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# Spotlight on Dementia and Equalities

Discussion Capture for:



Funded by:



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# 1 — Introduction

Alzheimer Scotland's Spotlight Series is an exciting platform developed by their Quality and Workforce Development team. Spotlight brings people together to shine a light on a diverse range of topics to help raise awareness and develop practice with the aim of upskilling staff and volunteers and empowering people with dementia and their families.

In early 2018, Alzheimer Scotland used their Spotlight platform to shine a light on Dementia and Equalities. Focusing on the five key areas identified in NHS Health Scotland's 'Dementia and Equality – meeting the challenge in Scotland' report published in 2016<sup>1</sup>. The areas highlighted were:

- Age – younger onset dementia (under the age of 65 years)
- Lesbian, gay, bisexual and transgender (LGBT)
- Learning disabilities
- Race and ethnicity – black or minority ethnic
- Disability – sensory impairment

Alzheimer Scotland recognises that people's experiences are different depending on the communities/protected characteristics that they have. There is a growing body of work around equalities, however there is so much more to do regarding putting it into practice. So, five workshops were organised to cover each of the above topics. They brought together practitioners and people living with dementia and their carers around the table to expose and explore the inequalities that exist and to discuss what action can be taken to address them. Each workshop was delivered co-productively with individuals and professionals who brought either lived experience and/or expertise in the focus areas.

The Lines Between, an independent research agency based in Edinburgh, were asked to support Alzheimer Scotland through the Dementia and Equalities Spotlight Series by attending the workshops and producing this resource to help capture, disseminate and share learning from the important discussions. You are invited to read this report in its entirety, or take each workshop report individually to find out the specific issues raised and suggested actions for each topic.

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1 [http://www.healthscotland.scot/media/1226/27797-dementia-and-equality\\_aug16\\_english.pdf](http://www.healthscotland.scot/media/1226/27797-dementia-and-equality_aug16_english.pdf)

## Context

The NHS Health Scotland Dementia and Equality report focuses on the issues with dementia experienced by population groups with protected characteristics under the Equality Act 2010<sup>2</sup> as outlined above (age, LGBT, disability, race and ethnicity). The report contains over 50 specific recommended actions, however there are four key overarching recommendations for promoting equitable dementia services that embed and promote human rights. They are:

### Recommendation 1: Continue to raise awareness

- This is fundamental to promoting early diagnosis. Further research and development work is needed to develop culturally sensitive information about dementia and available services and to establish the most effective ways of raising awareness of dementia. This includes using appropriate terms, recognising that the word dementia does not translate into all languages or that it may not have meaning to a person with a learning disability.
- Community connections, and the support of family and friends, need to be targeted as a key resource for both tackling stigma and encouraging early diagnosis and increasing quality of life within the community post diagnosis.

### Recommendation 2: Ensure robust services and support pathways

- There is a need to continue to ensure clearly signposted, robust, culturally competent, locally informed services and post-diagnostic support pathways.

### Recommendation 3: Ensure appropriate knowledge and skills

Essential to encouraging early help-seeking among different population groups with protected characteristics, and to providing a supportive post-diagnostic pathway, is:

- The need for an individualised care approach that recognises all aspects of an individual's identity, such as age, disability, race, religion and sexual/gender identity.
- The 'Promoting Excellence'<sup>3</sup>: a framework for all health and social services staff working with people with dementia, their families and carers' outlines the knowledge and skills, behaviours and attitudes the workforce needs in order to provide this type of service, linked to quality of life outcome indicators and stages of the dementia journey.

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<sup>2</sup> <https://www.gov.uk/guidance/equality-act-2010-guidance>

<sup>3</sup> <http://www.gov.scot/resource/doc/350174/0117211.pdf>

- The Promoting Excellence work programme will continue to develop as the evidence base for equality issues and dementia evolves. The aim is to ensure that the health and social care workforce in Scotland remains equipped with the knowledge and skills to deliver an individualised, culturally competent care approach.

#### **Recommendation 4: Further research is needed:**

- To determine the most effective ways to raise understanding and awareness of dementia among different population groups.
- To identify and evaluate the impact of culturally competent dementia friendly community approaches in increasing awareness of dementia and diagnosis rates.
- To collect Scottish incidence and prevalence data in relation to people with protected characteristics and dementia, including homeless people and prisoners.

#### **The Spotlight Workshops**

*“These workshops have been great, they’ve created a space where people can ask questions – it’s so much about communication.”*

(Participant)

The three-hour workshops provided an open forum for information sharing and discussion, where practitioners and volunteers from across dementia and other health and social care services could come together and talk about the issues raised. Each workshop followed a similar structure: context from Alzheimer Scotland and/or NHS Health Scotland, followed by an individual speaking about their experience of how dementia had affected their lives and how they had accessed services, followed by a specialist practitioner in the topic. Workshop participants were then given the opportunity to contribute through facilitated roundtable discussions using Ketso a creative engagement tool to help capture everyone’s ideas; they discussed what they had learnt from the contributors, what they thought needs to change to improve services, and the small things they could do to help make that change.

#### **Themes**

Although the workshops covered the five topics separately, there were clear commonalities and parallels between them all. The key themes that came out across all workshop discussions are summarised in the table below. More specific detail can be found in the individual workshop reports. All quotes in the table below are from workshop participants.

**Theme**

**Key messages**

**Awareness**

*“awareness will make it less scary, you can live well if you have good care.”*

Participants discussed the importance of increased awareness, not only of the general public, but also of professionals such as GPs.

Participants talked of the need to develop innovative ways of increasing awareness and educating the public and professionals to help reduce stigma and improve the lived experiences of those who may think they have dementia, and those with a diagnosis. Participants likened it to the change in how people are now talking much more openly about cancer.

Participants felt that there needs to be more awareness around:

- Medication: the various drugs available and the impacts they have regarding dementia.
- Services that are or need to be available to people with protected characteristics.
- The complex but often common challenges people with protected characteristics are facing.

**Attitudes**

*“People need to start thinking outside the box”*

Linked to awareness, participants also talked about the attitude of the general public and professionals towards dementia, and how damaging common assumptions can be, such as, dementia only happens to older people, or that dementia only impacts on memory. A number of discussions also focused on the attitudes of employers, and their need to take more responsibility for their employees who have a diagnosis of dementia; in other words, how to support an employee who may have had a diagnosis.

## Theme

## Key Messages

## Process

*“Get to know the person first {...} however boring your life is, there’s always a story there”*

Participants discussed the following topics in relation to the experiences of people with dementia:

- **Assessment and diagnosis:** changing the assessment/ diagnosis process, there needs to be a process that takes a more holistic approach, and takes into consideration the diversity of people, it should not be a standardized test for everyone.

