

# Learning disability and dementia project evaluation

Final report July 2018



## Executive summary

This innovation project ran from July 2017 to June 2018 in Herefordshire. The aim was to:

- Increase awareness and understanding of dementia within the learning disability community
- Better prepare people living and working with dementia for the changes dementia brings
- Raise awareness of and trial/promote the use of existing resources developed with support of Alzheimer's Society.

We worked in partnership with many community and social care organisations, including the Community Learning Disability Team and Community Dementia Service, both run by 2Gether NHS Foundation Trust. A Dementia Adviser worked with 11 people and their supporters to adapt to the changes dementia brings. Resources from Alzheimer's Society as well as other organisations working to support people who have a learning disability were introduced to people on an individual basis to meet their particular needs. 21 Dementia Friends sessions with a learning disability element were delivered to people who live and/or work with learning disability. Three of these were for people who have a learning disability.

Paid and unpaid workers (supporters) were asked to rate their confidence to support a person who has a learning disability and dementia before and after awareness sessions. Outcomes Stars were used with the supporters of the 11 people with whom we worked intensively. Outcomes Plans were created with the 11 people and case studies have captured the findings.

We found that people with a learning disability were familiar with the word 'dementia' and wanted to understand more and help others. They hadn't been receiving the same services as others post-diagnosis and had not always been told when they had dementia. Enabling a person who has a learning disability to be a Dementia Friends Champion helped us to create more Dementia Friends in this community.

We found that family carers did not engage unless dementia was being diagnosed. Almost all paid workers in learning disability services expressed not having been prepared for dementia previously. After engaging with the project, 100% said their understanding and confidence has increased.

The need for individuals to have portable life-stories that facilitate holistic understanding, planning and support is widely recognised. More needs to be done to ensure this happens consistently.

The report provides further detail about the project, including what has been concluded and the recommendations going forward. The commentary reflects work with a limited number of people and does not claim to be conclusive or fully representative of all people in the groups identified.

# Contents

|  |    |
|--|----|
| Executive summary.....   | 1  |
| 1. Background:.....  | 3  |
| 2. Methodology.....  | 5  |
| 3. Key findings.....   | 6  |
| 4. Facilitators and Barriers .....   | 10 |
| 5. Conclusions and recommendations .....   | 11 |
| 6. Final thanks .....  | 13 |
| 7. List of appendices .....  | 14 |
| Appendix 1: Facts and figures from Herefordshire Joint Strategic Needs Analysis .....            | 15 |
| Appendix 2: Resource list .....  | 16 |
| Appendix 3: Bibliography .....   | 17 |
| Appendix 4: Case Studies.....  | 18 |
| Appendix 5: Getting To Know You (Learning disability and dementia project assessment tool) ..... | 23 |
| Appendix 6: Evaluation tool for carers and paid workers (Outcomes Star) .....                    | 25 |
| Appendix 7: Outcomes plan for individuals .....  | 26 |
| Appendix 8: Awareness-raising session evaluation tool .....                                      | 27 |
| Appendix 9: Extracts from Herefordshire Learning Disability Strategy 2018-28 .....               | 28 |
| Appendix 10: Examples of feedback from participants in the one-to-one work.....                  | 29 |

# 1. Background:

Improved care and understanding of learning disability means that people with learning disability live longer, often with significant support in place before the experience of dementia may arise. Support people and services are likely to be specialists in learning disability with less understanding of dementia. While more people with a learning disability are developing dementia it is less likely to be detected in a timely fashion so the opportunities can be missed for them to understand, plan for their future and get the appropriate support to live well as long as possible with dementia.

In 2016, discussions began that in Herefordshire, interagency links had been missing between local services for people with learning disability, Alzheimer's Society local services and the Dementia Friendly Communities work.

In 2017, Alzheimer's Society allocated funding, through the Innovation work, for twelve months to explore the impact of:

Supporting people in Herefordshire affected both by learning disability and dementia including:

- People with learning disability
- Paid and unpaid supporters in family homes / in care homes or supported living / community supports

Equipping them with:

- Awareness of the signs of dementia and the different ways it may affect individuals
- Understanding of how to prepare the community, adapt the environment and support plan to enable the individual to continue to live well in their community.

## 1.1 Project objectives

- To increase awareness and understanding of dementia within the learning disability community
- To better prepare people living and working with dementia for the changes dementia brings
- To raise awareness of and trial / promote the use of existing resources developed with support of Alzheimer's Society

## 1.2 Expected outcomes

- People with learning disabilities have increased understanding of dementia
- Unpaid carers and paid support workers have increased understanding of dementia
- People with learning disabilities and dementia have a dementia friendly support plan designed to maintain lifestyle of choice
- People who support people who have a learning disability and dementia express greater confidence that they are better equipped to support life to be lived according to personal choice and preference.

The project work fell into the two distinct yet complementary strands of awareness raising and support for individuals. Both the Project Manager (Services Manager) and the Project Worker (Dementia Adviser) have worked on the awareness-raising while the Dementia Adviser has carried out the one-to-one work with individuals and their support networks.

Following discussions with the Operations Manager and Psychologist at the Community Learning Disability Team, work began with the Assistant Psychologist. On 30 June 2017, the information kick-off meeting was held, which included a joint presentation by Alzheimer's Society, Herefordshire Community Learning Disability Team and the Community Dementia Service (both delivered by 2Gether NHS Foundation Trust).

A relationship with the Learning Disability Partnership Board stemmed from this and the team were invited to meetings throughout the year. This helped to raise the profile of dementia and enabled involvement in the developing Herefordshire 10 year learning disability strategy.

Stakeholders were also invited to a project celebration event on 21 May 2018, day one of Dementia Action Week 2018. Attendees worked together to consider the key findings and translate them into action.

