

The importance of being Irish

Memory Loss and the
needs of the Irish community

September 2016

EXECUTIVE SUMMARY	3
CONCLUSIONS	5
KEY MESSAGES AND RECOMMENDATIONS	9
SECTION 1: INTRODUCTION	11
SECTION 2: RESEARCH OUTLINE	12
SECTION 3: PROFILE OF THE PARTICIPANTS	14
SECTION 4: AWARENESS AND DIAGNOSIS	15
SECTION 5: SUPPORT FROM DIAGNOSIS	21
SECTION 6: THE IMPORTANCE OF BEING IRISH	26
SECTION 7: FUTURE NEEDS	29
SECTION 8: ADDITIONAL INSIGHTS	31
SECTION 9: STAFF AND VOLUNTEER CONTRIBUTIONS	33
SECTION 10: CONCLUSIONS	36
APPENDIX 1: MEDIA CONSENT FORM	37
APPENDIX 2: DISCUSSION GUIDE FOR RESEARCH	38
APPENDIX 3: ETHICAL STATEMENT	40

Executive Summary

Leeds Irish Health and Homes is a registered society with charitable status under the Co-operative and Community Benefit Societies Act 2014 that provides housing, advice and support to the Irish community in Leeds. Established in 1996 it has over 20 years' experience of working with the Irish community.

The demographic changes in the Irish community over the past 20 years and the experiences that Leeds Irish Health and Homes (LIHH) have observed for their service users have sensitised LIHH to the prevalence of memory loss and its impact on the Irish community.

There has been a recent call to action in health and social care communities locally and nationally through policy initiatives such as the development of Dementia Friends, the Dementia Action Alliance and the Irish community in Britain's own campaign around dementia 'Cuimhne' (the Gaelic word for 'memory' and pronounced queevna) – Irish Memory Loss Alliance.

In 2009 LIHH was commissioned by joint-funding from Leeds City Council and NHS Leeds to produce a report on the health and social care experiences of older Irish people¹. Recommendations were made about dementia care, but there was no formal response to these.

During this period (2009 onwards), however, the organisation set up a partnership project with Leeds Irish Centre for a weekly morning group where people experiencing memory loss could come and enjoy cultural activities (the 'craic') whilst giving their carers a break. The group known as the Irish Memory Loss Group' (IMLG) is still in situ, and continues to support people of Irish heritage. The attendees tell the organisation that the Irish cultural experience resonates with them, providing comfort and reassurance.

More recently spurred on by the continued lack of insight into the experiences of the Irish community about memory loss and dementia in Leeds, LIHH has commissioned this qualitative study to explore the hidden stories and to speak out about the experiences and needs of people in the Irish community.

For the purposes of this report we have used the definitions of dementia and Alzheimer's according to [Alzheimer's UK](#) website:

The word dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease or a series of strokes. Dementia is progressive, which means the symptoms will gradually get worse.

¹ Mulligan E. and Daly B., A Study of Older Irish People's Experiences of Health & Social Care Services in Leeds. (2009).

Core Research question

What are the perceptions, health/social care experiences and needs of Irish people living with memory loss / dementia in Leeds?

Aims of the Research

- To inform medical and social care professionals about the process of assessment and diagnosis and experience of Irish people diagnosed with memory loss / dementia.
- To better inform the Irish community in Leeds about how to express family needs when diagnosed.
- To give a voice to Irish people affected by memory loss / dementia.
- To help inform LIHH's strategic direction in response to dementia.

Profile of research group

Overall 15 people were interviewed including Caroline Murphy, Older Person's Support Worker and Activities Co-ordinator and Philippa Dowson, Community Support Worker with LIHH; a volunteer BW who supports at the IMLG, and 12 individuals/couples experiencing or caring for someone with memory loss.

Of the 12 individuals / couples who were interviewed there were 16 people present at the various interviews. 5 interviews took place as couples and accounts for 10 people – although in two instances the person experiencing the memory loss was uncommunicative.

6 individuals were also interviewed. 5 of these were carers and one person was undiagnosed and lived on her own.

The Irish connection

Of the 16 interviewees present (excluding staff and the volunteer) that were interviewed all had an Irish connection.

- 13 were first generation Irish. They had all emigrated to England in the late 1940s to 1950s which means many have been resident in the UK for about 60 years. They come from a variety of Counties in Ireland including Mayo, Sligo, Galway, Leitrim, Portlaoise, Armagh and Roscommon.
- 1 person experiencing memory loss was 2nd generation Irish (with both parents having been Irish and her husband being Irish) and in turn although she had an English accent all of her cultural connections were related to the Irish community.
- 1 person from the Irish Traveller community was interviewed. She was a carer for her father and had been born in Leeds.
- 1 person interviewed was a 2nd generation Irish daughter of an Irish man who had dementia.

The people experiencing memory loss ranged in age from 71 up to 86 with the majority in their early 80s. Diagnosis had occurred for people at various ages. KM, the daughter of an Irish Traveller noted

that her father had been diagnosed at 54. Two had been diagnosed shortly after retirement – 67 and 71 – whilst for the remaining individuals it had come on in late 70s early 80s.

The medical diagnosis

Nine of the people interviewed have a medical diagnosis.

- 3 stated Vascular dementia
- 1 stated dementia
- 2 noted the medical diagnosis is a 'bit of both' – dementia and Alzheimer's
- 1 noted Alzheimer's
- 1 carer was unsure which but thinks it is Alzheimer's
- 1 has Parkinson's
- 1 has had a test for memory loss and she got '5 out of 12' questions right but this was 5-6 months ago and has not been followed up by her doctor with any visit to a memory clinic

Conclusions

Following a review of the findings from the research interviews there are a number of conclusions that can be drawn to help understand the importance of the Irish cultural heritage, connection and community for Irish people experiencing memory loss.

The significant reliance on family support: There is a reluctance to seek social care or medical help early on. This can be exacerbated by the expectation that family members will deal with family matters. This leads to reliance on spouses, sons and daughters to find out information and to sort practical and financial issues. The pressure and tension this can create in family relationships cannot be underestimated and indicates the support for the 'carer' goes wider than the spouse. It should also be noted that where there are extensive family networks supporting the individual and their primary carer, this does not preclude the need for the families to be supported as much as people who might be living on their own and experiencing dementia.