*“There needs to be extra layers brought in with the varying conditions and communities/characteristics.”*

- Does the ‘evidence’ match up with [MRI] scan? (i.e. what if the carer/family/partner/ is saying different to the result of the scan – how much of the family member input is taken into consideration? This includes GP awareness of the complexity of dementia and how they respond to people who suspect they may have dementia.
- **Post-diagnosis support:** Participants talked about a lack of consistency (for those with dementia as well as for their carers and families), the problem with waiting lists, a lack of awareness around entitlements, the limited support received was a diagnosis is given; lack of knowledge about where to get further information and support from; and a general delay between diagnosis and subsequent support. They suggested a **one stop shop** to help with issues like: mortgages, bank accounts, insurances, etc, benefits, support, similar to what is available for cancer – there should be more learning from cancer services.
- Participants talked about the importance of **Local Community support**, e.g. local police, local people, Dementia Friends.

## Theme

## Key Message

- Creating a **'safe space policy'**: participants talked a lot about the need for services to consider a 'safe space policy' and what this might mean in relation to the various protected characteristics, e.g. how does your service ensure it is inclusive and safe for all its service users? Could it have something on a lanyard to ensure people feel they can have those (safe) conversations. Are support workers trained sufficiently to have the confidence to ask questions around potentially sensitive issues e.g. sexual orientation?
- Participants talked about the importance of **outreach**, encouraging services to go to where the people with protected characteristics are, rather than expecting them to approach services, e.g. using social media effectively.
- Being **person-centred** – participants talked a lot about the importance of a person-centre approach and listening to people's stories - listen to people's life histories, value and respect them as people

**Workforce –  
partnership  
working,  
collaboration**

Participants talked a lot about the workforce; the importance of better education and training to improve awareness and attitudes and subsequently the services that individuals and their families receive. "Professionals struggle with symptoms so [individuals] get sent from pillar to post". But also, the importance of collaboration and partnership working, and having a collective voice to feedback to decision makers about what is working in relation to services, and what is not.

Participants provided suggestions on how collaboration and partnership working can lead to innovation, e.g. physiotherapy students linking in with dementia students, and Link Workers having a forum for knowledge exchange, training, awareness, and increasing their understanding. "Relationships make the difference!"

## Theme

## Key Messages

Participants suggested the need for open forums to discuss issues around services for those with protected characteristics, encouraging services to get out of their comfort zones e.g. encouraging LGBT awareness discussions to be had with care homes; how can they guarantee non-discrimination? How can they ensure they have a zero-tolerance approach within their homes?

Other issues relating to the workforce included:

- The need for a better understanding of equality – what works for one person may not work for another, people don't necessarily want to be treated 'the same'.
- The need to know who to contact, what resources are available, how to get the right support at the right time.
- The need to draw on lived experiences of people and where possible develop a workforce with a 'common shared experience', "empathy is a huge part of that connection with your service users [...] if you can't empathise, it makes good service provision difficult"

**Communication /  
Information  
provision**

*"It's about the right information at the right time!"*

Participants agreed there is a need to increase the sharing of information and resources. They noted that while there is a lot more awareness nowadays of dementia, it can be very one-dimensional, and leaflets/information can enhance the stereotypes, i.e. the imagery just uses older people. They suggested the use of social media, imagery, short films, posters at health centres, and the need for advertising/information provision to be more representative and reflective of those with dementia, e.g. better use of younger people, LGBT couples, ethnic minorities.

Theme	Key Messages
	<p>There was a lot of discussion about the use of language and terminology and the need to be careful with words, while at the same time recognising the limitations an overly ‘political correct’ approach can have on effective service provision “staff are walking on eggshells trying not to offend people.” Some talked of the ‘empowering’ effect of language and how when used well it can “open doors to a condition and support”.</p> <p>In relation to information for people with dementia and their carers and families, participants talked of the need for simple information, and courses to help the carers manage living at home and what sometimes simple changes they can make to the home to improve the experiences of those with dementia e.g. changing lighting, carpets.</p> <p>Participants discussed the positive impact of stories on dementia in popular culture, such as a recent storyline in Emmerdale, or famous people having a diagnosis of dementia.</p>
<p><b>Resources / Finance / Funding</b></p>	<p>The issues of resources and finance came up at each workshop. Participants talked of problems with workforce capacity, both in the community and nursing/care homes. They talked of the variation in access to professionals between areas across Scotland, and the financial cuts leading to difficulties in the effective delivery of services.</p> <p>They were keen to have a way of holding the Government to account, ensuring they are driving forward the recommendations in the NHS Health Scotland report.</p>

The remainder of this report provides details of the discussions at each workshop.

## 2 — Age: Younger Onset Dementia

7<sup>th</sup> February 2018

*Contributors: Morag (personal Story), Alzheimer Scotland*

### **Morag's Story**

Morag told the story of her 60-year-old husband who has younger onset dementia, he was diagnosed at 59. He started experiencing symptoms in 2014 and it took 3 years to get a diagnosis. An MRI scan in 2015 came back normal, so his symptoms were put down to anxiety, stress, and depression and his GP signed him off on Long Term Sick.

After 8 years of working nightshift he was no longer able to work the machinery, the main issue for him was forgetfulness. His employer told him to 'get his act together' and within a year had paid him off, refusing to keep his job open for him and offering no help.

They sought a second opinion, yet another GP also said it was depression and referred him to a psychiatrist who gave him an anti-psychotic drug. Every two weeks he would go back to the doctor, his symptoms were getting worse, so the doctor just increased the dose – Morag's husband was petrified, "He would be in a cupboard when I came home from work.", but the dose just kept being increased. Morag asked for him to be tested for dementia but there was nowhere to go for someone under the age of 60 "we just had to believe them, they were professional people."

Last year he finally went to the hospital to get assessed for dementia, he had to stay in hospital because Morag was going away for work and he couldn't look after himself at home. He had a single-photon emission computerized tomography (SPECT) scan that came back with a diagnosis of Lewy Body dementia. He spent 11 weeks in hospital.

### **Now:**

He doesn't speak well, he finds it hard to speak to people and is traumatised by the ridicule he faced before his diagnosis, people would laugh at him and think he was being funny.

## Morag's Story Continued

He was off sick for 3 years and got no support until they got in touch with Alzheimer Scotland; "now he has a better quality of life, not great but better. [...] To look at him you wouldn't know there was anything wrong with him, but you can't actually have a conversation with him, people don't understand it."

Morag was disappointed with the language used by colleagues, such as 'dafty', and feels peoples' attitudes need to change. She had to fight the stigma and thinks more people should be aware that dementia is not just about older people, there are younger people too. "It's so unexpected in the young."



*Workshop participants in discussion. Photography by The Lines Between.*

## The practitioner's perspective

Lynn Meek from Alzheimer Scotland works with people with younger onset dementia. She has been working with people experiencing younger onset dementia for 7 years and she noted the contrast to post-diagnostic support received for those with a dementia diagnosis compared to other conditions. Drawing on her own experience she told the workshop about the five key areas where she thinks improvements could make things easier for people with younger onset dementia.