**Organisations involved included:**

- Alzheimer's Society
- Aspire
- ECHO
- 2gether NHS Foundation Trust Community Learning Disability Team
- Herefordshire Carers Support
- Herefordshire Clinical Commissioning Group
- Herefordshire Council Shared Lives Care (At start of project Shared Lives provider was Ategi)

## 2. Methodology

### 2.1 Dementia awareness-raising for people who live and or work with learning disability

Between September and June 2018, 21 awareness sessions were delivered to a total of 206 people. Participants were asked to complete a data capture form face-to-face before and after the session to measure the impact on their understanding of how dementia can affect a person who has a learning disability. (Appendix 8)

The sessions were for paid and unpaid supporters and were run as a Dementia Friends session, followed by a session on how dementia affects a person with a learning disability. The use of the resource 'Supporting Derek' has been well received by participants. (Appendix 2)

Of the 21 sessions, three were delivered to 16 people who have a learning disability using the Dementia Friends resources adapted for people who have a learning disability. They were delivered to:

- ECHO Rep Group (ECHO is a participant-led Herefordshire charity which provides community opportunities for people who have learning disabilities)
- Our News Our Views team (Our news Our Views are a group of adults with a learning disability who have pooled their personal budgets to produce an accessible newsletter for the Learning Disability Community of Herefordshire)
- Residents of Merrivale farm (a small care home for people who have a learning disability)

### 2.2 One-to-one support for people who have a learning disability and dementia, with their support networks

The Dementia Adviser worked with 11 people and their supporters to help them to adapt to the changes dementia brings. They used the Getting to know you form (Appendix 5) and identified desired outcomes to record on an Outcomes plan (Appendix 7), as well as identifying resources relevant for them (Appendix 2). Time spent working with the supporters on how to achieve the outcomes varied according to each individual situation.

The following table displays how people were referred. Through these referrals there were a total number of 51 home visits. For examples of feedback and details of one-to-one work, see appendices 4 and 10.

| Source of referral                      | Number of referrals |
|---|---------------------|
| Self, family or friend                  | 2                   |
| Community Learning Disability Team      | 11                  |
| Other health / social care professional | 0                   |
| Care /support provider                  | 2                   |
| <b>Total</b>                            | <b>15</b>           |

### 3. Key findings

| Outcome Measures   | Target | Result   |
|--|--------|--|
| Number of Dementia Friends who have a learning disability  | 10     | 16   |
| Number of LD Dementia Champion /Co-facilitators who have a learning disability   | 2      | 1  |
| Feedback from people with a learning disability who shared a part of their lives with someone who has dementia.  |        | See Appendix 10  |
| Number of Dementia Friends created in paid workforce   | 250    | 167  |
| Number of Dementia Friends Champions in paid workforce   | 2      | 5  |
| Number of unpaid carers Dementia Friends   | 25     | 18<br>It is likely that this figure is actually higher as we omitted to capture from start whether all paid workers are also carers. |
| Total Number of Dementia Friends in learning disability community as a direct result of project work   | 289    | 206<br>This figure includes some family, doctors, people who have a learning disability and Dementia Friends Champions.              |
| Percentage of Support Workers who express increased confidence / success in supporting people with a learning disability and dementia  |        | 100% of participants   |
| Percentage of carers who express increased confidence / success in supporting people with a learning disability and dementia. (Appendix 4)   |        | 100% of participants   |
| Percentage of individuals who had one-to-one support identify adjustments made and planned from the support received.<br>(Qualitative feedback received. Case studies and individual stories, Appendix 4.)                 | 90%    | 73% of referrals (11 people).<br><br>To note, due to individual circumstances, support was not concluded for 4 people.               |
| % of support workers / carers of people in support group who identify adjustments made / planned arising from support received. (Qualitative feedback received. Case studies, Appendix 4, and Outcomes Stars, Appendix 6.) | 90%    | 100%   |

We have used a number of resources through one-to-one support and awareness-raising sessions. (Appendix 2)

## **3.1 People with a learning disability**

People who have a learning disability are already familiar with the idea of dementia and are not frightened by the word or to talk about it. Those we worked with wanted to understand more about the condition. They are not always told about their dementia diagnosis. (Appendix 4, Case Study 1)

Developing Dementia Friends Champions who have a learning disability to co-facilitate awareness sessions and support their peers is a powerful enabler.

## **3.2 People with a learning disability and dementia**

### **Baseline assessments**

It is recognised that for people who have Down's Syndrome, the baseline assessment of cognitive functioning should begin by age 30. Information received tells us that this may not have always happened which has meant that there may not have been an accurate picture of decline, and a delay in diagnosis. We worked with the Learning Disability Partnership Board reviewing drafts of the developing 2018-28 Herefordshire Learning disability strategy. (Appendix 9)

### **Sharing of information**

Some carers reported that strict interpretation of data protection was preventing the sharing of information between home carers and other supporters, creating barriers to the consistent application of person-centred best practice. The Dementia Adviser supported the carers to use an iPad to share essential information securely and to communicate effectively. These carers developed their own electronic system, working in many ways like the Wiki-Me tool being piloted in Herefordshire. (Appendix 3)

The system above can:

- Facilitate the joined up support between all involved professionals and supporters, building and saving a full life story which, historically, is often archived and lost
- Avoid duplication, lost information and missed opportunities
- Maintain and build on positive proactive strategies that support the person to live well.

### **Referral pathways**

Prior to this project, people who have a learning disability being diagnosed with dementia (and the people who support them) were not aware of the support available and had not been referred on to Alzheimer's Society or Community Dementia Services. This fits with some of the comments made at the kick-off information meeting on 30 June 2017 from stakeholders who expressed:

- Pathways should be more mainstreamed with referrals between community dementia services and community mental health services. There is concern over the lack of information for people on accessing social workers and the memory service.
- There is concern over overlap between services, each thinking the other has picked it up and the outcome would be that main issues get missed or people slip through the net.

## **Inclusion of people with learning disability and dementia**

Adhering to the principle of 'nothing about us without us' may be more challenging to achieve. People with learning disability and dementia have pre-existing cognitive impairments before dementia affects them and have often always had someone else speaking for or with them. Although they may fall into the young onset age range, their cognitive functioning and life history may mean that more work and creative thinking is needed to ensure their inclusion. Add to this the reluctance of family carers to engage with the topic of dementia and there is a danger that the individual does not get the benefit of support with their dementia.

### **Introductory awareness**

The introduction of some information and basic awareness can quickly make a difference. Comments received on the work done by the Dementia Adviser with Person A reflect the following:

'Recent adaptations to the home and looking at a more dementia friendly environment have helped Person A's anxiety. Shouting whilst in the bathroom has decreased.' (Feedback from carer, Appendix 10)

Carers also told the Dementia Adviser that:

- They now consider how Person A, with limited vocabulary, communicates pain via facial expressions.
- Since the project began they have valued the shared resources and tips and have had moments of clarity with Person A.

We worked with the Learning Disability Partnership Board which was reviewing drafts of the developing Herefordshire Learning Disability strategy 2010-2028 and includes the following:

'There will be widely available accessible information and training in order to raise the level of awareness of dementia across the learning disability community (professionals, paid staff, service providers, family carers and people with learning disabilities.'