The stoic nature of the Irish community can be a barrier to diagnosis: The common response to questions about ill health in the Irish community is 'we're grand' or 'I'm ok'. This minimising of need or indeed laughing off significant fears is a key cultural issue which poses a challenge to the professions and the community trying to provide support. It can create barriers to early diagnosis and in turn access and uptake of available support services.

Lack of understanding about the types of dementia: The majority of interviewees noted that dementia and Alzheimer's had occurred to them when their loved one was experiencing memory loss. This indicates that recent awareness promotion about the disease is getting through to the Irish community. However, even though most interviewees knew what the diagnosis terminology was, many seemed uninformed about what it entailed or actually meant. One interviewee even asked the researcher to explain the difference between dementia and Alzheimer's.

Medical support during diagnosis was viewed as generally positive: All interviewees, except one whose father had been originally misdiagnosed with stress by his GP, felt that their doctors had dealt

with their presentation of concerns about memory loss positively and efficiently. The Irish Traveller family did highlight the challenges of being able to access a local surgery during diagnosis.

Feedback is mixed about the medical support received post-diagnosis: The experience of the tests at the memory clinic appeared to go smoothly. Culturally sensitive issues arose for two families however, mainly around reading and writing, in particular how some spellings might have been learnt in Ireland. Many of the interviewees mentioned about 6 monthly visits from the memory nurse to check on the individual from a medical perspective.

Lack of signposting and support once diagnosed: The biggest gap in support seemed to come post diagnosis when the individuals and carers were sent home to deal with the situation. Although many mentioned Social Workers popping out to see them or some practical support such as putting in rails – there was a very strong sense that this support was patchy and disjointed across services and they often relied on the family to push for and investigate what was available to them. This in turn links with the reliance on sons and daughters often needing to navigate their way through a complex system of benefits over a period of time when the support needs of their loved one were continually changing.

All the experiences of the people interviewed highlighted a lack of wider information, signposting and access to additional day-to-day support for the individual or carer or family member once diagnosed – a sense they ‘just had to get on’ with it or ‘being forgotten’.

Lack of respite support for carers: It was clear amongst all interviewees, and mainly the carers, that the hardest issue was the lack of respite / sitting services available to give them a break on a regular basis. Those that had benefited from sitting services from organisations such as Shared Lives noted the value of this. However some had negative experiences where organisations had not identified cultural issues such as sitters needing to stop and pray in the middle of the sitting service having an impact on an Irish person experiencing memory loss.

Dementia awareness campaigns in recent years have had a positive effect on perceptions within the Irish community about the disease: All the people interviewed have told family and friends about their diagnosis or the diagnosis of their loved one. It appears that there is less stigma felt about the illness at present – probably due to the profile raising and awareness that has taken place over the last few years.

The Irish Memory Loss Group and the Irish aspect of LIHH’s support services are highly valued by all the Irish interviewees: All of the interviewees felt that the provision of support from an Irish organisation was very important. It short-circuited in many ways the discussions they had to have with the organisation as ‘they all understand you’ and ‘you can feel free with your own’. This did not stop them being happy to explore support from non-Irish organisations, but there were many instances where they felt the support from LIHH was more appropriate to their cultural needs and the needs of the person experiencing the memory loss. This Irish connection and cultural understanding is not experienced via other support options available in Leeds.

The IMLG provides a positive culturally sensitive social environment for people in the early stages of dementia to come together: The research participants that attended the group or had attended the group highlighted how much they valued coming together as an Irish community and the reminiscence activity that the group delivers felt relevant to them.

There is a gap in provision of culturally sensitive support for those in the later stages with more challenging behaviour: The IMLG group does not support people with more advanced symptoms and the experiences of the participants highlighted a gap in culturally appropriate services as the disease progressed. This gap in community provision for Irish people who are quite advanced in their illness and the families trying to manage the symptoms and personality changes that come with this including handling, how to deal with aggression and safeguarding issues all need to be explored further.

There are practical issues around the IMLG that could be addressed: A few attendees noted the challenge with the group starting too early at 10.30am – many found that their family members struggled to be up, ready and out so early in the morning. There are also wider issues around promoting the group, ensuring there are enough staff if numbers increase and transport barriers that have been registered.

Lack of transport resulted in carers now attending the group: The carers have developed their own informal support network at the IMLG and value the opportunity to discuss the challenges they face caring for their loved ones on a weekly basis.

People's Irish ethnicity has not impacted on quality of care and delivery from medical or support organisations: No one felt they had experienced any prejudice or discrimination throughout the journey of diagnosis and support because of their ethnicity. If anything the majority had praise for the care they / or their family member had received. However, there were culturally sensitive issues specific to people's Irish ethnicity that did arise in diagnosis and post-support that clearly had an impact for some people – such as spelling or generic support groups' activities being too broad and lacking in relevance for Irish people.

None of the individuals felt that their Irish ethnicity had affected access to any services or their treatment around memory loss and dementia. However there were a number of cultural areas specific to the Irish community that clearly affected people's experiences of memory loss and dementia including:

- the strong feeling of guilt about considering more permanent care options such as a care home and sense of failure in duty of care if they were to consider this option;
- for the Irish Traveller family the lack of confidence and trust in using doctors within their culture especially by men;
- the importance of cultural touchpoints such as Irish music or language in connecting with someone experiencing dementia – particularly in advanced stages;
- the positive role and continued recognition of the Catholic religion, mass and its prayers. It provides comfort and familiarity, especially recitation of prayer by the person even in advanced stages of memory loss. Although not identified in these interviews it is important

to note that for some Irish Catholics the connection to the church may have negative memories – especially if they experienced institutional abuse.

- the generic memory loss support services that our participants accessed were not geared up for people with an Irish cultural background. As TC highlights: “The books that were available ...or the games they played, looking back in time, the reminiscence, that was all to do with English history, like the World War or living through those times, which was totally different history to dad who was brought up in a rural area, farming. Nobody understood what he would be trying to talk about or relate to it, and he couldn’t relate to them.”

The negative perceptions around dementia by the Irish community have improved in recent years:

There was a strong acknowledgement that in the past Irish people were probably quite prejudiced and ignorant about dementia, referring to people being ‘senile’ or ‘raving’. In the past there was an associated shame with the disease but all interviewees felt this had changed in the community and people and families were now much more open about it. KM, the Irish Traveller, was the only one who noted that there was probably still stigma associated with the disease amongst the Irish Traveller community.

