’s Society
Supporting people to live well with dementia in Luton

Please contact 01582 470910 to confirm interest before attending

<table>
<thead>
<tr>
<th>Weekly Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monday</td>
</tr>
<tr>
<td>Cognitive stimulation group</td>
</tr>
<tr>
<td>St Hugh’s</td>
</tr>
<tr>
<td>11:30–1:00</td>
</tr>
<tr>
<td>Tuesday</td>
</tr>
<tr>
<td>Singing for the Brain</td>
</tr>
<tr>
<td>St Andrew’s Hall</td>
</tr>
<tr>
<td>10:30–12:00</td>
</tr>
<tr>
<td>Wednesday</td>
</tr>
<tr>
<td>Activity Group</td>
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<tr>
<td>Hightown</td>
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<tr>
<td>10:30–12:30</td>
</tr>
<tr>
<td>Thursday</td>
</tr>
<tr>
<td>Cognitive stimulation group</td>
</tr>
<tr>
<td>Chaul End</td>
</tr>
<tr>
<td>2:00–3:30</td>
</tr>
</tbody>
</table>

Alzheimer’s Society
Supporting people to live well with dementia in Luton

Please contact 01582 470910 to confirm interest before attending except for the Dementia Café where you are free to join us as you wish

<table>
<thead>
<tr>
<th>Monthly Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wednesday</td>
</tr>
<tr>
<td>Peer support Group for carers 1st Wednesday in the month 2:00–4:00</td>
</tr>
<tr>
<td>Friday</td>
</tr>
<tr>
<td>Peer support Group for carers 3rd Wednesday every other month 7:00–9:00pm</td>
</tr>
<tr>
<td>Dementia Café 2nd and 4th Friday in the month Hope Church 2:00–4:00</td>
</tr>
<tr>
<td>Young Onset Dementia Peer support group 3rd Friday in the month Hope Church 2:00–4:00</td>
</tr>
</tbody>
</table>

Young Onset Dementia Activity Group – contact office for details

Carers’ Information Support Program
CrISP 1

for carers/family of people recently diagnosed with dementia in Luton

Location: Chaul End Centre
515 Dunstable Road, Luton, LU4 8QN

Date: 5 weeks starting Thursday 11th Jan

Time: 1 – 3:30pm
Successes

Luton Town FC & Dementia Friends

We will be welcoming a group of people living with Dementia to our largest...
Successes

Year of You Luton @YearofYou_Luton · May 16
Live in Luton? Visit the @alzheimerssoc team at St Georges Sq. from 10-4 to find out more about dementia & the support available #DAW17
What’s coming up?

You are invited to the

Luton Alzheimer’s Society
Christmas Party

Friday 8 December

Contact 01582 470 910 for information

Enjoy a live Ukuleles Band Christmas Quizzes,
Party Games, a Christmas buffet and lots more!

Luton’s Dementia Friendly Carol Service

Saturday 9th December
3:00 p.m. to 4:00 p.m.
St John the Apostle
296 Sundon Park Rd, Luton LU3 3AL
Seasonal refreshments served from 2:30pm
and at the end of the concert
Donations accepted on the day proceeds to be shared between

Young@Heart Cafe
Shakespeare's Cafe
Sian Gilleard – Luton Dementia Friendly Community Coordinator
Involvement of people with dementia

Challenge stigma and build understanding

Practical support to enable engagement in community life

Accessible community activities

Community-based solutions

Ensure an early diagnosis

Consistent and reliable travel options

Easy-to-navigate environments

Acknowledge potential

Respectful and responsive businesses and services

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
- Ensuring that activities include people with dementia
- Businesses and services that respond to customers with dementia
- Easy to navigate physical environments
- Befrienders helping people with dementia engage in community life
- Empowering people with dementia and recognising their contribution
- Empowering people with dementia to have high aspirations, confidence and know they can contribute
The Luton Service User Review People (SURP) “The Adventurers” are a panel of people living with dementia supported by the Alzheimer’s Society. They meet monthly to discuss topics on both a national and local basis. This year the panel has worked in conjunction with members of LDAA to conduct audits of local facilities and services in order to provide feedback to how to improve these for people affected by dementia in Luton.
What is a Dementia Friend?

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.

www.luton.gov.uk
To become a Dementia Friend you can attend a one hour information session which is delivered by a local volunteer Dementia Friends Champion.