## **3.3 Carers**

Carers have generally been the hardest group to engage. In August 2017, Herefordshire Carers Support (HCS) reported that of the 5,399 Carers registered (as at June 2017) 969 had informed them that the person they care for has a learning disability. HCS shared information about the project and sent invites to Dementia Friends sessions for carers of people with learning disabilities. However, we received no responses from carers through this.

Carers seem more likely than people with a learning disability to fear and avoid the subject of dementia. The carers we have reached through one-to-one referrals have told us that they had not previously had support to understand dementia. Equipping carers with knowledge and understanding while their 'cared for' person is still a child could empower them to plan ahead for the best possible life as they age and if dementia occurs.

Carers do want support when dementia has started to affect them. Feedback includes:

- 'The project is providing so much support for myself, my brother and everyone at his care home, it has come just at the right time for him – it's been a real port in a storm. They have given us so much information.'

- 'There is a definite change in the Shared Lives home where my learning disabled daughter lives. I observe the person who has learning disability and dementia now listening to music through headphones, that the environment is dementia friendly. The rugs and patterns are all gone, the Shared Lives carers have really embraced the learning. The impact on other people who have a learning disability who live there is that they are more relaxed. They have stopped telling her to be quiet.' (Appendix 10)
- 'Watching the DVD really helped me understand what life is like through my daughter's eyes and I picked up on so many things that she does that are so like the DVD. It has given me food for thought.'

### 3.4 Paid workers

The Community Learning Disability Service provides bespoke training around an individual when they are involved with a complex support. However, people who work in learning disability services told us that they had not routinely had training in dementia. Dementia-awareness raising sessions (as compared to dementia training) do not appear to have been considered for the workforce prior to this project

There have been consistent positive responses to awareness-raising with 100% increase in understanding recorded. Comments include:

- 'Understanding the environment and more about dementia and what we can do to help support the individuals with learning disability and dementia.'
- 'I was impressed how a difference can be made by such simple changes.'
- 'It has been interesting to have a better idea of how someone with dementia sees the world around them.'
- 'Incredibly informative and I will do all I can to spread the word, I think it is so important for as many people to be aware of dementia.'

There is also feedback from paid supporters of people who received one-to-one support from the Dementia Adviser, including the following Shared Lives carer:

'I would just like to take this opportunity to express what a difference the input from Alzheimer's Society has made over the last 8 months for the ladies that we support. With your input after the diagnosis opening a window on the world of dementia to us we have been able to adapt to the needs with a more detailed and less frightening view of dementia. The support has enabled me to be confident when supporting the ladies in what is no doubt a frightening time for us all.

'Your sessions, factsheets and(...)visits have changed my whole view on dementia and I would like to truly thankyou as armed with this information I can continue to support the ladies(...)into whatever the future may hold(...). The project has been fantastic. I was completely in the dark before and would have been really stuck. The resources were very helpful and something to refer back to(...)and the staff(...)have taken all the learning from the awareness session on board and run with it.'

## 4. Facilitators and Barriers

These are the things that seem to have been:

- Positive enablers to the project (facilitators)
- Things that have reduced impact (barriers)

### Facilitators

- Project Team members from different organisations gave a wide variety of perspectives and connections.
- Regular communication with Innovation Team Project Lead provided structure, advice and creative solutions to overcome some barriers
- Inclusion in the Learning Disability Partnership Board: We are pleased to have been able to share the information and experience gathered with the Learning Disability Partnership Board and that dementia sits robustly under all the commissioning themes within the 2018-28 Learning Disability Strategy for Herefordshire. (Appendix 9)
- Strategic support within Herefordshire from Clinical Dementia Leadership within CCG has supported us to bring key organisational leads and professionals together, and supported communications and engagement.
- Positive engagement with the Community Learning Disability Team provided us with 11 referrals and ongoing support.
- Having a range of networks and leadership understanding and buy-in from organisations who embraced all aspects of the project helped add to the number of people involved in the project, extending reach.
- Support for communications both internally and externally meant we have been able to share our learning at a national level and that we reached out to more people who have been involved in this work.

### Barriers

- Organisations not having capacity to free up staff had an impact on the number of people involved and who we could support.
- Fear, stigma, lack of dementia awareness and carers' perceptions of dementia meant fewer people came forward to be included, especially carers.
- The project started as the summer holiday season began which impacted on timescales and momentum for the work.
- Inappropriate referral and /or person not aware of diagnosis was an unproductive use of resources
- No mechanism or network to link up new Dementia Friends Champions within this community may be a barrier to ongoing support?
- Where externally organisational engagement was at frontline rather than leadership level, energy was generated but not harnessed to maximise the benefit.

# 5. Conclusions and recommendations

## 5.1 People who have a learning disability

### Conclusions:

- There is more concern than evidence to support a prevalent view that people with a learning disability do not want to or cannot engage meaningfully with the subject of dementia.
- Opportunities exist for people who have a learning disability to develop new skills and valued roles as Dementia Friends Champions and influence their communities.

### Recommendations:

- Build on the Dementia Friendly Communities movement, targeting schools to raise dementia awareness of children, teaching staff and non-teaching assistants and parents of children who have a learning disability.
- Support more people who have a learning disability to become Dementia Friends Champions and team them up with Dementia Friends Champions within the workforce.

## 5.2 People who have a learning disability and dementia

### Update

In July, Herefordshire CCG Clinical Dementia Lead facilitated a group of health professionals from the Community Dementia Service and Community Learning Disability team to consider project findings. They have planned to meet again in early September 2018 to confirm any actions regarding:

- Pathway(s) alignment at the interface of Memory Assessment Service and Learning Disability team
- Information and access to support for people with learning disability following diagnosis of dementia

A pilot project has been underway in Herefordshire. A digital platform has been being developed and trialled in Herefordshire with children and young people with special educational needs and disabilities, their families and the people who work with them. This is now being extended to include adults with support needs and offered to people living with both learning disability and dementia. (Appendix 3)

### Conclusions:

- Without understanding of what was 'normal' cognitive functioning for a person with a learning disability and dementia, there may not have been an accurate picture of decline and therefore a delay in diagnosis.
- People have not always had equal access to information and support.

### Recommendation:

A mechanism is needed for the myriad of interventions including life story work and person-centred planning to be held safely and shared appropriately for the lifetime of the person. Whilst people living with a learning disability and dementia are being encouraged to join the current Wiki-Me pilot in Herefordshire (Appendix 3), a strategic approach from commissioners may be needed to ensure engagement of all providers in using tools adopted by individuals to enhance the communication and holistic support provided to them by all people in their networks.