Being Irish was not perceived as an important consideration in their care going forward: However there was a clear sense this is because they had not really thought about it in detail before and were uninformed about what an Irish specific care package might look like or how it might benefit their loved one.

Future needs that the interviewees identified revolve around practical day-to-day support, financial advice on managing affairs, and the carer’s desire to keep the loved one at home for as long as possible.

The carer’s most pressing priority and pressure is around the need for more frequent breaks and regular respite support: The carers that were interviewed were all very accepting of the situation they found themselves in and showed a very loving attitude to caring for their family member. Most did share some of the pressures that come with being a primary carer and acknowledged there might be some ways that additional support would be useful. Most of their suggestions revolved around more frequent breaks / respite for the person they were caring for – whether daily or for a week or two. They acknowledged that these services are out there but are not available for long enough periods of time or regularly enough. The sitter being Irish was not essential but clear benefits were mentioned when the sitter had an Irish connection or understanding.

Carers would also value more support and social opportunities for themselves: This ranged from a specific coffee morning with other Irish carers, individual visits from a worker from LIHH ‘so you are not forgotten’; and sometimes outings where the couple could attend together and enjoy a day out with support from LIHH – although it was noted these should not be trips far away.

No one explicitly said that future support had to come from an Irish organisation but they did note the Irish connection made a difference especially to the person experiencing memory loss as the familiarity and connection they felt in their community was important.

The potential need for a care home at some stage came up frequently with mixed thoughts from the interviewees: People who had made the decision felt that in hindsight they should have made the decision earlier for the benefit of their loved one. For families considering the option there were obvious feelings of loss: “I think you can’t compensate for an empty chair.” Alongside the perception, especially from KM’s family that her father would ‘rather be dead’ than be in a care home. With the addition of the Traveller culture on top of the Irish connection for KM’s family there was a sense that no care home or day centre would be able to truly accommodate and embrace the cultural mores of their father, his heritage and community.

Some unexpected outcomes of the research included:

- People’s ability to retain their sense of humour in stressful situations
- The emotional and physical strain that memory loss places upon families – especially the primary carer – the isolation, the 24/7 on call pressure of caring and the sense of loss about the future they had envisaged.

Key messages and recommendations

With the timely appointment of a Dementia Services Development Manager at Leeds Irish Health and Homes there are a number of key areas this qualitative research has highlighted which could help to inform the development of dementia services for the Irish community. The following key messages and recommendations have been clustered to help identify who should take responsibility for actions that might arise from this report.

- **For Commissioners:**

1. Ensure that strategic responses to dementia include the voices of the Irish community. LIHH can help with this.
2. The Leeds Dementia strategy should include actions around support that is appropriate to the Irish community in order to help them live independently for longer.
3. Look at post diagnosis pathways to address the perceived gap in services. Communicate a clear pathway.
4. Further investigation and action around the support provided to Travelling communities experiencing dementia. Reference Leeds GATE / Irish in Britain March 2016 report: [Dementia in Gypsies and Traveller: a brief guide for commissioners and providers](#)².

- **For Service Providers:**

1. Be aware ‘I’m alright’ may mask support needs of Irish service users. Seek advice and help from LIHH to break through this cultural barrier.
2. Refer Irish people with early stage dementia to LIHH for individual support.
3. Work in partnership with LIHH to promote culturally sensitive services for Irish people with dementia and their families.

² http://leedsgate.co.uk/sites/default/files/media/document_uploads/Dementia-in-Gypsies-and-Travellers.pdf

- **For LIHH**

1. Raise the profile of the needs of the Irish people with dementia and their families.
2. Become a Dementia Friendly organisation and invest in continual training of the Board, staff and volunteers around memory loss.
3. Irish Community Support Workers to support people through the pathways of dementia services, particularly post diagnosis and into residential care if required.
4. Offer cultural awareness training for service providers and commissioners supporting Irish people with memory loss and dementia.
5. Promote more widely the IMLG, the individual support and any emerging dementia services that will be provided by LIHH to the wider Irish community and health and social care professionals.
6. Review the role, purpose and activities of the IMLG. This includes having a process for identifying when the group is no longer appropriate due to the advancement of symptoms.
7. Consider training and guidance for Irish families (primary carer and extended family) about how to manage the advancement of memory loss – perhaps delivered by an Irish carer who has experienced memory loss in their family so they can share their own experiences.
8. Review the recent release of NHS baseline data on the Dementia Atlas for Leeds.
9. Conduct an audit or review of local care homes / day centres /memory groups and home care provision to see if LIHH can identify Irish individuals with memory loss and connect with these individuals if they are interested (taking into account Data Protection for the individual).
9. To use the findings of the report to inform the development of future dementia support services for the Irish community across the city.

- **For the Irish Community**

1. When you observe significant memory loss in a family member or close friend, seek, and/or encourage the person, or their family to seek medical help.
2. Once a diagnosis of dementia has been given, and acknowledged help the diagnosed individual to find out as much as possible about the services available in the local area.
3. Think about how you may have to communicate differently with the person experiencing memory loss. When you are dealing with people with dementia, do not try and keep communicating with them as they used to be. Give them time, repeat as necessary, rephrase if needed and be very gentle with them.
4. The incidence of dementia is increasing in Britain and Ireland due to the ageing population. It is important therefore that each community looks out for its elderly members in particular, and works closely with them to ensure that they are supported to live well with dementia at home for as long as possible.
5. Think about a care home before it becomes a crisis: “We tried to cope and felt it was our duty...I think that dad would've benefited more by going into a home, earlier, and we thought he would benefit by being with us longer, to be with his loved ones.”
6. Talk about legal and financial matters as early as possible – such as making a will, organising power of attorney or making advanced directives about future health care decisions.
7. Concentrate on some of the positive aspects of your relationship happening in the present: “we had many years of cherished moments...so many times where we were just so close and we wouldn't of had that opportunity if he didn't have dementia.”
8. Family carers must acknowledge that the individual needs of the person with dementia are paramount but these cannot be met if the carer is not taking care of themselves.

Section 1: Introduction

1.1 Researching the dementia experiences of the Irish community based in Leeds

The demographic changes in the Irish community over the past 20 years and the experiences that Leeds Irish Health and Homes (LIHH) has seen their service users go through have sensitised LIHH to the prevalence of memory loss and its impact on the Irish community.