**Pre-Diagnosis**

**GP Awareness:**

It often takes a lot of time to get a diagnosis; quicker diagnoses would significantly improve the experience of those with younger onset dementia.

**Post-Diagnosis**

**Respect and Dignity:**

People speak a lot about how they were given the diagnosis, they are sent away on that day, no-one takes them into a room to talk through what's going to happen, and their options etc. meanwhile people are left devastated; "I didn't know what to do" (Archie, workshop participant). There is a big drive for ensuring services show respect and dignity but filling in forms for benefits relies on you telling them that you can't do things e.g. deal with money, which is very undignified.

**Financial:**

Linked to this, many are still working and/or have mortgages, children, car etc. No-one tells them about the benefits they are entitled to, often leading to debt. Filling in benefits forms can be a very stressful and disempowering experience (as above).

**Treatment in Work:**

People often talk about being disciplined for not doing their job properly.

**Care:**

With all the will in the world, it's very hard to care for someone at the end. It's difficult to find services that will support people with dementia who are under 65.

## Spotlight on Dementia: Age Stakeholder Discussions

### General Public / Age community

Awareness of Y.O.D  
 Campaigning for money to support those economically affected by YOD  
 Dementia is an umbrella term (people get mixed up)  
 Different types of dementia  
 Equality in workplace  
 General awareness  
 Media narrative - images  
 Needs greater awareness and understanding of young onset dementia to reduce stigma  
 No discrimination between age  
 Painting a new picture of dementia  
 Perception (in public)  
 Realising that dementia can affect any age

### Workforce/Professionals

Increased professional awareness (GP's)  
 More awareness within general practice  
 More GP awareness - Carry out assessments earlier  
 More GP engagement  
 Understanding needs

### Training

Education for general practice and customer service organisations  
 Educational approach for family  
 GPs / Professionals need to listen to service user experience  
 I think GP's should be more acutely aware of early onset dementia, therefore referring earlier  
 Increased professional awareness (GP's)  
 More GP awareness - Carry out assessments earlier  
 More GP awareness of YOD carry out assessments earlier  
 More GP engagement  
 More specialist training  
 More training in mental health teams re: younger onset  
 Understanding needs

### Collaboration

Need of more resources: Peer support, One-one support, Community groups  
 Clearer pathway between services  
 Community connections

### General Public / Age community

Attitudes  
 Combating the stigma  
 Equality in workplace  
 Media narrative - images  
 Needs greater awareness and understanding of young onset dementia to reduce stigma  
 No discrimination between age  
 Painting a new picture of dementia  
 Perception (in public)  
 Perceptions/attitudes  
 Stigma



### General Public / Age Community

Community connections

### Identification

Have the right information at beginning  
 Better/quicker diagnosis for Y.O.D  
 Increased professional awareness (GP's)  
 More awareness within general practice  
 More GP awareness of YOD - carry out assessments earlier  
 More GP engagement

### Pathways

Care pathway from diagnosis  
 Clearer pathway between services  
 GP referral pathways  
 I think GP's should be more acutely aware of early onset dementia, therefore referring earlier  
 More consistent approach  
 More resources at the right time  
 Unclear pathways from diagnosis to PDS in LD

### Post Diagnostic Support (PDS)

Benefits system needs to change  
 Care homes not suitable for under 65s  
 Consistent counselling - and support for families of younger onset people to access in Scotland  
 Lack of support immediately after diagnosis  
 Lobbying local service providers to do better on prompt diagnosis  
 Long term facilities  
 More link workers  
 More resources for Y.O.D and family supports  
 More specialized facilities  
 Not just given a pack and left - Have a 'Macmillan nurse'  
 PIP needs to change, disempowering  
 POS should start from day of diagnosis 'no waiting list'  
 Quality better than quantity  
 Respite - nothing age appropriate  
 SDS is means tested  
 Support starts for more earlier

## Spotlight on Dementia: Age Stakeholder Discussions



## Spotlight on Dementia: Age Stakeholder Discussions



### 3 — Lesbian, Gay, Bisexual, Transgender (LGBT)

14<sup>th</sup> February 2018

Contributors: John (personal story) and LGBT Health and Wellbeing

#### John's Story

John has a diagnosis of Parkinson's and Lewy body dementia<sup>4</sup>, in his own words he offered some insight into his experience of living with these conditions.

"I got my diagnosis in December 2014, the GP thought it was a pulled muscle, stress, they thought I had vertigo, so they sent me for tests and 4 months later they realised I had Parkinson's, they gave me high dose of Levodopa, the drugs stopped the tremor but gave me horrific hallucinations [...] They tried to wean me off the Parkinson's meds, but after a few weeks I was hallucinating for up to about 16 hours a day – children, spiders, animals, people with knives, the first time it was very frightening, [...] it really shook me up. [...] they were getting worse and lasting longer, for some reason they were very sinister and violent [...] I had the hallucinations for about 6-7 months and it was a homeopathic doctor that managed to stop them.

But what was so scary was that there was no-one to help me with it. I'd seen up to 25 doctors in a year, but only 2 had any knowledge of Lewy body. [...] Finally, whilst I was in Gartnavel hospital they had someone who was a specialist, and she recognised that I had Lewy body and that the drugs for the Parkinson's was making the hallucinations worse.

Every time [hallucinations] happens it's as terrifying as the last time. It's like being in a horror film [...] it makes you so tired. My body is getting stiffer, but I can't be treated with Parkinson's drugs. Sometimes I can't open my eyes for 2 hours in the morning. Sometimes I'm watching TV at night and my eyes close themselves, that's one of the side effects of Parkinson's.

When I was diagnosed I was sent to another doctor – who gave me 2 mins, she said, "John, make a will, get a power of attorney, get your affairs in order, you've got Lewy body Dementia and Parkinson's." And the next thing I knew I was back in the street thinking – what did she say? I was suicidal.

<sup>4</sup> <https://www.alz.org/dementia/dementia-with-lewy-bodies-symptoms.asp>

There has been a lot of support, from Alzheimer Scotland, I was referred to the Riverside Community mental health team who connected me with them, I got some confidence back because Susan (Link Worker) had some knowledge about Lewy body, she was a big help to me and made a big difference in my life. You never think for one minute that you're going to get dementia. I was a fashion designer travelling all over the world – from one week to the next my life changed, within a couple of months I was in sheltered housing, I couldn't dress myself, couldn't do anything.”

John now lives in sheltered housing with lots of older people, recently there was a gay story line on the TV and his fellow residents made some derogatory remarks using homophobic language, he felt awkward and fearful. This effected his confidence and ability for him to be who he wants to be or who he is with in his new home surroundings.