## **5.3 Carers**

### **Update**

People who have had one-to-one support met in June to share experiences. They agreed to keep in touch and to meet again as a self-managing group at Alzheimer's Society Hereford office in September 2018. They were introduced to the Young Onset Dementia Adviser as point of contact and had a Wiki-Me demonstration. (Appendix 3)

### **Conclusions:**

- Fear and stigma associated with dementia in the Herefordshire learning disability community seems to remain higher for carers of individuals with a learning disability. We suspect this is due to the Dementia Friendly Communities movement not having been seen as relevant to this group.
- This may have compounded the reluctance to engage proactively with the subject of dementia planning and increased the need for reactive support when dementia arises.

### **Recommendations:**

- Build on the Dementia Friendly Communities movement, targeting schools to raise dementia awareness of children, teaching staff and non-teaching assistants, parents of children who have a learning disability.
- Support for life story work, tools like Wiki-Me. (Appendix 3)

## **5.4 Paid care and support workforce**

### **Conclusion:**

People working in learning disability services in Herefordshire have not always been prepared for or equipped to recognise signs of dementia or support people who have a learning disability and dementia.

### **Recommendations:**

- Incorporation of Dementia Friends sessions into induction of all health and social care staff.
- Support for Dementia Friends Champions within learning disability organisations to co-facilitate sessions with Champions who have a learning disability.
- Support for life story work, tools like Wiki-Me. (Appendix 3)

## 6. Final thanks

Thanks goes to the following people and organisations involved in the project:

To the project team for their constant support as members and engaging many others:

- Nicky Benson – 2getherNHS Foundation Trust / Community Learning Disability Team
- Tracy Crumb – Our News Our Views
- Dave Davies – Shared Lives Manager (Ategi and then Herefordshire Council)
- Natasha Howard – Alzheimer’s Society (Innovation Team, Research and Development)
- Maggie Percy – ECHO (for extra choices in Herefordshire)

To Jacinta Meighan-Davies, Clinical Programme Manager at Herefordshire Clinical Commissioning Group for bringing key people together to maximise impact.

To the organisations who supported the project in various ways:

- Alpha Grange Limited (Merrivale Farm)
- Alzheimer’s Society
- Aspire
- Ategi
- Crossroads Care Forest of Dean and Herefordshire
- ECHO
- East Bank Care Home
- Elizabeth Fitzroy
- 2Gether NHS Foundation Trust Community Learning Disability Team
- 2Gether NHS Foundation Trust Community Dementia Service
- Herefordshire Carers Support
- Herefordshire Clinical Commissioning Group
- Herefordshire Council Shared Lives Care
- Herefordshire Learning Disability partnership Board
- Herefordshire Mencap
- Macintyre Charity
- Salters Hill Charity (now Walsingham)
- Voyage Care

## 7. List of appendices

- Appendix 1: Facts and figures from Herefordshire Joint Strategic Needs Analysis
- Appendix 2: Resource list
- Appendix 3: Bibliography
- Appendix 4: Case studies
- Appendix 5: Getting To Know You (Learning disability and dementia project assessment tool)
- Appendix 6: Evaluation tool for carers and paid workers (Outcomes Star)
- Appendix 7: Outcomes plan for individuals
- Appendix 8: Awareness-raising session evaluation tool
- Appendix 9: Extracts from Herefordshire Learning Disability Strategy 2018-28
- Appendix 10: Examples of feedback from participants in the one-to-one work

## Appendix 1: Facts and figures from Herefordshire Joint Strategic Needs Analysis

There are estimated to be 700,000 people with a learning disability in the UK of whom 60,000 are estimated to have Downs Syndrome. (2011 figures) One in three people with Downs Syndrome will develop dementia by their fifties. This rises to two in three people in their sixties.

Herefordshire Joints Strategic Needs Analysis 2017 identifies the following:

- In Herefordshire there are estimated to be 2,600 people aged 18-64 who have a learning disability.
- 600 have moderate to severe learning disability.
- 200 live with parents.
- Just over 500 are in receipt of Adult Social Care Services.
- A further 950 people aged 65 and above have a learning disability of which 150 have a moderate to severe learning disability.

## Appendix 2: Resource list

These resources were used in the one-to-one support work and also awareness-raising sessions.

- Alzheimer's Society (October 2014). *Factsheet ER1: What is dementia?* Easy read version. Also available at [www.alzheimers.org.uk](http://www.alzheimers.org.uk).
- Alzheimer's Society (October 2014). *Factsheet ER2: Supporting a person with dementia?* Easy read version. Also available at [www.alzheimers.org.uk](http://www.alzheimers.org.uk).
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- Alzheimer's Society (November 2017). *Booklet 819: Making your home dementia friendly*. Also available at [www.alzheimers.org.uk](http://www.alzheimers.org.uk).
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- Resources through Macintyre Charity, available at: <https://www.macintyrecharity.org/our-expertise/dementia/>

\*'Supporting Derek' is a practice development guide, including a short film, to support people working with people who have a learning disability and dementia.

## Appendix 3: Bibliography

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- *Learning Disabilities in Herefordshire Needs Assessments-Summary Report* (February 2018) version 0.001. Herefordshire Council.
- Watchman, K. (June 2016). ‘Investigating the lived experience of people with downs syndrome with dementia: overcoming methodological and ethical challenges’, *The Journal of Policy and Practice: intellectual disabilities*.
- Watchman, K., et al. (2017). ‘International summit consensus statement: intellectual disability inclusion in national dementia plans’, *American journal of Alzheimer’s Disease and other dementias*, 1-8.
- Wiki-Me information available on YouTube: <https://youtu.be/AdjKMnph6hw>.