Recent policy initiatives such as the National Dementia Strategy 2015, the development of Dementia Friends and the Dementia Action Alliance and the Irish community in Britain's own campaign around Dementia 'Cuimhne' (the Gaelic word for 'memory' and pronounced queevna) Irish Memory Loss Alliance, have produced a call to action in health, social care, communities and national and local politics. These initiatives are aimed at making sure that people experiencing dementia and/or memory loss have access to good quality intervention which allows them to remain independent in their own homes and communities for as long as possible and experience person-centred culturally sensitive care which maintains their dignity.

In 2009 Leeds Irish Health and Homes (LIHH) were commissioned by joint-funding from Leeds City Council and NHS Leeds to produce a report on the health and social care experiences of older Irish people³. Recommendations were made around dementia care amongst others, but there was no formal response to these.

LIHH did identify as part of this report the increasing needs of the Irish community around memory loss and dementia which led to a Dementia Support Worker being funded from reserves for two years. This post was not continued as long-term funding was unavailable due to the funding climate at the time.

During this period (2009 onwards) however the organisation set up a partnership project with Leeds Irish Centre for a weekly morning group where people experiencing memory loss could come and enjoy cultural activities (the 'craic') whilst giving their carers a break. The group is still in situ and continues to support people of Irish heritage for whom, carers tell the organisation, an Irish cultural experience resonates with them more.

More recently in 2015 a conference was held in Leeds entitled: 'Leeds Black and Minority Communities Awareness Conference, delivered in partnership by the NHS, Leeds City Council, BHI (Black Heath Initiative) and Touchstone.

The event was primarily about bringing together minority communities, health agencies, charities, community groups and the NHS to initiate a discussion towards exploration of solutions to known barriers around dementia care and support.

The evaluation report acknowledged 'White Irish' as one of the largest ethnic minority communities in the UK but there was no evidence or commentary about the experience of dementia in the Irish

³Mulligan E. and Daly B., A Study of Older Irish People's Experiences of Health & Social Care Services in Leeds. (2009)

community and the impact the 'invisibility' of being White Irish has on people experiencing memory loss – especially in accessing medical and support services. Spurred on by last year's conference, LIHH commissioned this qualitative study to explore these hidden stories and evidence the experiences and needs of people in the Irish community experiencing memory loss.

Section 2: Research Outline

2.1 Core Research question

What are the perceptions, health/social care experiences and needs of Irish people living with memory loss / dementia in Leeds?

2.2 Aims of the Research

- To inform medical and social care professionals about the process of assessment and diagnosis and experience of Irish people diagnosed with memory loss / dementia.
- To better inform the Irish community in Leeds about how to express family needs when diagnosed.
- To give a voice to Irish people affected by memory loss/ dementia.
- To help inform LIHH's strategic direction in response to dementia.

2.3 Methodology

Qualitative interviews took place between February and June 2016.

Participants were recruited via Leeds Irish Health and Homes Memory Loss group; people who had contacted them for support around memory loss and other channels such as church bulletins.

In identifying the sample the researcher set out to take into consideration an appropriate mix of gender, age, different stages of dementia and a mixture of narratives from people with memory loss, as well as their carers. Overall 15 people were interviewed including Caroline Murphy, Older Person's Support Worker and Activities Co-ordinator and Philippa Dowson, Community Support Worker with LIHH; a volunteer BW who supports at the IMLG, and 12 individuals/couples experiencing or caring for someone with memory loss.

- 3 direct interviews with people experiencing memory loss took place as their symptoms indicated that they were in the early stages of dementia. One of these individuals has Parkinson's and his memory loss is associated with this disease but he attends the Irish Memory Loss Group and so his experiences were relevant to this study.
- 1 interview took place with someone who thought they had memory loss but it had not been medically diagnosed.
- 7 interviews took place with current or past carers of Irish individuals with memory loss. 2 of these interviews took place with the person experiencing memory loss present but they

were uncommunicative throughout the interviews and the questions were answered by their carers.

- Most of the interviews were with females. Only one male carer was available to share his story. Males experiencing memory loss were present at some of the interviews – two were in advanced stages of dementia and therefore uncommunicative and two were happy to contribute directly to the research.
- 1 interview was withdrawn after transcription as they decided they didn't want their story to be made public.

The loosely structured interviews generally took place, where possible, in participant's homes to ensure they felt comfortable and at ease.

All interviews were fully transcribed and, consent requested⁴ for use of their stories in this report as well as in any publicity and communications relating to the report. A short video was also filmed with some of the participants of the research and can be viewed here

<https://www.youtube.com/watch?v=flxoAENNbVw>

2.4 Discussion areas

In advance of designing the research questions the following discussion areas were agreed:

- What does the term dementia /Alzheimer's mean to individuals or what did they know about it before diagnosis?
- Establish insights into participant's Irish background and heritage and what this means to individuals with memory loss and their carers.
- Symptoms and diagnosis – explore how and when people became aware that something was wrong and what happened between acknowledging this and diagnosis.
- What support was provided or suggested from the point of diagnosis and by whom?
- What was the experience of NHS /social care support in dealing with their memory loss?
- Did people receive support from any other organisations or individuals? If so, what was that support and how valuable was it?
- What was the impact on relationships – family, friends?
- In what way is people's Irish ethnicity important in relation to their experiences of health and social care support for their memory loss?
- Exploration of the needs of the respondent moving forward – whether that is the person experiencing memory loss or the carer.

A discussion guide was then developed for the different groups of participants – staff, volunteers, people with memory loss and their carer's. Overall the questions remained very similar in order to ensure cross referencing of findings was effective. A sample set of questions developed for use with people experiencing memory loss and or their carer is included in Appendix 2.

⁴ See Appendix 1 for consent form outline. All signed consent forms are filed with LIHH.

2.4 Ethical Statement

In advance of the research an ethical statement was agreed by the organisation and the researcher.

Leeds Irish Health and Homes and the commissioned researcher Anna Franks agreed to deliver the research within the suggested ESRC Framework for Research Ethics. See Appendix 3 for the Ethical Statement.

Section 3: Profile of the participants

In total 16 people were present over the course of the interviews. 5 interviews took place as couples and accounts for 10 people – although in two instances the person experiencing the memory loss was uncommunicative.

6 individuals were also interviewed. 5 of these were carers and one person was undiagnosed and lived on her own.

3.1 The Irish connection

Of the 16 interviewees (excluding staff and volunteer) that were interviewed all had an Irish connection.