There is an open Dementia Friends Session being held in The Green Room at St John the Apostle, 296 Sundon Park Rd, Luton LU3 3AL on Wednesday 29th November from 2:30 to 3:30pm.

If you would like to attend please book a place on the Dementia Friends website www.dementiafriends.org.uk

Or leave your details on the sheet on our information stand over lunch

If you are unable to attend you can learn the key messages by registering online https://www.dementiafriends.org.uk/register-digital-friend
A Dementia Friends Champion is a volunteer who encourages others to make a positive difference to people living with dementia in their community. They do this by delivering the Dementia Friends Information Sessions to give information about the personal impact of dementia, and what they can do to help.

It's easy to get involved. Dementia Friends Champions will attend a free one day induction, receive support when they need it, and be part of over 10,500 volunteer Dementia Friends Champions creating Dementia Friendly Communities together.

www.luton.gov.uk
These are the nearest upcoming Dementia Friends Champions Induction days. If you would like to attend please book a place on the Dementia Friends website [www.dementiafriends.org.uk](http://www.dementiafriends.org.uk) or if you would like to be informed when there is a local session available to attend please see me over lunch.
Let’s create a dementia-friendly generation

Teach about dementia: free resources for teachers and youth groups.

Alzheimer’s Society
United Against Dementia

Key stage 1-4 teaching packs:
- Accredited by the PSHE Association
- Embed students’ learning and broaden understanding across the curriculum
- Give you the opportunity to link up with local dementia services for volunteering opportunities for your pupils
- Contribute towards key aspects of the national curriculum, enabling pupils to gain knowledge and understanding linked to PSHE & Citizenship.

Request for free: alzheimers.org.uk/youngpeople

One in three young people know someone living with dementia
Dementia Friendly Resources

Supporting employees who are caring for someone with dementia

Creating a dementia-friendly workplace
A practical guide for employers

CARERS UK
the voice of carers

employers for carers
Dementia Friendly Resources

A guide to making general practice dementia-friendly

Visit us alzheimers.org.uk

Dementia-friendly housing charter

Guidance on delivering a dementia-friendly approach to housing

www.luton.gov.uk
Who makes a Dementia Friendly Community

We all can!
Let us take action

Please write on the post-its on your table:

• **One person** (and who they are) or organisation that you would like to influence in working with us to create a Dementia Friendly Community in Luton.

• **One action** you will take following today’s conference

Please come and stick these on the display board at our stand we will share the information after the conference.

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Back by 2pm please
‘Friends with Voices’

A collaboration from across Luton

DAA
Luton Dementia Action Alliance

www.luton.gov.uk
‘What the future holds for people with dementia and the impact on the BAME communities’

Dr Sen Kallumpuram
Consultant Psychiatrist & ACD
Luton Community Mental Health Team for Older People
Luton Population

- Luton has a population of 215,000
- 26,000 above the age of 65 years
- Population is younger and super diverse
- Over 50% BAME background
- Dementia Prevalence in Luton 1600
- There should be around 600-800 from BAME

(mid year OFN)
Luton Older Peoples Team

- Our team receives over 1000 referrals/year
- 70% of the referrals for a dementia diagnosis
- 30% of the referrals are from BAME groups
- Referral numbers from BAME groups *slowly increasing* - the community is ageing!
- Our aim is to have **better engagement** with BAME
DEMENTIA: An umbrella term

- Alzheimer’s disease
- Vascular dementia
- Frontotemporal dementia
- Dementia with Lewy body’s
- Progressive supranuclear palsy
- Parkinson’s disease dementia
- Corticobasal degeneration
"Neuronal Forest" with healthy neurons unaffected by AD

Shrinking neuron with tangles inside

Plaque
Brain Atrophy in Advanced Alzheimer’s Disease

Normal

AD
MRI- Alzheimer’s disease
MRI- vascular dementia
Neurotransmitters in the Brain

- Acetylcholine
- Serotonin
- Dopamine
- Norepinephrine
- Glutamate
- Histamine
Neurotransmitters in Dementia

- Glutamine
- Serotonin
- Dopamine
- Acetyl Choline
The stages of Alzheimer’s Disease

- Seven primary stages of dementia
- The fast scale was developed at the New York university medical Center’s Aging and Dementia Research Center
Progression of Alzheimer’s disease

Clinical abnormalities

- Conspicuous behavior at work
- Forgetfulness
- Mood swings
- Attention disturbances

- Conspicuous cognitive deficits
- Restricted everyday activities
- Orientation disturbance
- Apraxia, agnosia, aphasia
- Behavioral abnormalities

- Loss of independence
- Decay of memory and speech
- Incontinence

Mild stage
Moderate stage
Severe stage

Restricted independence

Complete dependence on nursing care
Dementia – what does the future hold?