## Appendix 4: Case Studies

| Case Study 1   |
|--|
| <p><b>Summary</b></p> <p>Client B has a 'border line' learning disability as a consequence of meningitis when she was a child. Client B lives alone and is <b>unaware of her diagnosis</b> of dementia. The referral to the project came from referrer A at the Community Learning Disability team whilst social services were in the process of identifying Client B's needs. Client B would like to stay in her own home. Practical advice was sought on the best way to support Client B with her diabetes and hoarding issues.</p>   |
| <p><b>Key issues identified. What outcomes were desired?</b></p> <ul style="list-style-type: none"> <li>• There is confidence that Client B takes her medication because she accepts assistance with it.</li> <li>• Client B's home environment is more dementia friendly.</li> <li>• Client B reduces the hoarding of food in her home.</li> </ul>  |
| <p><b>Action taken</b></p> <ul style="list-style-type: none"> <li>• TE met with Client B twice. The first time she was chatty but said numerous times that she did not want to move out of her home. Client B was aware that her mother had passed away and missed her very much. When TE asked Client B if she could visit her again Client B said she did not want to be visited at her home, only at the Hub.</li> <li>• On TE's second visit to the hub Client B did not want to engage with TE at all. She said TE was asking too many questions and that she did not want to talk to her.</li> <li>• Discussion via email with Referrer A over engagement with Client B and scope of project. Suggestions made of ways to plan for the future offered via email to Referrer A. Offered to deliver a Dementia Friends session to new staff team when in place which was to be arranged as and when needed.</li> <li>• <b>Resources given:</b> Making your home dementia friendly, The memory handbook and The dementia guide.</li> </ul>  |
| <p><b>Outcomes for Person with dementia (the <u>change</u> that occurred as a result of the work done)</b></p> <p>The referrer has increased knowledge the Alzheimer's Society and the help that is offered with dementia<br/>Desired identified outcomes not met due to:</p> <ul style="list-style-type: none"> <li>• Expectations of referrer were outside the scope and aims of the project</li> <li>• Client B's unwillingness to engage/reluctance to talk</li> <li>• absence of family/carer or established paid worker</li> </ul>   |
| <p><b>Outcomes for Carer</b></p> <p>No present family carers and no regular paid staff team. In the process of changing providers so as new staff team not in place offer of future awareness session was made at the time</p>   |
| <p><b>Learning:</b></p> <ul style="list-style-type: none"> <li>• Referrers may misinterpret support available or have unrealistic expectations despite clear communication around what the project aims to achieve and how these outcomes fit with individual needs.</li> <li>• Individuals need to know about their own diagnosis in order to accept support offered to assist them to live well in the future.</li> <li>• Without any clear nominated support/carer to work with, life story work proves very difficult.</li> </ul> <p>Client B was unaware of her diagnosis of dementia. The referrer felt that there would be no benefit to Client B to have this information; consequently Client B did not understand the purpose of TE's visits and did not want to engage. Had Client B been supported to understand her diagnosis she may have accepted in-put. As TE was therefore unable to spend time and develop a relationship with Client B she was unable to:</p> <ul style="list-style-type: none"> <li>• support Client B with managing her diabetes, (medication and food hoarding)</li> <li>• explore any life events /circumstances that may have led to Client B's present lifestyle</li> <li>• offer any assistance with dementia friendly home environment</li> </ul> <p>TE was unable to find evidence that the concerns relating to her medication and food hoarding have resulted in any crisis situation. This could very well be how Client B has always lived.</p> |

## Case Study 2

### Summary

Client K lives at a residential home and has Down's Syndrome. Client K was diagnosed with dementia in 2015. The staff team at the residential home asked for some support around dementia and assistance with planning for the changes that dementia may bring for Client K.

Concerns raised about Client K's lack of interest in leaving the home. Whereas he would regularly go into town and meet friends for a drink he had become nervous and unwilling to do this.

### Key issues identified. What outcomes were desired?

- Dementia Friends awareness session would help support staff in their knowledge around dementia
- Support plan enhanced with dementia specific element and life story work
- Client K able to resume going out and re-engage in activities

### Action taken

- Two sessions of Dementia Friends with learning disability add on for all staff
- Several visits by Dementia Adviser to discuss support strategies for now and to plan for the future.

**Resource shared :** Jenny's diary, The dementia guide, The memory handbook, 'Learning disabilities and dementia' factsheet, 'What is dementia?' and 'Understanding and supporting a person with dementia' factsheets.

### Outcomes for client K:

Client K's anxiety around going out seems to have diminished following our suggestions and alternative strategies. Client K is now happy to leave the home via the back door. After discussion and suggestions Client K has been encouraged by the staff to re-engage in old familiar task such as sweeping the floor, playing ball, wiping up the dishes. Client K seems more like his old self.

### Outcomes for Carer

Staff express increased confidence in:

- knowledge around dementia
- having clear goals to work towards to support Client K in the future
- being aware of the support available through the Alzheimer's society should they need additional support in the future

### Feedback

- 'The information from the project is brilliant.'
- 'The staff that attended the awareness raising session returned and told the team it was brilliant and as a result we would like all the team to attend a second session.'
- 'Prior to the one-to-one support Client K was anxious and wouldn't go outside. As a result of suggestions we are able to support Client K to go outside.'
- 'Previously, Client K just sat in a chair and was completely disengaged but the ideas brought in have encouraged staff to work differently and as a result the individual has re-engaging in home life.'

### Learning

The people who support Client K said that prior to the project input they understood how to support a person with a learning disability well but didn't have the knowledge and information they needed to support a person with learning disability and dementia. The lack of knowledge made some staff feel anxious in their supporting role. This demonstrates that had these staff been equipped with information and understanding **before** a critical situation arose they would have had the confidence and proactive strategies to maintain Client K's lifestyle. Their perceptions have been challenged and they have changed their approach to supporting a person with a learning disability and dementia.

**Key messages:** Proactive dementia awareness raising for all staff would

- Equip staff with confidence that they CAN enable the person / people they support effectively
- prevent deterioration in the lifestyle / wellbeing of the person they support and maintain them at home(whatever home is)
- Motivate staff, promote retention and make best use of resources

### Case Study 3

#### Summary

Client L is supported to live in her own home with a team of support staff. Client L was diagnosed with a possible dementia in May 2017. Initial contact was made in October 2017. The referral was to help support the staff team to understand the changes they may encounter and support them to better support Client L in the future. Client L was not receiving any Dementia services prior to her referral. Although Client L has three staff, TE was only able to engage with one of them (who is also a family carer)

#### Key issues identified. What outcomes were desired?

- Increased understanding of dementia through Dementia Friends and learning disability awareness session
- A section in Client L support plan, to incorporate changing needs due to her dementia to support current and future staff best support Client L.
- Some life story work for Client L to share with people that don't know her well

#### Action taken

- Dementia Friends and learning disability session arranged and booked but later cancelled as although the session was free, Client L's family felt that could not afford the cost of paying the staff to attend. Spaces offered on other sessions not taken up.
- Client L's 'Getting to know you' plan has begun but further arranged visits have been sporadic as family/staff have cancelled and rearranged,
- After frequent phone calls with Client L's relative who felt that we couldn't tell her anymore about dementia than she already knew, it was arranged that that TE would support Client L and a member of staff / family carer to plan and adjust her support plan to incorporate some of the changes brought about by dementia.

