

DAA

Luton Dementia
Action Alliance



Making Luton a Dementia Friendly Community

**Luton Dementia Action Alliance
Launch Event
Report**

29th November 2013



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Executive Summary

Aims of the event

To launch the Luton Dementia Action Alliance (LDAA) and its vision for Luton as a Dementia Friendly Community

Objectives

- Raise the profile of the alliance and its work to create a dementia friendly community
- Participants to understand the key components of a dementia friendly community
- Participants to understand dementia as a condition and its impact on sufferers and carers
- Recruit more organisations to join the LDAA
- Provide opportunities for organisations to network
- Recruitment of Dementia Champions and Friends

Value

The Conference helped delegates to enhance their knowledge of dementia and how it affects people living with dementia and their carers. Raised awareness of the National Dementia strategy, National Dementia Action Alliance and Luton's Dementia Action Alliance and how we can work together to create a Dementia Friendly Community.

Achievements

- 22 Organisations committed to signing up to the LDAA
- 4 organisations completed their National Dementia Action Alliance Action Plans
- Luton Adult Learning is developing a Dementia awareness training course as a direct result of attending the event. They have also nominated a member of staff to attend the Dementia Champion's training, enabling them to deliver their own Dementia Friends information sessions
- 20 organisations have expressed an interest in their organisations delivering the Dementia Friends information sessions to their workforce
- 100 individuals trained as Dementia Friends on the day

Background

42% of the population know someone with dementia and it is estimated that 820,000 people in the UK are living with the condition; this figure will double within the next 30yrs. The annual cost of dementia to the UK economy is 23bn and is set to rise to 27bn by 2018.

The Dementia Challenge was launched in March 2012 by the Prime Minister David Cameron to tackle one of the most important issues we face as our population ages. It is an ambitious programme of work designed to make a real difference to the lives of people with dementia and their families and carers, building on progress made through the 2009 National Dementia Strategy.

The PM's Challenge on Dementia is a challenge to the whole of society as well as government. It focus's on three key areas:

- Driving improvements in health and care
- Creating dementia friendly communities that understand how to help
- Better research

A **dementia friendly community** is one that shows a high level of public awareness and understanding, so that people with dementia and their carers are encouraged to seek help and are supported by their community. Such communities are more inclusive of people with dementia and improve their ability to remain independent and have choice and control over their lives

Luton Borough Council developed its 'Joint Commissioning Strategy – People with Dementia' in partnership with local agencies in 2010 and with crucial input from key stakeholders – including people living with dementia and their carers.

In 2013 the Director of Housing and Community Living decided to take further steps and decided that Luton Borough Council will facilitate the development of Luton as a Dementia Friendly Community

Luton's Dementia Action Alliance Core group was established to lead on the development of Luton as a Dementia Friendly Community and develop the Action Alliance. A launch event was delivered on the 29th November 2013

Dementia Friendly Communities Launch Event

Held on the 29th November 2013, Venue 360, Luton

Aim of the event

To launch the Luton Dementia Action Alliance (LDAA) and its vision for Luton as a Dementia Friendly Community

Objectives

- Raise the profile of the alliance and its work to create a dementia friendly community
- Participants to understand the key components of a dementia friendly community
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- Recruit more organisations to join the LDAA
- Provide opportunities for organisations to network
- Recruitment of Dementia Champions and Friends

On the day

173 delegates attended on the day, representing carers, people living with dementia, public sector organisations and private companies

Order of the day

Speakers

Cllr Hazel Simmons - Leader of the Council

Bernard Conroy – Living with dementia

Elaine Whitworth – Caring for a person living with dementia

Dr Ian Sherriff – University of Plymouth, Academic lead on dementia

Pam Garraway – Director of Housing and Community Living, LBC

Kimberly Radford – Joint Commissioning Manager Older People, LBC

Agenda

0930hrs	Registration & refreshments
1000hrs	Welcome & Aims of the event – Kimberly Radford, Commissioning Manager, Adult Social Care, LBC
1005hrs	Luton's vision for a Dementia Friendly Community – Hazel Simmons, Leader of the Council
1015hrs	My life living with dementia – Bernard Conroy
1030hrs	Caring for dementia – Eileen Whitworth
1045hrs	Carer's Call to Action – Kimberly Radford

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1055hrs	Break
1115hrs	Dr. Ian Sherriff – Urban & Rural Dementia Friendly Communities
1145hrs	Luton's Way forward and getting involved – Kimberly Radford
1215hrs	LBC's Action Plan – Pam Garraway, Director of Housing and Community Living, LBC
1230hrs	Lunch and networking
1330hrs	Dementia Friends Information Session workshops – Anna Flynn & Maria Collins
1430hrs	Close

Opened by the Leader of Luton Borough Council, Cllr Hazel Simmons, the theme of the conference was 'Making Luton a Dementia Friendly Community' and included a number of discussions about how everyone can work together to remove the stigma and raise awareness of dementia within the community.