*Workshop participants in discussion. Photography by The Lines Between.*

## **A practitioner's perspective**

Maruska Greenwood from LGBT Health and Wellbeing<sup>5</sup>, a community initiative that promotes the health, wellbeing and equality of lesbian, gay, bisexual and transgender (LGBT) people in Scotland, spoke to the workshop about the issues faced by LGBT people with dementia and their carers.

<sup>5</sup> <https://www.lgbthealth.org.uk/>

The key points raised by Maruska were:

- Despite making up 1 in 15 people in the population, LGBT people are relatively invisible, especially older LGBT people. They still face acute inequalities, now and historically. Discriminatory attitudes remain widespread, and stigma, prejudices, stereotypes and assumptions persevere. Harassment and hate crime is a real fear for people in the LGBT community. For many, it's all about feeling safe.
- Older LGBT people have experience of less tolerant times which impacts on their trust and willingness to access services. Their expectation of equal treatment is relatively low.
- Older LGBT people are more likely to: live alone, be single as they age, not have children, and less likely to be in regular contact with their biological family. They are much more likely than their peers to have no-one to call on in a crisis.
- Older LGBT people are much less likely to use services for older people, and often avoid coming out to service providers when they do.
- There is currently limited understanding of the impact of discrimination on individuals, their needs, and the access issues they face in relation to services.

*“From visiting older friends in retirement and nursing homes, I know that they have felt the **need to hide their sexuality** from other residents and carers.”*

- LGBT people who have dementia might: **Not be ‘out’** to their GP and be reluctant to engage with (mental) health services, **may be uncomfortable** with care home staff or paid carers knowing about their sexual orientation or gender identity and avoid seeking support; **feel out of place** in traditional dementia support groups. Seeking assistance with **personal care** particularly difficult for trans people.
- The individual with dementia may: re-experience difficult and distressing times; forget that laws and attitudes have changed; forget that they are out or have transitioned, or who they are ‘out’ to; and because of loss of inhibition, be more open in expressing their identity. **Prejudice** from others can be particularly difficult in these circumstances.
- LGBT carers may: be caring for family of origin or ‘family of choice’; be dealing with challenging birth family dynamics, assumptions around being single, having no dependents; lack of acceptance of LGBT identity; find they are excluded as their relationship is not accepted by a partner’s biological family; face discrimination and assumptions when using services. They can’t always share experiences with other carers, such as carer support groups e.g. feeling unwilling or unable to share their story of losing a life partner.

- The issues above mean that many avoid getting home support, accessing day care or seeking other kinds of help. LGBT people and their carers need to know services are safe and non-judgemental.

*“my identity might be problematic [...] I might not be accepted for who I am”*

### **Recommendations for making services LGBT-inclusive:**

- Ensure that staff are informed, open and able to provide culturally appropriate care
- Make sure LGBT people are visibly and pro-actively welcomed and know their confidentiality will be respected
- Have in place workforce development training, which challenges assumptions and increases awareness
- Create a safe space and address issues of prejudice and discrimination, including from other service users
- Send out strong message about inclusivity – ‘we have thought about it, we want to welcome you. We have an inclusive service.’ Then the service user can choose whether to come out to you – but you have done your bit
- Need to be willing to address issues. Be clear that if another user or residence is making someone feel uncomfortable – **that needs to be challenged.**

## Spotlight on Dementia: LGBT Stakeholder Discussions

### General Public / LGBT community

Awareness of facilities available  
 Awareness of LGBT community  
 Better conversations – as partners of people with dementia  
 Breaking down the barriers  
 Get more role models  
 Good conversations  
 Hidden dementia and LGBT identities – double invisibility  
 Invisibility  
 Open communication and conversations  
 Possibility of living well with dementia – awareness of this!

### Workforce/Professionals

Awareness and training of staff and service users

### Training

Incorporating into training “awareness”  
 Knowledge and understanding by carers and other people of dementia and LGBT  
 Listening and not assuming

### Information Provision

Education of service provider staff

### General Public / LGBT community

Acceptance  
 Ageism within the LGBT community  
 Attitudes and stigma needing to change  
 Attitudes and values  
 Awareness raising with LGBT community  
 Challenge ideas around older people and sexuality  
 Challenging attitudes  
 Creating ‘safe’ environment  
 Give more confidence to LGBT (older)  
 It’s a sensitive subject, we need to feel less awkward, we need to talk about it!!  
 More public engagement – change attitudes  
 Objective perspectives  
 Our comfort to conversate about sexuality  
 People being scared they’ll ‘get it wrong’  
 People scared to challenge attitudes  
 People’s attitudes

### Organisational policies and guidelines

#### Identification

Identifying LGBT people with dementia  
 Monitoring of sexual orientation – gender identification as part of assessment  
 Need to ask gender questions at assessments/ diagnosis

#### Post Diagnostic Support (PDS)

After diagnosis: representation at point of research  
 Including questions on sexuality in application forms

#### Pathways

Care pathways for LGBT people – how to achieve inclusion



## Spotlight on Dementia: LGBT Stakeholder Discussions

**General Public / LGBT community**  
 Awareness on all included  
 How do we see this 'invisible' population?  
 People with dementia can learn – awareness raising is possible  
 Understanding of diverse identities L, G, B and T

**Training**  
 Workforce development: needs resources and leadership



**General Public / LGBT community**  
 Aspects of dementia that can bring discrimination out  
 Challenging each other – creating a culture where this is ok  
 Change is so slow, people resist change, shame  
 Change of attitudes  
 Closed minds  
 Cultural beliefs  
 Deep rooted beliefs/culture  
 Discrimination within LGBT community for Bi identity (exclusion within and outwith)  
 Do people feel safe to talk?  
 Fear of responses, cultural  
 How does treating people 'equally' really mean?  
 Lack of peer support for LGBT people  
 Lack of provision understanding of sexuality  
 Making assumptions  
 Other's beliefs and perceptions  
 People's values  
 Public attitudes  
 Religious prejudices  
 Secrets and lies, historical issue, outdated language  
 Self-stigma  
 Sensitivity around having open and honest conversations (language)  
 Stigma  
 Taboo = sex  
 Upbringing, age, life experiences, training, attitudes  
 Willingness to challenge discrimination  
 Worried about being offensive, worried about our own attitudes

**Identification**  
 Number of people waiting to be diagnosed

**Post Diagnostic Support (PDS)**  
 Clinical time required to complete baseline assessments  
 Mainstream support vs inclusion – what is best for individual

**Pathways**  
 Inconsistency in systems/pathways  
 Processes are very embedded and taken-for-granted  
 Realising people are individuals and may not fit in certain standard procedures  
 Volume of people needing input

## Spotlight on Dementia: LGBT Stakeholder Discussions

### General Public / LGBT community

Education and awareness raising  
Wear my ribbon badge more  
Young people with dementia – raising awareness