**Resources shared:** Jenny's diary, The dementia guide, The memory handbook, 'Learning disabilities and dementia', 'What is dementia?' and 'Supporting a person with dementia' factsheets

#### Outcomes for Client L

- On Client L's request signs have been implemented within her home, on kitchen cupboards, toilet and bedroom. Extra signs have been made for use in the future.
- Supported the beginning of Life story work in the form of a film and photo albums with detailed information about the pictures. . Client L is keen for all staff both now and in the future to know about her life, her interests and what she enjoys doing daily.
- Client L has been supported to review her support plan, incorporating areas that Client L would like current and future staff to know about her as well as goals she would like to work towards.
- Client L has detailed in her plan, important key health facts that all staff should know about and the implications to Client L if not met. Client L feels confident that all staff /family will have a greater understanding of who she is by watching her life story and reading her plan.

#### Outcomes for Carer

- One carer has a clearer understanding of dementia and the changes that Client L may experience in the future. She has actively assisted in supporting Client L to plan for the future and feels more confident in the support she can give.
- Both the carer and Client L are now aware of the Alzheimer's society and how to access support should they choose to do so in the future

#### Feedback – prompt people why/ what makes a difference?

'Having the getting to know you plan and objectives to work towards for the future is very helpful.' (Family carer)

'I do like the signs and want to put my photo on my bed room door.' Client L (person with a learning disability and dementia)

## Case Study 4

### Summary

Client P shares a home with 7 other people. Client P was referred into the service for advice and support with dementia, for himself, the staff and the others living within the home. At the time of referral Client P was undergoing tests for dementia.

### Key issues identified. What outcomes were desired?

- That staff feel confident to support Client P now and in the future with changes his dementia may bring
- Client P feels confident that all current and future staff know about his life, what he enjoys doing and places he likes to visit.
- Client P family feel reassured that P's future in his home is safe and secure
- Other individuals living and spending time with Client P have a greater understanding of Client P's changing needs.

### Action taken

- Five Home visits to help plan life story work with Family carer, staff member and Client P. Family carer has been instrumental in gathering photos and memorabilia from Client P's life; this has in itself shown the value of this piece of work, as it has generated enthusiastic discussions and memories for Client P.
- Arranged and delivered dementia awareness session with learning disability to the staff team
- Delivered a second adapted session to the clients of the home. (Co-facilitated with Dementia Friends Champion who has a learning disability)
- Discussion with carer around power of attorney and the future
- Discussion around Dementia friendly environments and possible changes that could be made for the future.

**Resources shared:** Jenny's diary, The dementia guide, The memory handbook, 'Learning disabilities and dementia', 'What is dementia?', 'Understanding and supporting a person with dementia', and 'Lasting power of attorney' factsheets.

### Outcomes for Client P

- Client P is more relaxed and enjoying the time reminiscing and chatting with his carer on past life events.
- Life for Client P is calmer now with additional understanding from other residents.
- The home is considering environmental changes they can make to best support Client P

### Outcomes for Carer

- Family carer feels supported and confident that the staff are being supported and getting to know P well
- staff are more aware of the importance of discussing with Client P's his life and past interests. Sharing family photos and provoking memories.
- staff team express more confidence to support Client P
- With their knowledge of dementia, they are all actively looking and making changes to the environment that consider best support for Client P

### Feedback

'The project is providing so much support for myself, Client P and everyone at his care home, it has come just at the right time for him – it's been a real port in a storm. They have given us so much information.' (Family Carer)

'Since the clients of the residential home attended the learning disability dementia friend's awareness session, they have all felt so proud to be dementia friends. They have spoken about dementia and asked questions which the staff team are able to answer. One client in particular is much more patient and shows understanding to the client with Dementia.' (Manager of Care Home)

### Learning:

People with a learning disability have a capacity to understand Dementia; they have already noticed the changes in their friends/family. Giving information allows for understanding, patience and support.

## Case Study 5

### Summary

Client S has lived within a Shared Lives family unit for over 10 years. Client S has no other family. Client S attends Day Opportunities 5 days a week. Client S was diagnosed with Alzheimer's disease in March 2017. Although the carers had a basic knowledge about dementia they were unsure how to apply what they knew to supporting Client S. They asked for support and guidance generally as well as help with engaging day support in implementing required changes with Client S's support consistently. Key issue identified had been that changes occurring during the day were causing Client S confusion and distress which manifested when she came home.

### What outcomes were desired?

- Shared Lives Carers and Day Support staff to have a greater awareness/understanding of dementia
- All involved in S's life have greater understanding of her needs and the changes her dementia brings.
- All share consistent approach to the identified support needs where ever Client S is.

### Action taken

- Dementia Friends with learning disability awareness session planned and delivered to shared lives staff
- Planned and delivered awareness session with Day Opportunities staff
- Discussion around changes to the home to allow Client S to find her way/ signage/ lights
- Life story work instigated, additions made to S's support plan to adapt to the changes with dementia.
- Meeting with Day Opportunities manager to assist ongoing communication between home and the centre using Client S's iPad for daily communication / support plan sharing (everyone working the same way with Client S) and photographs to compliment Client S's life story work.

**Resources shared:** Jenny's Diary, What is Dementia; Supporting a person with dementia, Learning disability and dementia, Lasting power of attorney, Continence and using the toilet, eating and drinking

### Outcomes for Client S

- Shared Lives family have a greater understanding of dementia and how best to support Client S.
- An agreement is in place that Client S can use her iPad for communication between the centre and home. It holds her very detailed support plan so that each place has a clear picture of Client S's needs and how they are being met. Photographs of Client S day are taken on her iPad to help build up her life story work/ generate conversations with her friends and home life.
- Client S is experiencing more continuity between home and day opportunities. She is no longer distressed, but if anything occurs it is recorded on the iPad so everyone understands and can address.

### Outcomes for Carer

- Shared lives carers have increased confidence that all support staff working with Client S are working in the same way and giving her continuity.
- Carers have a higher degree of understanding and knowledge of dementia and how it may impact Client S – they feel confident to support her in the future.
- Carers have gained and demonstrated new skills

### Feedback

'TE is always on hand to offer advice, information and support. I don't know how we managed before – we've learned so much. Our patience has helped them to be more relaxed. We have learned to distract them or take them to another place.' TE also suggested loading information on to an iPad, so that useful details can be shared easily between home and staff at the community hub. 'It makes everything very transparent, 'If they're having a bad day, we can tell why – maybe their routine has changed.'