- 13 were first generation Irish. They had all emigrated to England in the late 1940s to 1950s which means many have been resident in the UK for about 60 years. They come from a variety of Counties in Ireland including Mayo, Sligo, Galway, Leitrim, Portlaoise, Armagh and Roscommon.
- 1 person experiencing memory loss was 2nd generation Irish (with both parents having been Irish and her husband being Irish) and in turn although she had an English accent all of her cultural connections were related to the Irish community.
- 1 person from the Irish Traveller community was interviewed. She was a carer for her father and had been born in Leeds.
- 1 person interviewed was a 2nd generation Irish daughter of an Irish man who had dementia.

The people experiencing memory loss ranged in age from 71 up to 86 with the majority in their early 80s. Diagnosis had occurred for people at various ages. KM, the daughter of an Irish Traveller noted that her father had been diagnosed at 54. Two had been diagnosed shortly after retirement – 67 and 71 – whilst for the remaining individuals it had come on in late 70s to early 80s.

3.2 Career and work history

The career and job history of the people experiencing memory loss was varied. On the male side it was predominately in the construction industry – from individuals running their own construction firm to pipe fitting and two of the men working in the same local factory making blades for Rolls Royce and jet planes. On the female side careers had been in nursing, tailoring and the tax office in Leeds. All had generally remained in the same role for many years – for some 50+ years

3.3 Family

Most of the people interviewed had families – some with sons and daughters living close by. It was clear in the research that this was an important aspect in how much help and support people felt they needed. Many felt that sons and daughters were available to sort things out for them and the relative experiencing memory loss. For some however, not all family lived close by and it was when they were on their own with the loved one experiencing memory loss that they admitted it was challenging.

3.4 Overall health in life

4 of the 12 people interviewed noted that the person experiencing memory loss generally had good health ‘apart from a few aches and pains’. These ranged from high blood pressure for a number of years; 13 years of falls before being diagnosed with an aneurysm 5-6 years ago; bowel cancer ‘but otherwise healthy’; diabetes, arthritis, ulcers and bad chest.

The remaining interviewees all noted that the person experiencing memory loss were generally very healthy for most of their life: ‘physically still good’ and generally ‘a healthy strong man’ were terms used.

Section 4: Awareness and Diagnosis

4.1 The medical diagnosis

Nine of the people interviewed have a medical diagnosis.

- 3 stated Vascular dementia
- 1 stated dementia
- 2 noted the medical diagnosis is a ‘bit of both’ – dementia and Alzheimer’s
- 1 noted Alzheimer’s
- 1 carer was unsure which but thinks it is Alzheimer’s
- 1 has Parkinson’s
- 1 has had a test for memory loss and she got ‘5 out of 12’ questions right but this was 5-6 months ago and has not been followed up by her doctor with any visit to a memory clinic

It was clear that for some of the interviewees there seemed to be a lack of understanding about what dementia and Alzheimer’s actually meant.

4.2 Initial signs of memory loss

For half of the individuals the first sign that there was something wrong is strongly linked to a particular incident. Two noted they were actually in Ireland and one other on holiday in Benidorm when disorientation set in. For one it was related to losing money, another wandered off and another actually fainted and ended up in hospital in Ireland whilst on holiday.

There was a general sense from all their carers that even without a physical incident there was something ‘not right’ about the current behaviour which prompted a visit to the doctors.

For the other half it was more of a slower acknowledgement with increased forgetfulness, a compulsiveness around checking security on windows / doors / cars or getting lost – either when walking or driving.

“I was aware of it. I would forget things very quickly.” (CH)

“It was two years ago I stopped (driving). I should know the road like the back of me hands – I come up to the roundabout and if she didn’t tell me I would have gone round it the wrong way.” (MC)

“Well, he’d ask me things 2-3 times, and I’d say, “Well, I told you that.” Then I thought, well, maybe it’s more than just, you know.” (DC)

4.3 Did Alzheimer’s or dementia occur to people at the time?

The majority of interviewees all noted that Alzheimer’s or dementia did occur to them at the time.

“You hear so much about it these days you’re sort of ready for em. Well you got to understand that before that, she was so forgetful.” (BH)

“You see, well, I worked as a home help and a warden for twenty-odd years so I’d noticed the symptoms from other people.” However with regards to her husband’s awareness about the memory loss: “Well he said there’s nothing wrong with him, you see. That’s the end of the conversation and he doesn’t – you can’t keep more or less on to him you know.” (MH)

“We knew it would happen so we didn’t expect any different about it. We just assumed it was going to happen. I’m expecting it to happen to me.” (KM) Her father’s family in particular has very high incidences of memory loss with 5/6 brothers being diagnosed with Dementia/Alzheimer’s and a nephew just recently being diagnosed as well on the same side of the family.

“I’m afraid the family, his mother had it, and 3 or 4 of the family – sisters and brothers...I didn’t tell them (daughters) about what happened because I didn’t even want to admit to myself because I thought this will be the end.” (DC)

4 individuals said that it didn’t occur to them:

“Just thought I was getting forgetful.” (CH)

“Never gave it a thought – I had good health and I had never been in hospital, only for football.” (MC)

4.4 Visiting the doctor

Many of interviewees explained that once they went to the doctor with their concerns they felt they were dealt with efficiently and referred to the local Memory Clinic.

Some referred to the test they had to do and how they felt:

“Really anxious. I was glad when it was over with. To be asking me questions. I’ve gone through them long enough while I was at school”. (CH)

“The doctors were helpful. They were very good. They listened to me and they said to send him to a special doctor in dementia. They took my word for it and did a little test...and sent him to see somebody.” (DC)

For one couple the diagnosis was at hospital due to his investigations around a urine infection and the scan showing a bleed on the brain. The gentleman was transferred immediately to The Mount (Psychiatric unit) and “they were super there – they have been super everywhere.” (SH)

However, for others, there was mixed feedback on the doctor’s support during and post-diagnosis, almost a feeling that once they had been referred to the hospital for a scan or onto the Meanwood Memory clinic the doctor had no more to do with it, – a sense there was no on-going support from the GP.