### Workforce/ Professionals

Make people aware of your sexuality eventually  
& communication

Look at funding  
Maureen Watt – what resources are you putting to LGBT and dementia  
Promote the Equality Dementia  
Research and address this health inequality  
Research regarding LGBT and dementia to increase understanding

### General Public / LGBT Community

Media awareness  
Outreach to include social media – online platforms

### Training

Develop and deliver training  
Increase awareness through training materials and delivery  
Keep age and age-related illnesses on the agenda within the workplace  
Raise awareness (in meetings)  
Raise awareness of gap in LGBT and aging training resources

### Information Provision

Email HR re application forms  
Looking into ways to encourage LGBT community into activities we run  
Outreach – go to where LGBT community is

### Collaboration

Role of others: raise awareness with Scottish Government, Care Inspectorate  
Share feedback with team lead and colleagues  
Start talking to Link workers about LGBT issues



### General Public / LGBT community

Come out more  
Create safe spaces  
Empower individuals to challenge others and peers  
Get role models to share experiences  
Helping change people's attitudes  
I can remain aware of my own attitudes and language  
No bystanders – challenge views and behaviours  
Normalising language  
Open up conversations with people about  
Safe space for all protected characteristics – owned by everyone  
Tackle/challenges assumptions  
Use gender neutral language x2

### Post Diagnostic Support (PDS)

Add sexual orientation and gender identity in application for assessment  
Include questions on protected characteristics on SDWG application form  
Monitoring and measure impact and inclusivity

## 4 — Sensory Impairment

14<sup>th</sup> March 2018

*Contributors: British Deaf Association<sup>6</sup>, the RNIB<sup>7</sup>, and Stuart and Grace (personal story)*

Avril Hepner and Lucy Clark from the British Deaf Association talked about their experiences of Profoundly Deaf people and dementia. Avril talked about her experience with her father's dementia, and Lucy about the project 'Deaf with Dementia in Scotland'. The following provides the key points from their presentations.

- There are around 600-800 profoundly deaf people with dementia in the UK.
- 90-95% of profoundly deaf people have a hearing family, who may not have sign language. As dementia worsens this can be very isolating.
- Only 5% of profoundly deaf people are born into a deaf family.
- Lucy's project Deaf with Dementia in Scotland looks at support for profoundly deaf people.

### Avril's Story

Avril's father was profoundly deaf and had dementia, she first noticed changes on a holiday to Croatia, she now recognises them as the first steps in his journey.

The first disadvantage was that they had to wait 18 months for an assessment. The people assessing her father were very well qualified but there was a huge number of people present in the room; he found it very difficult, he felt outnumbered, and it would've been better had it been 1:1. She felt the assessment was not as good as it could've been, modifications could have been made, for example: the questioning was not that good for a profoundly deaf person; they were a spoken question in a signed format rather than in a way that is appropriate for a deaf person. They would've been better if they'd been more visual.

<sup>6</sup> <https://bda.org.uk/project/dementia>

<sup>7</sup> <http://www.rnib.org.uk/eye-health/sight-loss-other-medical-conditions/dementia-and-sight-loss>

Deaf Connections<sup>8</sup>, a voluntary organisation delivering specialist services to adult deaf people across Scotland, went to him when he was in hospital to look after and talk to him. However, Avril often had to intervene with professionals to organise his care and to help them appropriately support her father. She felt this took away the personal, precious, last few weeks of her time with her dad, she feels she lost about six weeks of time with my dad through having to liaise with professionals.

### **Avril highlighted a number of key issues for the deaf community:**

- Dementia is quite new in the deaf community. Individuals are not always able to recognise that they have dementia, and tend to be behind in receiving information about the condition.
- A profoundly deaf person can deteriorate rapidly due to isolation and lack of communication and stimulation, with the risk of leading to depression. Compounded by the fact that profoundly deaf people don't always understand English, therefore accessing appropriate services can be challenging. A profoundly deaf person in care can feel very isolated very quickly, for instance hearing patients can interact with staff and other care home residents, profoundly deaf people are often not able to do this. Any activities to do with music aren't great for profoundly deaf people, things need to be very visual e.g. Laurel and Hardy type comedy.
- Many profoundly deaf people worry about their care for the future "If I was diagnosed, what would happen?"
- There are a certain risk factors relating to the deaf community and dementia, for example, they may lose the ability to sign fluently, and may revert to oral; and they may face other issues such as accessing lawyers to sort power of attorney or wills, accessing benefits they are entitled to, accessing relevant health and social care services when they need them. They become very reliant on family and other care providers.

<sup>8</sup> <https://www.deaf-connections.co.uk/about>

### **Avril offered some solutions that may help improve experiences for profoundly deaf people with dementia:**

- Profoundly deaf people may not be able to understand written English that well, so they need more visual approaches to information and assessments, e.g. virtual memory assessments. So, service providers should consider how they can modify how you would approach something
  - There are a lot of resources available, but it is all in English, and not necessarily accessible for profoundly deaf people, add dementia to the equation and it's even worse.
  - Use of language was excellent – so we needed someone to assess his language and understand BSL better, particularly in context of profoundly deaf person.
- It's important for professionals to be aware as possible of issues related to profoundly deaf people. There are lots of ideas available on line.
- There needs to be more specialist training of working with profoundly deaf people, they should be familiar with the Deaf Care Model.



*Workshop participants in discussion. Photography by The Lines Between.*

## A practitioner's perspective

Linda Cruickshank from the RNIB Adult social care practice and development team shared her experiences of working with people with a visual impairment and dementia.

Her main points were:

- Sight loss increases with age; 1 in 5 people aged 75 and over are living with sight loss.
- Dementia impacts on your vision. Your visual cortex and how your brain interprets things. At least 250'000 people in the UK have dementia and sight loss
- Sight loss leads to a number of risks, such as an increased likelihood of falls and perceptual problems.

Linda outlined some important aspects of having dementia and sight loss:

- Someone might think that stumbling or falling over is to do with dementia and might not associate it with sight loss so it's not treated.
- Conditions that cause problems for people with dementia and sight loss - If lighting is poor it can lead to falls or cause distress because they can't see properly. It's important to eliminate shadows from rooms to avoid confusion, patterns can also be very difficult for people with sight loss and dementia
- Sight loss might be quite big by the time tests are done, and when the person gets glasses they can get a fright! Often find people with dementia won't tolerate glasses
- Some don't disclose their sight loss because they're scared people will think they're "going mad" and will "take them away".
- Undiagnosed / untreated sight loss can lead to isolation as people become frightened of going out because of bumps and falls.
- Some might suffer hallucinations, Charles Bonnet Syndrome. Visual hallucinations, if you lose your sight quite rapidly, some get quite frightening hallucinations.
- People risk being labelled as aggressive when they've felt threatened and retaliated because they can't see. Sometimes challenging behaviours might be because of dementia, might be because of sight loss.
- The more you speak about it the more aware people will be.