### Learning:

- All organisations need to be involved from the beginning to ensure continuity between services.
- Developing understanding that personal information belongs to the person, not the organisation supporting them and that their ability to share it throughout their life is critical to living well / being understood with dementia.
- Given the tools proactive supporters make things work for people. More detailed induction / support for staff and carers saves resources and enhances lifestyles

## Appendix 5: Getting To Know You (Learning disability and dementia project assessment tool)



|                                      |
|--------------------------------------|
| <b>Date:</b>                         |
| Full name:                           |
| Known as:                            |
| Address:                             |
| Date of Birth:                       |
| Do you have a diagnosis of dementia? |

### We are here to help you to adjust to the changes dementia brings

|   |
|---|
| What experience of diagnoses did you have?      |
| What support did you receive after diagnoses?   |
| Did you receive any information about dementia? |

### P. Practical changes

*(prompts - getting around at home ( Signs, lighting flooring )or in the community, continuing contact with friends and family. Keeping up pursuits / work / things you enjoy, food and drink (hydration) eating and swallowing,)*

**How do you show how you are feeling, unwell, how do you communicate. My likes dislikes**

### E. Emotional Wellbeing

*(prompts – mood, anxiety, confidence, time to myself, self-esteem, music, memory box/ life story)*

## S. Social Aspects

*(prompts: keeping in contact / dealing with different environments/ communication )*

**Complete a One Page Personal Outcomes Plan from this Getting to Know You discussion.**

*What interests and hobbies do you have/ have you had in the past?  
What might you be interested in trying now or in the future?*

*Do you have any cultural, spiritual or strong beliefs/values that you would like us to be aware of?*

*Is there anything else you would like to tell us which will help us to support you?*

*(prompts – health, mobility, eyesight, hearing, dietary needs)*

| <b>Have you had information on:</b>                       | <b>Yes</b> |
|---|------------|
| Community Care Assessment                                 |            |
| Carers Assessment   |            |
| Benefit check   |            |
| Pension   |            |
| Attendance Allowance                                      |            |
| Personal Independence Payment/Disability Living Allowance |            |
| Council Tax Exemption                                     |            |
| Housing Benefit   |            |
| Disability "Blue" Badge                                   |            |
| Carers Allowance  |            |
| Power of Attorney (EPA or LPA?)                           |            |
| Do you have a support plan...                             |            |

Review date: \_\_\_\_\_

# Appendix 6: Evaluation tool for carers and paid workers (Outcomes Star)

Name

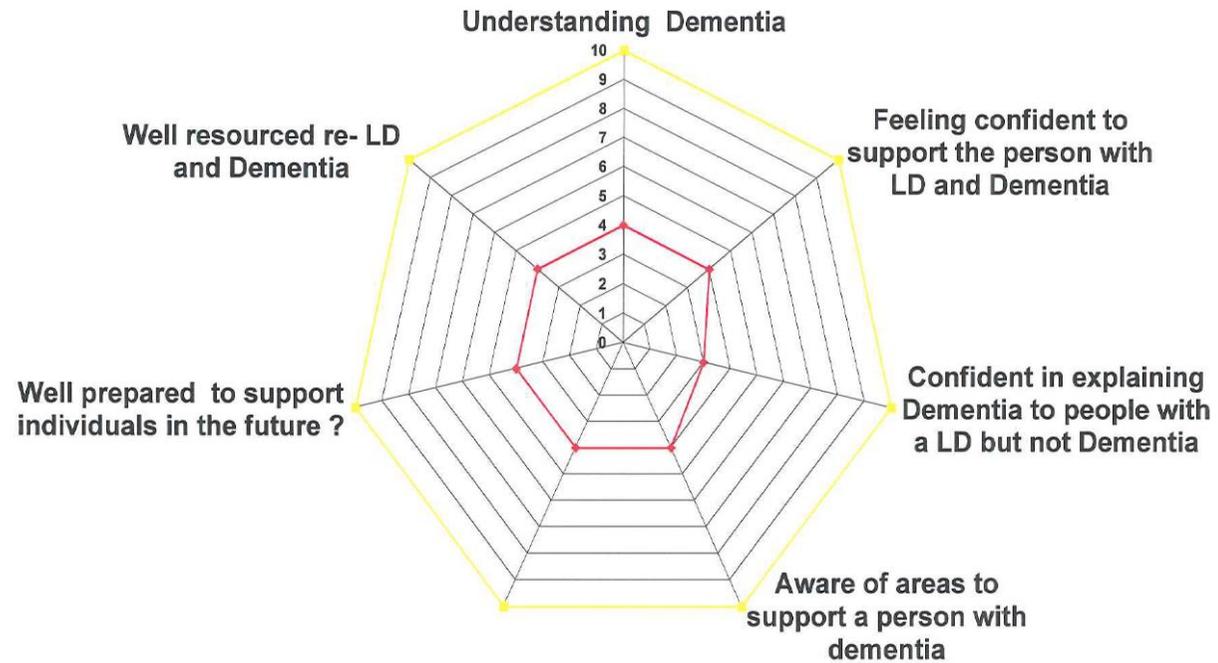
## I AM: Individual Assessment Map

Alzheimer's Society

Leading the fight against dementia

Assessment 1 date 15.08.17 (red).....

Assessment 2 date ...13.04.18...(Yellow).....



## Appendix 7: Outcomes plan for individuals

To support me to live well with dementia I have identified the following outcomes to work towards:



Name:

| Date | Objective | Person identified outcome (SMART) | Action | Who | By when |
|------|-----------|-----------------------------------|--------|-----|---------|
|      |           |                                   |        |     | date    |
|      |           |                                   |        |     | date    |

|                         |       |
|-------------------------|-------|
| Signature:              | Date: |
| Supported by signature: | Date: |
| Review date:            |       |



## Appendix 9: Extracts from Herefordshire Learning Disability Strategy 2018-28

The council works with developers and housing providers to implement elements of this design ethos to improve outcomes for people with learning disabilities experiencing dementia in all its forms.

Commissioning organisations routinely utilise adaptations and technology at an early stage to reduce the impact of dementia and enable people to remain independent for longer.

The council will implement a process for identifying people with learning disabilities at point of dementia diagnosis in order to aid progression planning. Dementia awareness will be a standard part of the learning disability annual health check. This is of particular importance for adults with Down's Syndrome, so the annual health check should pay specific consideration to dementia symptoms in this group from age 30 onwards. The Public Health Team will look at ways of raising awareness of dementia amongst the learning disability community, ensuring that people are successfully directed toward all sources of information

There will be widely available accessible information and training in order to raise the level of awareness of dementia across the learning disability community (professionals, paid staff, service providers, family carers and people with learning disabilities). Adults with learning disabilities will be supported to access mainstream dementia diagnosis services wherever possible. Dementia awareness and potential diagnosis will be a routine part of GP annual health checks for people with learning disabilities over 40 and for people with Downs Syndrome over 30.