Kimberly Radford, Joint Commissioning Manager for older people at Luton Borough Council presented some revealing facts about dementia and the UK population

One of the highlights of the event was the personal accounts of Bernard Conroy who is living with dementia and Eileen Whitworth a carer. An energetic and engaging key note speech was delivered by the University of Plymouth's Dr Ian Sherriff who is a member of the Government's Dementia Challenge group and a leading academic on the condition. Pam Garraway, the Director of Housing and Community Living and lead on Luton's Dementia Friendly Community urged organisations to follow Luton Borough Council's lead and show their commitment by joining then LDAA and completing their own individual Action Plans.

The conference concluded with 100 people attending a 'Dementia Friends' information session. Enabling delegates to learn a little bit more about what it's like to live with dementia and how they can turn that understanding into action.

Dementia Friends Information Session

This workshop was delivered to 100 delegates by Dementia Champions Maria Collins and Anna Flynn.

Delegates were taken through dementia and its impact on family and carers and enjoyed a dementia raising awareness group exercise. Suggested actions to improve service delivery and lives of those living with dementia can be found at Appendix iii.

Outcomes from the event

- 22 additional organisations committed to signing up to the LDAA
- 4 organisations completed their National Dementia Action Alliance Action Plans
- Luton Adult Learning is developing a Dementia awareness training course as a direct result of attending the event. They have also nominated a member of staff to attend the Dementia Champions training, enabling their organisations to be self sufficient in delivering their training programme
- 20 organisations have expressed an interest in their organisations hosting the Dementia Friends Information sessions
- 100 individuals trained as Dementia Friends on the day
- Raised awareness of Dementia and Luton's Dementia Action Alliance

Quotes from the day

Cllr Mahmood Hussain, Portfolio Holder for adult social care, said: “It was great to see public sector organisations, private companies, carers and people living with dementia all come together to discuss and learn about dementia and make a commitment to supporting people with the condition.

Gill Lintott, Alzheimer’s Society Operations Manager for Cambridgeshire and Bedfordshire, said: “It was a great privilege to be part of such an inspiring launch event for the Luton Dementia Action Alliance. Having so many people and organisations together in one room talking about dementia was fantastic and it really does feel like the beginning of new and exciting times for the town.

“There are more than 1,800 people with dementia in Luton. From bus drivers to the boardroom, from the bank to the beauty salon, we all have a role to play in helping people with dementia to be part of their community. I hope more businesses and organisations will now come forward to join the Dementia Action Alliance and play their part.”

Next Steps

1. Core Group meeting on the 9th December 2013 to decide the next steps for establishing the Luton Dementia Action Alliance
2. Address the questions raised via the Voice Board
3. Continue with the media campaign
4. Ensure delegates have access to the post event information

Appendix i

Feedback from the Evaluation Forms

Response to the questions

1. **Overall, how satisfied were you with the venue and the facilities?**

- 55 Very satisfied
- 1 Satisfied

Comments included; lovely food, excellent facilities, parking easy, A1, acoustics good as an hearing aid user, easy access, spacious

The less than positive comments made referred to the air conditioning, which made the venue feel cold whilst turned on and venue staff made noise during the presentations

2. **How satisfied were you with the speakers/presenters?**

- 52 very satisfied
- 4 satisfied

Comments included; engaging and inspirational, grassroots & practical, very passionate, emotive, humorous, knowledgeable, stimulating

Could have been more representative of the diverse make up of Luton, some presentations could have been shorter in time

3. **Was the content of the programme appropriate and informative?**

- 49 very satisfied
- 7 satisfied

Comments included; excellent, well done, very useful, very informative with facilitated networking, highlighted the lack of provision and services available, raised awareness, engaged individuals to become involved, highly appropriate, highlighted different aspects of dementia and agencies, good stands

On the less positive note one comment was made - too many bits of paper

4. **Was the event well organised?**

- 46 very satisfied
- 9 satisfied
- 1 not satisfied

Comments included; very well done, information received in a timely manner, delegates made to feel welcome, information stands excellent, refreshments very welcome, excellent, there weren't any hiccups, ran very smoothly,

Less positive comments; directions were confusing, late start, talked at for 2hrs with no opportunity to ask questions, ran overtime, joining instructions confusing and the reception did not know what it was about

5. What kinds of sessions would you like to see included at future events?

- Examples of outcomes
- What organisations have done together, with the results and ongoing work
- Businesses talking and giving practical examples
- More definitions from experts
- More on the dementia diagnosis
- Some kind of advice on how to avoid developing dementia
- Dementia and risk assessment
- Funding opportunities for groups
- Question and answer session
- Update on progress
- Micro training session on how to become engaged with someone in the later stages of dementia
- Progress and celebration of any successes
- Recognising Alzheimers
- More information on agencies with their contact details
- Updated on the National and local strategies
- How dementia links with other conditions e.g. learning disabilities
- How to spot a dementia sufferer in a crowd
- How to access services
- Service pathway
- More information regarding respite care
- More carer focused – learning from each other