## Stuart and Grace's Story

*“Visual impairment is not just about sight loss, Alzheimer's is not just about memory.”*

Stuart has Alzheimer's, he was diagnosed 6 years ago, aged 59. Initially doctors attributed his symptoms on his age, he found himself hiding his symptoms because he thought it was a brain tumour, he never thought it would be dementia. After a few months of worsening symptoms, burning pots, tripping and falling over things that weren't there, anticipating things such as glass doors, he went back to his GP.

His GP referred him to a mental health unit. Following 8 weeks of tests, he was diagnosed with posterior cortical atrophy dementia<sup>9</sup>, he didn't have a clue what it meant, no-one knew what it was. The most common symptoms are consistent with damage to the posterior cortex of the brain, an area responsible for processing visual information, people with the condition have difficulties with visual tasks such as reading a line of text, judging distances, distinguishing between moving objects and stationary objects, and an inability to perceive more than one object at a time.

They sought support from the RNIB; a support worker took Stuart for a walk, and found that his perception was bad, steps, edges, things were too close or too far away. They noticed that when he was coming into his house from the outside he was almost collapsing, it turned out to be the pattern on their carpet. They now have a plain carpet with a tiny pattern, and Stuart can easily determine where each step is, it made an incredible difference. His sight loss also affects other things, like sensitivity to hot and cold, his sense of taste, and crossing roads, he struggles to judge the speed of cars. Previously they had a white bathroom, which seemingly had no edges, they had to change the toilet lid, and eventually got a wet room. They also did a 6-week course, and Grace was given with information on the other small changes she could make, such as walking 2.5 steps ahead of Stuart when they're outside.

<sup>9</sup> <https://www.alz.org/dementia/posterior-cortical-atrophy.asp>

Another hurdle for them was accessing financial support. The pressure they were put under was horrendous. The forms had 30 questions in them; but only 6 actual questions, the others were there to try to catch you out. They were struggling with it for 18 months, and lost 15 months' worth of money (you now get support from diagnosis), they ended up borrowing money from family to get by.

“the social security system has got to change, you're already under so much pressure from your illness, you really don't need that crap.”

Stuart has 'friends' who now cross the road rather than speak to him; he and Grace are trying to get rid of the stigma by talking to people, telling their story, speaking in schools and raising awareness.

*“We just want people to listen, things won't improve unless we work together to change.”*

## Spotlight on Dementia: Sensory Impairment Stakeholder Discussions

### Workforce/Professionals

Awareness among health professionals, GPs  
Awareness of experiences working with people with sensory impairments  
Knowing rights

### General Public / S.I. community

Assumptions that we made  
Awareness  
Education  
Education  
Education  
Real people involvement

### Training

Better awareness of Dementia and impacts of it by professionals we are seeing  
BSL Advocacy  
BSL Experts  
BSL/English interpreters  
Mac training opportunities for staff  
More staff to be trained in Dementia  
Time constraints for Link Workers - not aware of Link Workers in Renfrewshire for S.I.

### Information Provision

Awareness of services dedicated toward sensory impairment

### Collaboration

Greater networking  
Multi-uses

### General Public / S.I. community

Attitudes towards disabilities  
Change mind-set - open to change  
Empowerment

Budgets for accessibility  
Funding opportunities?  
Increase resources  
Money  
More Links resources  
More resources  
Resources  
Benefits?



### Identification

Shorter waiting lists

### Post Diagnostic Support (PDS)

Deaf Care Support  
Homecare BSL  
Improved access to services for people with sensory impairments and Dementia  
Infrastructure - interpreting services  
Mainstream services not suitable  
Right support  
Specialist Dementia Care Home for deaf dementia  
Respite  
Rurals/Islanders support  
Will / POA

### Pathways

Everything needs to change about our procedures and systems  
GPs to refer on  
Inflexibility in systems/processes  
Referral pathways

### Workforce / Professionals

Accessibility of services and resources for people with Dementia and learning disability  
Be open with new information

### General Public / S.I. Community

Access to information

## Spotlight on Dementia: Sensory Impairment

### Stakeholder Discussions



## Spotlight on Dementia: Sensory Impairment

### Stakeholder Discussions



## 5 — Race and Ethnicity

19<sup>th</sup> March 2018

Contributors: MECOPP<sup>10</sup>

Suzanne Munday and Ashiy Shafique from MECOPP came to speak to workshop participants about their project supporting South Asian people with dementia, and their carers. The following provides some important insights and learning from the project.

### **The Jeevan (life) Project (living well with dementia)**

MECOPP are currently in their third year of providing a South Asian Dementia Link Worker through their Jeevan Project. The Jeevan Project is Scotland's only dedicated support service for South Asian people with dementia and their families/carers. It is a three-year pilot project funded jointly by the Scottish Government and the Robertson Trust. It comprises six key elements: awareness raising; supporting timely diagnosis; post-diagnostic support; challenging stigma; information provision; and, support to carers.

Accurate data on black and minority ethnic (BME) people with dementia either at UK or Scottish level are not available; this makes it difficult to do an accurate needs assessment, so commissioners they don't always know the need and demand for services. BME people with dementia tend to be less visible within their own communities and wider society. In many communities there isn't a word for dementia, there is stigma attached to it, and knowledge and information provision is limited and challenging. If you don't have the right words in your language, it can be a barrier to accessing support. The consequence of this is that many are diagnosed later which means they access services much later which means that families are coping for longer before they also get support.

There are some common problems and misconceptions within some BME communities, such as: how people understand dementia, some groups think you can catch it, some think you can take a pill and cure it, some believe you have it because of 'Karma', in other words you've not lived a 'good' life. Some also believe that everyone will get dementia. As generations progress, communities are moving away from stigma, but it is embedded. The word dementia is now very recognisable, and people understand the impact more, yet families still try to keep it internalized. It's about turning understanding into something tangible.

*"You can catch dementia, so it is better if you stay away."*

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<sup>10</sup> <http://www.mecopp.org.uk/>

## Issues faced by South Asian people with dementia:

- The older South Asian population tends to have higher levels of poor education.
- People (your community) withdraw from you so you become more isolated, often leading to a delay in seeking a diagnosis. People become more inward looking and insular, for fear of reaction when people find out about your condition.
- The word caring doesn't exist in some BME communities, there is a certain amount of cultural reticence, caring is kept within the family, and is part of the role you take on, largely for the women, seeking support can sometimes be seen as a failure.
- People don't know about rights and entitlements. Self Directed Support can be extremely difficult to access, and consequently is not being used how it should be.
- When accessing services, the use of interpreters can be problematic. For example, sometimes the gender of interpreters can be important, gender roles are very prominent in some communities, and particularly acute in some minority ethnic communities. Ensuring the consistency of interpreters is key. It's about asking someone if it's ok and not assuming that they want a certain gender. It is important to not use younger members of the family (i.e. children) to interpret.
- When planning for the future, people can be resistant to developing Personal Plans, people don't want to be thinking about the things they can't do or what will happen when they die. In South Asian culture they don't have an open dialogue about death, they don't talk about what'll happen when you die, and the project found that there wasn't buy-in for the process. People like to live in the immediacy. Some, due to previous experiences of poor service provision, can lack faith in the future and the services that would be available to them, and navigating the system can be very daunting.