“Yeah and the doctors. We haven’t seen the doctors for ages and ages...the doctor has come to the house to see him. But other than that only because I rung them.” (KH)

One family did note that they were disappointed by the misdiagnosis of their father/ husband with the first GP. The gentleman had taken himself to a private doctor initially as he was concerned about his forgetfulness. They checked him out and said that he was working too hard and needed to retire. “He went to the doctor initially on his own, and then must have disclosed that to us and we went to hear the results. Me, mum and dad and we were absolutely delighted to hear that because you could do something about it. He had misdiagnosed it. It was the beginning of Alzheimer’s.” (TC)

With regards to the Irish Traveller who has memory loss his daughter highlighted many issues with the support they received from doctors. To start with there is an issue with regard to which doctor’s surgeries will take on Travellers. She noted that her mother and father have had to register with a doctor 4 miles away from where they live due to boundaries.

“But they don’t care love. Once you’re a Traveller they think ‘don’t be minding about them’. Push you under the carpet and forget about them.” When the gentleman’s wife took him to the doctor’s they did do the memory test and referred him to a memory clinic but KM also highlights the challenges relating to this process for her father who cannot read or write:

“Me dad can’t read or write anyway....showing him things they asked him to pick out things...They asked him this yoke – it was a square or something – he didn’t know what that was and mammy looked and says how his life went from being a sensible man to that happening to him. It was hard thing.”

When prompted about whether an alternative test for not being able to read or write was offered KM noted: “No they were just giving him the same. My mum explained to them. They were saying ‘Oh but he must....’ My mammy said to them, “Look, he don’t understand. You don’t – they think we

are very thick people – we had to explain to him...mammy said, “I’ll explain to him, he don’t understand.”

KM did acknowledge that her father had had symptoms for about 3-4 years by this stage which probably impacted on the medication he could have to help stabilize the deterioration. “We have it too far before they seen him. We didn’t go to a doctor for a long time because we expected it to happen.”

SH highlighted how supportive their current doctor has been and continues to be: “He was a brilliant man. He was at a meeting with Michael and Sabina (the daughter) and he said ‘if that was my dad this is what I would do...’ And I thought that was very nice. Absolutely brilliant and I won’t forget him for his kindness.”

4.5 Support after diagnosis

Many of the interviewees mentioned about 6 monthly visits from the memory nurse to check on the individual from a medical perspective. However, all the experiences of the people interviewed highlighted a lack of wider information, signposting and access to additional day-to-day support for the individual or carer or family member.

One individual was happy to just utilise the support of the family: “They did offer help but we thought she has 2-3 sisters and family’s around...we’re fine so far. We’ll see how things go. So far so good.” (CH and BF)

One participant noted how she felt very lucky that one daughter worked for the Department of Work and Pensions and another was a care worker. This meant that they knew what support their dad could access and could investigate and get information for their mum. The mother noted that after the memory clinic “We went home and got on with life.” They felt no one came out to see them or tell them about support services available: “I suppose there’s so many people in the same position. There’s so little staff to organise.”

This particular family did note that there have been 3-4 different social workers assigned since after diagnosis and although they have utilised respite in three different places they did not feel that any of them were secure enough as the individual has a tendency to wander off.

With regards to the experience of the Irish Traveller family after diagnosis it was apparent that the family and community support on site was essential: “They know - small children and babbies – they say, ‘All right ole daddy you’re not allowed ‘and take him back up by the hand. My daddy was (wandering) down by the gate.”

For this Irish Traveller family the interview highlighted some obvious challenges this community can face with regards to them reading information or leaflets that might be given to them: “She (sister) can find it. My daughter can read and if we need anything we can find it that way – it’s the only way you can do it love – I can’t read and write myself.”

One carer noted that the memory nurse cancelled and has stopped coming now. She helped get some practical support such as rails at the door and a speech and language therapist came after PH had a stroke but there was a feeling that there is a lack of on-going support. "Well they prescribed the medication you know that memory clinic. And then that was about it really." (KH)

The memory nurse did recommend Shared Lives – a Local Authority provision that offers a sitting service for families with memory loss - which KH has taken advantage of. They provide four hours sitting a week and by co-incidence her husband's sitter was Irish. When questioned if it made a difference that she was Irish KM noted: "Well probably in a way I think because it's not that I wouldn't trust anyone else or anything but we were on the same wavelength. And plus the fact she does it on a regular basis."

One family felt they got no support after the diagnosis from the memory clinic. DC highlighted: "Never got any help...he went on the tablet...and we didn't get any help of any kind. I was terrified really. You know, you're frightened. You don't know what is going to happen." (DC)

It did transpire that they had received help from Care and Repair to adapt the house downstairs and a physio also came to help maintain her husband's mobility but it is interesting that this practical help was not associated with advice and signposting.

SH looked after her husband for 19 months after diagnosis and received lots of practical support such as a mat for the bed to identify when he got up at night and a link to Telecare which has an alarm pen to use in emergency. She also took her husband to a Memory Loss Group in Alwoodley and received home visits from a support worker from LIHH.

For one family they felt that they only really got help at crisis point. "His GP had no experience with the dreaded disease, so they had no idea how to treat him or myself. I rang Dementia in Armley and a nice lady called Colleen came to see us. She got him into Bay Tree one day a week - two when he would go." She also got someone to sit with her husband for 2 hours a week, "it was lovely because he was in the engineering business." However this gentleman retired to Spain: "I didn't have anyone after that. They did send somebody else from Alzheimer's but he was Sikh or something, so she says: 'He will have to kneel down and pray at certain points' and I thought that is going to be no good for him so I said 'Don't bother...'. They never sent anybody after that." (AM). This experience does seem to highlight a lack of cultural awareness in an already sensitive and vulnerable situation for the individual experiencing memory loss.

His daughter also felt frustrated with the medical advice: "The geriatric consultant we had was hopeless. He just didn't seem to know. He did what he had to do with the memory check and whatever else. He offered no support or explanations of anything. In truth I had read about the dementia drugs that were coming onto the market...I suggested these would be good for dad. He hadn't even heard of them...and they were available. Only for my nursing background I could act as an advocate for mum and dad."

At one point after a difficult week the daughter suggested respite: "We hadn't even thought about it as no-one gave you any advice." During respite her father had some challenging episodes and was

admitted to LGI. Berkeley Court did not want to take him back but the consultant noted they had 'an honour of care'. The daughter kept asking about The Mount and being told her father was not bad enough and 'we were literally kicked out into the car and had to come back to Berkeley Court.'