6. What did you like most about the event?

- The venue
- The quality of the speakers
- Everything
- That people who suffered with dementia spoke about how they felt
- Learning and becoming more aware of dementia
- Hearing how LBC are going to try to get dementia awareness up and running

- The informality made it really friendly and feel good
- Handouts
- Free food
- The real enthusiasm in the room
- Learning about carers
- The sound quality
- Bringing many people from many areas together
- Plans and vision for Dementia Friendly Communities in Luton
- Balance of head and heart
- Networking
- The programme
- Very well facilitated
- What we can do as a community
- Well organised

7. What did you least like about the event?

- Lack of opportunity for the group to participate and ask questions
- Too much emphasis on the carer being a partner or spouse
- Very emotional – good and bad
- Speaker's timekeeping
- Only one day
- Not enough focus on BME communities
- Leaving to go home
- Air conditioning too cold
- Presentation slides a bit out of time
- Couldn't join the afternoon session because it was fully booked

Appendix ii

Voice Board

To allow delegates the opportunity to make comments or ask questions in relation to the delivery of services to people living with dementia and their carers. We placed a Voice Board in the venue. A notice was placed with the Voice Board informing delegates that although Luton Borough Council may not be able to take ownership of some of the comments, we would ensure that the comments would be passed onto the relevant agency for an appropriate response.

The following comments made and questions asked:

“Make it known that a discount can be given on Council Tax for people diagnosed with dementia” (Sue Ruffett)

“Doctors, please read the patient’s notes before you visit. How many times have I been asked if I realised my dad seemed very forgetful, did I know why?” (Sue Ruffett)

“We want people with dementia to stay at home. Many people with dementia become immobile, why then does a care package, when awarded not include night carers?” (Sue Ruffett)

“Hospital consultant signed DNR and put it in my Father’s notes on transfer to the care home. No-one asked the family, only the care home” (anonymous)

“When will Luton have its own Dementia Strategy? Maybe we should use the National Dementia Strategy” (Ron Greenham)

“My mum could not claim Carer’s Allowance because she gets State Pension. She cared for my dad 24/7, it nearly killed her! She was his carer, does this make sense?” (Sue Ruffett)

“Dr Sherriff referred to a new national Strategy, is this correct?” (Ron Greenham)

Questions have been referred to the correct agencies. The questions to Ron Greenham have been answered.

Appendix iii

Dementia Friends Information Session – Suggested Actions

	SUGGESTION	CONTACT DETAILS	FOLLOW UP	OTHER
1	Create website for more information	None		
2	Further training – for champions			
3	Increase all awareness amongst all LBC staff to deliver vision of dementia friendly Luton			
4	Discuss dementia friendly Luton with all local business to engage in process			
5	Share information with local community groups that LBC staff come into contact with			
6	Provide carers with support on local services			
7	Communicate with local groups with support from LBC/Social Services etc. Signing up to become Dementia Friend/volunteer	Pat 01582 611913		
8.	Art and craft activities to reduce depression and loneliness			
9.	Promote the alliance via personal social media sites. e.g. Facebook, and provide web link to dementia awareness key messages			
10	Look at ways of making technology more user friendly for those with dementia			
11	Have dementia awareness programmes in community workshops Luton wide			
12	Introduce PAT dogs to day care (participant willing to bring his dog into day centres or residential homes)	Elaine Robinson 01582 965385 Dave Magill 01582 618180		
13	Provide advice on dementia-proofing individuals homes			
14	Realise the importance of our work	mross@livability.org.uk		

15	Support development of dementia champion training for each team in LBC	James Stevens Part 2 Management 01582 756321		
16	Ensure all LBC buildings have signage appropriate to those with dementia			
17	Better identification of carers needs and signposting			
18	Share information and tips with customers, colleagues, friends and family contacts i.e. what works, signposting etc.			
19	Identify Dementia Friends Champions for Luton for future contact/training/support and make this known on LBC website			
20	Identify work place dementia friends champions and publish this within organisations			
21	Adaptations under Disabled Grants - create visual contrast in shower area as standard part of installation Edge to shower area Grab rails Around shower unit RNIB approved shower Toilet seats etc.	Dave Stevenson LBC 01582 546186		
22	Compile simple information folder with computerised version for staff	Sue Ruffett LTC/CCS		
23	Spread awareness by requesting information boards to pass on information to patients and staff			
24	Increase personal awareness			
25	Ask questions about memory and offer help			
26	Organise neighbourhood search for missing individuals with dementia			

Useful Links

www.alzheimers.org.uk

www.dementiaaction.org.uk

www.dementiauk.org

www.institute.nhs.uk

www.gov.uk/government

www.dementiachallenge.dh.gov.uk/strategy