*“Muslim community do not use the services because of their culture, language barriers and lack of understanding of their needs.”*

*“It is very hard to accept help and support because of our culture, caring for relatives is our responsibility.”*

- Things are changing; today's generation is very different to the first generation, and they have different hopes and aspirations for the future.

MECOPP provided some of the key learning from the project and advice on how services can improve provision for BME people with dementia (focusing on the South Asian Community)

- Often, it's not about big changes, it's about making the small changes. Sometimes just speaking to people might be enough.
- It's important to look at how reflective your workforce is, and consider the value of having specific skills, e.g. language skills, within your workforce. They found that the provision of personal care by only English speaking (paid) carers can be very distressing for the service user. Having someone who speaks the language "opens doors straight away and opens up pathways to accessing support".

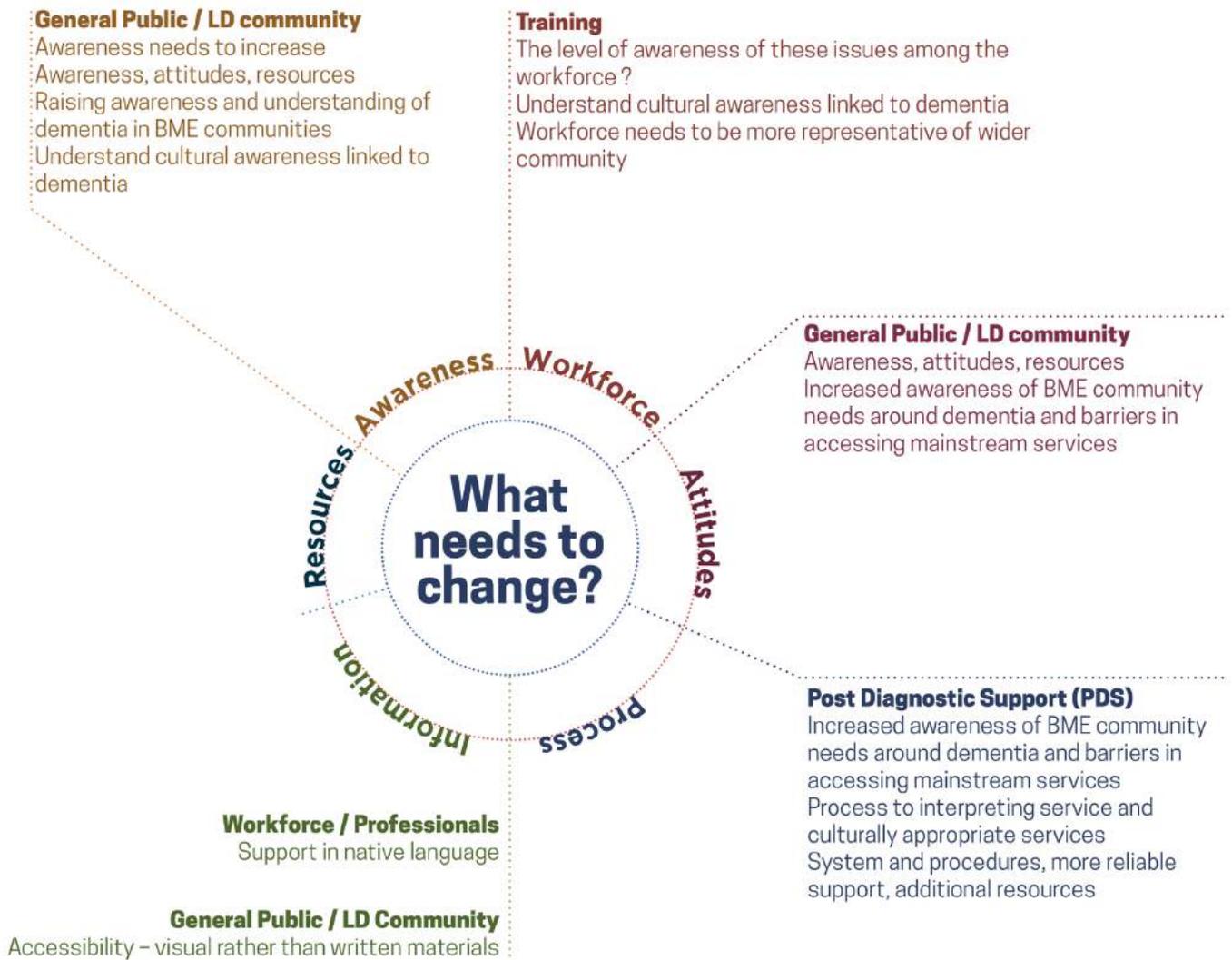
*"My greatest asset is that I can speak that language"*

MECOPP link worker

- It takes time to change perceptions and combat stigma and taboo, but it's important to train / upskill the community you're working with as much as possible. For example, looking at: what is dementia? What are the behaviours, symptoms, and progressions expected of the condition?
- Look at rights and entitlements and support the community to access what they are entitled to e.g. Self Directed Support provision, short breaks, overnight breaks.
- Word of mouth works the best, many of their service users heard about the project through the community.
- It's important to have a multi-agency approach and have every agency on board if you want it to be successful. MECOPP are available to provide on-going support to providers so if they have a question they can contact them. MECOPP are also developing a glossary of terms to include standardized terminology.
- MECOPP are thinking about how the service can be mainstreamed "when the project stops, what happens to these people?". A key thing is workforce development and training, to help mainstream what they have learnt from the project. Promoting excellence through NHS Health Scotland, raising awareness of the knowledge and skills that need to be throughout the system.

# Spotlight on Dementia: Race and Ethnicity

## Stakeholder Discussions



## Spotlight on Dementia: Race and Ethnicity

### Stakeholder Discussions



# Spotlight on Dementia: Race and Ethnicity

## Stakeholder Discussions

### Workforce/ Professionals

Be thoughtful about the 'additional' layer of stigma/discrimination? people from BME?