- Preventing well
- Diagnosing well
- Supporting well
- Living well
- Dying well

Prof Alistair Burns
Current Thinking on Treatment of Dementia

- Treating the disease: when to start?
- Treating the person and supporting the carer
- Treating/controlling risk factors
- Anti-dementia medication: Donepezil, Rivastigmine, Galantamine & Memantine
- Managing behavioural symptoms
- Cognitive stimulation groups
- Physical exercises and cognitive activities
- Diet and nutrition
- Better end of life care
Non pharmacological interventions (evidence based)

- **Cognitive stimulation therapy**: It has the potential to improve cognitive function, reduce carer strain, delay institutionalisation and improve the quality of life.

- **Multi-component carer counselling and support**: better outcome if given early and may delay need of care home placement.

- **Peer support groups** and individual behavioural therapy programs may alleviate depressive symptoms.
Preventing Dementia!
Can we???
THE ALZHEIMER'S CONTINUUM

**Preclinical**
- No symptoms, but brain changes have begun

**Mild Cognitive Impairment**
- Memory or other cognitive complaints
- Abnormal when formally tested
- Impairment is not bad enough to impact daily functioning

**Dementia**
- Memory and other cognitive difficulties bad enough to impact daily life

Cognitive function

Ageing

MCI

Dementia

Years

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Dementia Prevention

How to protect against dementia

- Volunteering
- Meeting friends
- Learning a second language
- Reading
- Puzzles
- Crosswords

Social engagement
Cognitive stimulation
Education
Tips to enjoy Healthy Ageing

- Keep your mind active
- Keep you physically active
- Eat a Healthy Diet
- Check your blood pressure, Blood sugar and Cholesterol every 3-6 months
- Take your tablets as prescribed
- Take fewer worries
- Enjoy a good night sleep
BAME & Dementia

- In UK 25,000 People with dementia from BAME communities
- It is to rise to 172,000 by 2051
- 7 fold increase in 50 years
Dementia & BAME

- Lack of primary contact with dementia
- Lack of culturally appropriate resources
- Stigma towards mental illness
- Fear of social isolation
- Resulting in delay in seeking help & support
- Attending to services when family is in crisis
BAME & Dementia

- Dementia is a part of normal ageing
- Lower levels of awareness
- Not sure where or how to find information
- Exacerbated by language barriers
- Higher levels of Stigma
- Different cultural understandings
- Lack of online resources in their language
Communication matters

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Caring & BAME

- Using a services as a source of shame
- Should be managed at home
- Duty of care as a part of the culture
- The Silent carer & the Lonely carer
- High carer stress – depression
- Loss of earnings
- Effects on multigenerational household
Way Forward

- **Establishing links** with culturally-appropriate community groups
- **Working closely with community leaders**
- **Joint working** for various agencies
- **Person centred care** that focuses on the individual rather than the disease
- **Understanding of challenges** based on the person’s cultural background
Intergenerational work
Dementia Information Event
For Older People and Carers

South Asian Wellbeing Partnership Project working with Luton Borough Council, Alzheimer’s Society Luton and East London Foundation Trust (ELFT), has organised an information event to raise awareness of Dementia and mental health wellbeing.

Date: 5th October 2017
Thursday
Time: 11am - 2:30pm
Venue: Holy Ghost Parish Centre
33 Westbourne Road
Luton, LU4 8JD

Free information, advice, workshop and pampering sessions for older people and carers.

The Partners are:
- CYCD
- Bangladesh Community Khidmat
- Pakistan/Kashmiri Ujala
- Indian/all
- Guru Nanak - Indian/Sikh/all
- Guru Ravidass - Indian/Sikh/all
- Dilkhsa - Indian/Gujarati/all
- Hindu Centre - Indian/Gujarath/all

For more information please contact:
Fazal Khan on 01582-519900
Email: f.khan@cycd.org.uk
or
Naasrin Haq on 01582-547702
Email: Naasrin.Haq@luton.gov.uk

Refreshments and lunch will be available.