Adults with learning disabilities will be supported to access mainstream dementia diagnosis services wherever possible. Dementia awareness and potential diagnosis will be a routine part of GP annual health checks. People with learning disabilities perceived to be at risk of earlier onset dementia will be routinely screened for the condition from the age checks for people with learning disabilities over 40 and for people with Downs Syndrome over 30.

For individuals with Down's Syndrome the annual health check will incorporate a cognitive function test from the age of 30 and establish a baseline record / development of the individual's life story with the involvement of the carer / family to support future anticipatory care planning.

## Appendix 10: Examples of feedback from participants in the one-to-one work

- ‘The project has helped so much; the resources have helped the staff team. Since your first visit I have gone on the Alzheimer’s Society website and looked at more information. It’s been so helpful. One of the biggest things is having a greater understanding of being in the moment with Mo, her reality, it has helped us to recognise where she is and work within in her world. We have found your input very calming you haven’t been intrusive and worked in a very implicit way that has helped the staff team get on board. Supporting people with a learning disability does not seem so scary now.’ **(Residential Home 1, Manager)**
- ‘The project came at just the right time; we had no experience at all of dementia prior to one client being diagnosed. It couldn’t have been timed better. The extra support has helped; we have understood the importance of adapting the environment and changed the carpets so they are all the same colour. Things we wouldn’t have thought of. The awareness session was fantastic. The resources we have received have been usefully and easy to read and understand. The more you learn the more you want to find out.’ **(Residential Home 1, Deputy Manager)**
- ‘The information from the project is brilliant. The worker who attended the Awareness rising session returned and told the team it was brilliant and as a result we would like all the team to attend a session. ‘Prior to the 1:1 support starting with a specific individual who has learning disability and dementia the individual was anxious and wouldn’t go outside. As a result of suggestions about how to support him to go outside he now does go outside. Previously he just sat in a chair and was completely disengaged but the ideas brought in have encouraged staff to work differently and as a result the individual is now sweeping the floor, playing ball, wiping up the dishes, re-engaging.’ **(Residential Home 2, Manager)**
- ‘Thank you for all the support and information we all really appreciate all the help you have given us.’ **(A Support Worker)**
- ‘Watching the supporting Derek DVD really helped me understand what life is like through SC eyes and I picked up on so many things that SC does that are so like the DVD. It has given me food for thought.’ **(Family Carer)**
- ‘It has really helped being able to talk to you and off load what we are feeling.’ **(Support Worker)**
- ‘The input from the project has been fantastic; I was completely in the dark before and would have been really stuck. The resources were very helpful and something to refer back to, The rest of the team dip in and out and have taken all the learning from the awareness session on board and ran with it, taking the responsibility to look at lightening and home environment between them.’ **(Shared Lives Carer)**
- ‘Since the clients have attended the learning disability dementia friend’s awareness session, they have all felt so proud to be dementia friends. They have spoken about dementia and asked questions which the staff team are able to answer. One client in particular is much more patient and shows understanding to the client with dementia.’ **(Residential Home 3, Manager)**
- ‘The project is providing so much support for myself, PJ and everyone at his care home, it has come just at the right time for him – it’s been a real port in a storm. They have given us so much information.’ **(Family Carer)**
- ‘Our patience has helped them to be more relaxed. ‘We have learned to distract them or take them to another place.’ Tracey also suggested loading information about both women onto an iPad, so that useful details can be shared easily between home and staff at the community hub they attend. It makes everything very transparent, ‘If they’re having a bad day, we can tell why – maybe their routine has changed.’ **(Shared Lives Carer)**

- ‘There is a definite change in the shared Lives home where my learning disabled daughter lives. I observe the person who has learning disability and dementia now listening to music through headphones, that the environment is dementia friendly. The rugs and patterns are all gone. The Shared lives carers have really embraced the learning. The impact on other people who have a learning disability who live there is that they are more relaxed. They have stopped telling her to be quiet.’ **(Family Carer)**
- ‘After contacting the Alzheimer’s Society, it wasn’t long before they were on the scene. This came just at the right time for P and (...)was like a breath of fresh air! I have been invited to all the meetings(...)and to the staff training session. I took all my parents’ family photo albums for P to look at with T and M to put together a life story book. They were amazed at how much P is able to remember of his childhood, including names of family friends and all the cars that we owned! Part one of the life story book has already been completed! T has got to know P really well and he has loved chatting to her. The learning disabilities project has provided so much support for us all. It has been a real port in a storm. We have been given so much information and advice.’ **(Family Carer)**
- ‘I would just like to take this opportunity to express what a difference the input from Alzheimer’s Society has made over the last 8 months for the ladies that we support(...)it has been an emotional roller coaster(...)I am putting together this email together a few days before traveling to Mexico with the ladies that have been diagnosed, one with Alzheimer’s and the other with frontal lobe dementia. Of course when arranging the trip we had to take on board the general deterioration of the ladies but again with your input after the diagnosis opening a window on the world of dementia to us we have been able to adapt to the needs with a more detailed and less frightening view of dementia. The unconditional support together with the time and commitment you have shown have enabled me to be confident when supporting the ladies in what is no doubt a frightening time for us all. Your friends training, fact sheets and above all T’s visits have changed my whole view on dementia and I would like to truly thank you as armed with this information I can continue to support the ladies that have become part of our family into whatever the future may hold. One of the biggest things I personally have learnt is that having dementia does not have to be all consuming once we are informed of a way to work alongside it.’ **(Shared Lives Carer)**
- Tracy Crum from Hereford has a learning disability and has been involved in the project. She became a Dementia Friends Champion and led sessions for other people to become Dementia Friends. She said, ‘I’ve really enjoyed doing the Dementia Friends Champion training because it’s something I have never done before. I have enjoyed delivering sessions and also making use of the accessible, easy-to-read resources. I’ve completed about 4 sessions since March this year and it makes me feel really proud.’
- Some feed- back from people a learning disability who participated in Dementia Friends sessions and gave the following feedback:
  - ‘You didn’t go too fast and I understood the information.’
  - ‘The video helped me.’
  - ‘It was a good idea.’
  - ‘I enjoyed the session.’
  - ‘Young people can get dementia.’
- They also made constructive suggestions on further improvements we can make to the session:
  - ‘Gather all pictures after each exercise, so that everyone knows that exercise has ended and you are moving on.’
  - ‘Give each person one picture. Not all together as can be confusing.’
  - ‘Hand up for yes and no might be better than the tick and cross cards in some groups.’
  - ‘Action sheets need to have bigger writing.’