### General Public / LD community

Ask service-users about their preferences and wishes  
Be more aware of the special communities in need  
Be thoughtful about the 'additional' layer of stigma/discrimination? people from BME?  
Education others and raise awareness  
Promote inclusivity

### Collaboration

Pass on knowledge to colleagues from event  
Share today's learning at our departmental meeting

### Training

Ask yourself how your culture, sex, background, etc. is affecting the one you support  
Be more aware of the special communities in need  
Promote inclusivity

### Information Provision

Pass on knowledge to colleagues from event  
Share today's learning at our departmental meeting



### Post Diagnostic Support (PDS)

Ask service-users about their preferences and wishes

### Workforce / Professionals

Engagement with communications and marketing  
Look to engage more with minority communities in my area  
More outreach work to BME communities

## 6 — Learning Disability

21<sup>st</sup> March 2018

*Contributors: Key Housing, Life through a lens*

### Key Housing<sup>11</sup>

Key supports adults and young people with disabilities and long-term conditions throughout Scotland; 2018 is their 40th Anniversary Year, and they are currently working with 50 people who have dementia, most of whom also have a learning disability. They reflected on and shared their experiences of working with people with a learning disability who also have dementia.

It is now universally agreed that the prevalence of dementia in people with a learning disability is approximately 2 to 3 times higher than in the general population. The prevalence of Alzheimer's type dementia in persons with Down's Syndrome exceeds that of the general population. Because more people with Down's Syndrome are living longer there is a higher prevalence, more than half over 60 years old have dementia. This, they said, means that support must change.

### The Challenges

#### Diagnosis and the Dementia Pathway

- Can be difficult to get family history and life stories
- Memory issues may be associated with the learning disability, leading to challenges around communication and what can be associated with dementia
- Supporting people who have complex needs

#### Post Diagnostic Support (PDS)

- Our aim is to continue to support individuals at home for as long as is appropriate to their condition
- But, a diagnosis does not equate to an increase in support hours.

#### Accessing Specialist Support

- Difficulties accessing additional "mainstream" services, e.g. day care, etc

<sup>11</sup> <https://www.key.org.uk/>

- There is often the assumption that Key can provide everything to the people they support. But they are recognising their limits and trying to access other service that might be available to provide extra support.

## Supporting the person

It's important for services to consider:

- How they can support the person to understand their diagnosis.
- How to support other people with learning disabilities to understand the person's diagnosis – helping them to understand that their neighbour is changing.
- There are often smaller circles of support around the person – and there is an equal need to support them – e.g. – their friends, others who play a part in their lives.
- The role of support team can be impacted



*Workshop participants in discussion. Photography by The Lines Between.*

## The 'Life through a Lens' Research Project <sup>12</sup>

Evidence-based strategies and methods to help people with learning disabilities and dementia to cope and manage their symptoms are important to maintain or improve their well-being and that of their carers and family. The workshop also heard from a Dr Kate Mattheys, a researcher from the University of Stirling, currently working on the research project 'Life through a Lens', focusing on non-drug interventions with people who have a learning disability and dementia.

The project aims to understand whether use of certain methods such as music, technology and changes to signage and the environment in services and care homes can help people with learning disabilities. The researchers will make use of an existing resource that they developed, called Jenny's Diary, which helps people with learning disabilities to communicate about dementia. The researchers will test their ideas on small groups of people who are affected by both conditions so find out whether any or all of them can be of benefit.

There are 7 people involved in the research, and 4 co-researchers. All are using different interventions, e.g. photobooks, apps to personalize their stories, making rooms in their house more dementia friendly, e.g. lights and changes to bathroom floor, using an adapted telephone.

The workshop participants had some additional discussions on the issues raised by the presentations:

- People with learning disabilities are not always getting access to the same amount of drugs as those without a learning disability.
- People are sometimes prescribed a lot of inappropriate medication acting as a sedative.
- Using technology can make a huge difference keeping someone at home, by making them feel safe and secure, e.g. use of key safes, installing door monitors.
- Multi-disciplinary teams are working with people with Learning disabilities in community teams – it's important for them to make local connections and have conversations with other professionals and practitioners.
- How accessible is information about post-diagnostic support to people with a learning disability?
- There are so many assumptions made around complex needs – other support gets in the way
- Supporting through diagnosis: paid carers should not be advocates, they should not have an advocacy role.

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<sup>12</sup> More information on the research and its progress can be found here: [https://www.alzheimers.org.uk/info/20053/research\\_projects/817/helping\\_people\\_with\\_learning\\_disabilities\\_to\\_access\\_non-drug\\_treatments\\_for\\_dementia\\_symptoms](https://www.alzheimers.org.uk/info/20053/research_projects/817/helping_people_with_learning_disabilities_to_access_non-drug_treatments_for_dementia_symptoms)

# Spotlight on Dementia: Learning Disability Stakeholder Discussions



## Spotlight on Dementia: Learning Disability Stakeholder Discussions



## Spotlight on Dementia: Learning Disability

### Stakeholder Discussions

- Training**
- Actively involve people with LD
- Be adaptable on a daily basis
- Embed examples that are more diverse in training programmes
- Ensure staff have the necessary knowledge and skills
- Have patience and make all the support individualised
- Increase my own knowledge
- Plan training for workers who are or are going to be supporting
- Review key strategy
- Update staff teams about Dementia Pathway and 3rd party orgs e.g. A. Scot.
- Collaboration**
- Build relationships
- Discuss with other teams
- Effectively communicate with colleagues across the sector & third party
- Integrating services across NHS, Social Services, Alzheimer's Scotland, primary care sector, knowledge, training, etc.
- Involve CLDT, work with outside agencies
- Learn more about existing resources & engage more with them
- Link up with local teams
- Make connections with other relevant organisations & experts

- Information Provision**
- Advertise my service (PDS)
- Enable staff to seek advice & ask questions

- Make health and S.W. colleagues aware of D.S. & Dementia link & symptoms
- Raise awareness & share knowledge with colleagues & people with Dementia who we work with
- Share information with colleagues
- Share these great 'activities' with all of my services
- Share stories with partners to cement what is possible!
- Sharing contacts and information
- Sharing information
- To deliver more holistic supports and services
- Working collaboratively to market what is going on
- Networking
- Pool resources

#### General Public / LD community

- Advocate for change
- Assess ideas and decisions from the perspective of people with Dementia & L.D.
- Dementia awareness within local L.D. community
- Raise awareness
- Raise awareness
- Think about language & communication

#### General Public / LD community

- Be patient, understanding

- Increase the visibility through research



#### Post Diagnostic Support (PDS)

- Ask more questions, help individuals plan our questions for appointments
- Provide services

#### Workforce / Professionals

- Be aware of new strategies and share this with the service user
- Collect a case study about SDS for someone with LD and Dementia
- Gather experiences

#### General Public / LD Community

- Dissemination/ website / research
- Find another word for 'intervention'

Our thanks go to all those who contributed to and participated in the workshops.

If you are looking for more information please visit [www.alzscot.org](http://www.alzscot.org) or [www.iriss.org.uk](http://www.iriss.org.uk). Iriss will share information about this report via their social media pages.

If you are looking for support,  
contact the Dementia Helpline:  
Freephone 0808 808 3000  
[helpline@alzscot.org](mailto:helpline@alzscot.org)