Sponsored by the Indian Orthodox Church, UK Diocese
Thank you
“I Just don’t know”
(a legacy to Bert)

Jenny Moody
MBE
Decision Making and Capacity

Presented by

Siobhan Rooney
Partner
Wills Trusts & Probate
Pictons Solicitors
Agenda

- What is a Lasting Power of Attorney?
- How do Powers of Attorney work?
- Common Concerns
- Why you should make one?
- Other options to a Lasting Power of Attorney?
- What happens if I don’t have one?
What is a Lasting Power of Attorney?

‘A Lasting Power of Attorney (LPA) is a legal document that lets you (the ‘donor’) appoint one or more people (known as ‘attorneys’) to help you make decisions or to make decisions on your behalf.’

www.directgov.uk

Created under the Mental Capacity Act 2005

Replaced Enduring Powers of Attorney
What is a Lasting Power of Attorney?

There are two types of Lasting Power of Attorney:

- Health and Welfare
- Property and Financial Affairs

It is no longer possible to create an Enduring Power of Attorney but EPA’s created before 01\textsuperscript{st} October 2007 remain valid.
What is a Lasting Power of Attorney?

Health and Welfare Lasting Power of Attorney:

This type of Lasting Power of Attorney enables your Attorney’s to make decisions in relation to your wellbeing, for example:

- Your medical care
- Your daily routine, (washing, dressing, eating)
- Moving into a care home
- Life-sustaining treatment

This type of Lasting Power of Attorney can only be used when you are unable to make your own decisions

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What is a Lasting Power of Attorney?

**Property and Financial Affairs:**

This type of Lasting Power of Attorney enables your Attorneys to make decisions on your financial matters, for example:

- To manage a bank or building society account including authority to make withdrawals
- To pay bills on your behalf
- To collect benefits or a pension on your behalf
- To sell your home

This Lasting Power of Attorney can be used as soon as it’s registered, with your permission.
How do Lasting Powers of Attorney work?

Donor completes a Lasting Power of Attorney form which is witnessed and signed by Attorneys who consent to act.

Signed by a Certificate Provider to confirm capacity

Registered at the Office of Public Guardian (£82 fee EACH)

Once registered can be usually used immediately
Common Concerns

• My Attorney will run off with my money

• I will be excluded from decision making

• I will lose control
Common Concerns

- Restrictions and limitations can be provided for in the Lasting Power of Attorney
- Appointment of more than one Attorney
- 5 principles enshrined in the MCA:
  - Presumption of capacity
  - Supported decision making
  - Making unwise decisions
  - Decision making in a person’s best interests
  - Less restrictive option
Why Make a Lasting Power of Attorney

- Allows you to control decision making and your views to be taken into account when otherwise they wouldn’t be.

- Takes pressure and burden off family members to take decisions

- Stops fighting between family members who may have differing views

- Cheaper than a Court of Protection application!
Other Options

Advance Directives AKA Advanced Decisions or Living Wills

Not truly a Power of Attorney but may be useful alternative or addition to Lasting Power of Attorney for Health and Care decisions

Only come into play when a specific situation arises (e.g. medical decision)
What happens if I don’t have a Lasting Power of Attorney

Nothing (if lucky!)

OR

Court of Protection Application to appoint a Deputy to deal with your affairs
What happens if I don’t have a Lasting Power of Attorney

Where a person lacks capacity in relation to matters concerning his/her health and welfare or property and financial affairs, the Court of Protection has jurisdiction to appoint **deputies** to make decisions on that person’s behalf in relation to their matter or matters.
What happens if I don’t have a Lasting Power of Attorney

Deputyship applications:
- Made to the Court of Protection
- S16(4) MCA two principles:
  • A decision by the court is to be preferred to the appointment of a deputy to make a decision, and
  • The powers conferred on a deputy should be limited in scope and duration as is reasonably practicable in the circumstances
- Not usually successful for health & welfare decisions
Things to consider.....
What else can I help you with?

- Probate including contentious
- Court of Protection & Deputyship
- Care Issues
- Trusts
- General Estate Planning and Wills

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Thank you for coming today