Only it happened again and this time the family were admitted to St James and fortunately an Irish nurse that knew the family said she would speak to a consultant who was sympathetic to people with dementia. The Consultant got her father admitted to The Mount where the geriatric consultant told her mother: "I can't believe how you've kept it all together as a family. It shows the strength of your family that you have been able to do this for so long because he had never seen the likes of it. I can't believe you didn't get help before you did." She pointed out: "When he said that to mum she just burst into tears. She had the relief that somebody after 13 years, had understood that things are that bad. That somebody was going to help and take the weight off her shoulders." (TC)

Overall his daughter feels that: "I do think they used to look at us and think, 'They've got a good supportive family we don't need to intervene'. That's why we were left to the very last when things got to a crisis point before we got very much help at all. Whereas I do see some people even in the services through Irish Health and Homes and they get lots of support, and that's because they are a support network...We didn't have any support for any of us. I think one by one we were very under pressure with it."

4.6 Sharing the news with family and friends / Impact on relationships

Positively all the people interviewed have told family and friends about their diagnosis or the diagnosis of their loved one. It appears that there is definitely less stigma felt about the illness at present – probably due to the profile raising and awareness that has taken place over the last 5+ years.

"We've been open about it and just lived with it and that's it." (CH)

"I mean, when you get to our age, the friends I've had have passed on...I had a friend about fifty-odd years, you know. We were very good friends and she died a year ago so that was the real thing I had because I could ring her up and chat away, you know." (MH). This lady also noted a school friend of her husband still visits every week which is positive for him and something he enjoys.

KH felt it helped to let other people know: "Because they don't expect miracles and the other thing was a few of the men still come to see him which is nice."

SH was very open about it and explained it to family and friends. She noted they were: "Very very sorry. You know he was so active – a creative mind. A lot of them were really shocked and sorry – like I would be for anyone. Even if you had a bad friend you wouldn't wish it upon them. And family have been so good."

Some women felt a bit awkward about sharing the news:

"I didn't deny it. I said he wasn't able to remember things, it wasn't good. I didn't call it dementia or anything. I just said he was having problems...I think I wasn't sure or I'm still not sure whether it was what they used to call it in Ireland...senile dementia. I wasn't sure about whether it was that with his

mother having it. I didn't admit to it being...of course it still isn't. He has the Vascular which I'm still not for sure that it's Alzheimer's but I am sure it is now because of how he is now." (DC)

"It took a while in order...you know, some people, when you talk to them they think 'Oh there is nothing wrong with him, he's wonderful' – you know...In the end (they were supportive). I didn't like talking about it in the beginning, or say what is wrong with him. I'd be ashamed in a way." (AM)

Section 5: Support from diagnosis

Following on from the medical support people received immediately after the diagnosis such as the memory nurse checks, the research was also interested to find out what additional community support had been provided for the people with memory loss and their carers.

Interestingly at the time of completion of the qualitative interviews for this report the NHS launched the [Dementia Atlas](#).

This online tool has created a baseline understanding and sets out what is currently known about dementia care and support across the country, based on available national data. The data is grouped in themes based on NHS England's well dementia pathway which serves as a framework to ensure people with dementia have a better experience of health and social care support from diagnosis through to end of life.

In the 'Indicators' panel a range of data supporting themes of 'Preventing well', 'Diagnosing well', 'Supporting well', 'Living well' and 'Dying well' are mapped. It is outside the range of this report to cross-reference this data but its existence is acknowledged and it is suggested the data is utilised by LIHH in shaping its dementia strategy moving forward.

In relation to this specific research it highlighted that following on from diagnosis individuals received varying levels of support from other community organisations. This section also explores whether they had received support from Leeds Irish Health and Homes and if so what value they placed on the Irish connection with this organisation.

5.1 On diagnosis what help did people receive and from where?

After the diagnosis at Meanwood Memory Clinic BH noted: "We had a visit a few times but not for a while now as they said to ring up if we wanted any help." The family have continued to provide the main support network for CH & BH. Their son was also receiving support from Leeds Irish Health and Homes and he suggested his parents get in contact about support and they did.

MC and EC have received information about Carers Leeds. EC has considered going on some of their trips. She is not sure how she got connected into their magazines.

MH's daughters also took on the responsibility of finding out about respite for their father and they have gone on to try three different care homes – none of which felt secure enough for MH's

husband who often wanders off. However she values the weekly visit from a sitter through Moor Care called John who gets on well with her husband as it gives her a break.

KH remembers a social worker who she thought was a student social worker coming and taking herself and her husband down to 'The Green'. "I think it was like a residential home or like a day centre." The transport support to and from The Green would have been valuable but KH noted: "I talked about it but he hates getting up early in the morning and that was that...he went and stayed for a few hours but said 'I don't want to go there'." KH was also nervous about the fact it was only from 9.30 until after lunch and that if she went out and they dropped him off early or she got stuck coming home the problems it might cause.

KH has also utilised the sitting service by Shared Lives. She spoke about the Swarcliffe Good Neighbours scheme and said she might try their luncheon club and outings. She noted she would probably try this over Leeds Irish Health and Homes' memory loss group as they provide transport to and from the activities.

The gentleman who has memory loss linked with his Parkinson's has had a lot of support from Parkinson's UK. They have helped to establish a care plan for him and they also support via Moor Care who provide a sitting service.

KM particularly noted the support herself and her family have received from Leeds GATE (Gypsy and Traveller Exchange). She also highlighted that actually it is her family which directly share the responsibility of supporting her mother and giving her a break – over and above any direct service provision.

Although ES is not medically diagnosed she did praise the help she got from her support worker at Leeds Irish Health and Homes. ES also attends some of the LIHH luncheon groups and social activities such as outings. She did say that 2-3 nurses from Donisthorpe Hall visit her and help her bathe but did not expand on how she found that service.

When asked about whether they received any additional support from social care or other organisations DC was clear: "No. The only people that have given us any help or any advice or any company you might say was Health and Homes." DC's husband has attended the IMLG for a number of years.

Later on in the conversation DC did note that Care and Repair had helped in practical ways adapting the downstairs toilet and shower and putting rails in which had all been helpful. She also mentioned a physiotherapist who visits in order to retain her husband's mobility for as long as possible.

For AM and TC the level of support outside of the medical interventions was limited. Their husband/father did attend the IMLG and also the Bay Tree group but AM recognised early on in his illness that actually there were four Irish men she knew of "all going to different places, and I said (to EM – dementia worker at LIHH at the time) it's a shame that they can't all get together. And be together in one group. They are still Irish at heart and they have more in common with the Irish." From this point the IMLG was born and EM organised the space at the Irish Centre and it's been

running ever since. The challenge came when her husband's disease progressed: "He did like it. He still liked wandering off, and of course they didn't have enough staff for it. They weren't really geared up for dementia people. I mean they are not trained either and he'd start wandering off, so they had a job with him at times."

SH had been signposted in the direction of a carers group by the social care worker they had a link to but she noted that she didn't really have time to attend. Her husband did go to the IMLG and also another Memory Loss Group in Alwoodley – which she couldn't remember the name of. SH was very confident that the Irish specific group made a difference at the time: "It did then...it wouldn't now but it did then because he was more conscious of it – oh yes it certainly did...with it being the Irish Centre and knowing Tommy McLoughlin and three or four of the people at it and then getting to know the crowd as well."

When prompted about the Memory Loss Group with no Irish connections and asked if it was different SH noted: "It wasn't the same...I noticed that it was good, very good don't get me wrong but that was missing – the connection and what he was most used of – the conversation the chatter....things that happened when they were young and he could relate to all that."

The lady who actually ran the group at Alwoodley does come to do activities at Donisthorpe Hall (which is where SH's husband is cared for) and now recognises the impact Irish linked activities have on people with that culture. For example SH notes that if she has musicians there she asks them to play an Irish tune for PJ.

5.2 The importance of an Irish organisation providing memory loss support and its value

In all instances the people interviewed knew about the existence of Leeds Irish Health and Homes. Some receive one-to-one support visits at home from Outreach staff; seven of the interviewees/ the people they care for attend the Irish Memory Loss Group and others dip in and out of specific social activities organised by LIHH such as the Irish Tea Dances, St Patrick's Day party or Christmas events.

All of them felt that the provision of support from an Irish organisation was very important. It short-circuited in many ways the discussions they had to have with LIHH as 'they all understand you' and 'you can feel free with your own'. This did not stop them being happy to explore support from non-Irish organisations – but there were instances where they felt the support from LIHH was more appropriate to their cultural needs and the needs of the person experiencing the memory loss.

For CH the Irish connection is very important. Although Catherine is 2nd generation Irish and born and brought up in Leeds she highlights: "Oh I just love anything Irish." She clearly lights up when talking about how much she loves Irish music and dancing and particularly loves attending the Tea Dance's that Leeds Irish Health and Homes organise.

She is less interested in attending the IMLG: "I just don't know what's the reason but I am just not bothered about groups like that. I have sisters and if I want I go out with them." She did also note that the start time of 10/10.30 is too early for her as she likes a lie in.

MC is quite engaged in LIHH services. He is an active member of the Walking Group and often attends social events such as the St Patrick's Day party and the Monday luncheon club. It appears that these non-specific memory loss groups and activities are as valued by MC as much as the the IMLG – especially the social aspect, remaining active and meeting people he knows from the community. He does also attend the IMLG. He noted that when it started there was quite a big group of them but many of the original group have passed away.

MC doesn't get direct one to one visits at home from LIHH but believes this is down to him being still very active: "Now you see they know I am not to...probably if I was you know...the facilities are there but they know that I am mobile and I go on the walks and that."

The value MC and his wife place on LIHH support is clear as he says: "We're absolutely blessed. There are not many cities in the UK that can compare...I'll tell you one thing about them I wouldn't be here today – the facilities they have..."

MH's husband attends the IMLG and 'looks forward to it'. The group also gives MH a break (even though she attends with him as there is no transport so she has to drive him). "I'm able to relax more here because he'll talk to other people whereas at home if I go upstairs he follows me. Downstairs he follows me. You know."

MH feels the Irishness of the group is important: "Definitely. It is because even though...at night or even during the days, if there is nothing on I always put me Irish records on for him, you know", as she sees her husband react to the music in a positive way.

MH highlights that she is quite open to attending non-Irish groups but feels there is a valued difference for her husband: "Well, not for myself because I mean for for him I think it's better, the Irish group because you see, being in a construction company, he's always worked with Irish people. He's never been like me where I worked with all nationalities...he's always leaned to the Irish, you know."

The gentleman who has Parkinson's does attend the IMLG. As a couple they used to have a Support Worker who visited them and he encouraged him to go in the first place. "It's some good chat going on most of the time." And he thinks that it is a good thing that it takes place at Leeds Irish Centre. His wife definitely feels that if he went to a different group that did not have all the Irish links (films, music, pictures, and food) "he wouldn't be as interested in going."

KH's husband does not attend the IMLG – but she did not clarify why. She did touch on the issue of there being no free transport and whilst she would be happy to pay the distance and return trip once a week was perhaps too much.

She did note that they have attended the wider social events LIHH put on for the community such as the Tea Dance. KH does feel that the Irish connection at these Tea Dance's makes a difference: "I think it wouldn't for me but I think it would for him because that was the problem down at that 'Green'. There were people talking but he didn't seem to join in with them at all – we just sat there." Yet when he attended the Irish Tea Dance he met lots of people he had known and met over the

years from the Irish community and was much more chatty. He also loves Irish music as his brother was a musician: the social aspect of Irish events and meeting people they know from the community clearly adds value to any outings for this couple.

KM's father has never attended the IMLG. She knows about the group and is considering getting in contact about it. KM was unsure about whether LIHH had been in contact since her dad's diagnosis. She knew someone had provided suggestions about day centres to consider for her dad but she was unsure which organisation they were from.

Although ES is not actually diagnosed with memory loss she would happily attend the group if her memory deteriorated. For ES there are potential barriers: "I don't like going anywhere on my own at first. Then when I get in I don't want to get out if you know what I mean." The cost of a taxi (£7.50 each way from her house) also felt prohibitive.

DC's husband had attended the Irish Memory Loss Group for a few years. At the beginning DC was not sure about him attending: "I don't know, I didn't think they could help, you know do anything for us...I suppose I wasn't admitting to myself that he was bad enough to go." He didn't want to go on his own: "The first thing he said was, "Are you coming?" That's what he said." When he had been to the group DC noted: "I didn't get much feedback. I just asked him who was there or something and I might ask him what did they do."

One of the challenges for them now is that DC has to drive them if her husband goes to the group which she doesn't mind but when he was picked up in the minibus and went on his own she noted: "It was a change for me. I'm not on my own very much, so I didn't do it very much, but I was able to do the things that I didn't want to drive him around for...pop to the shops or go round to my sister for a while." She also finds that the start time 10/10.30 'a bit too early in the morning to be heading out.'

Now that more of the carers attend the IMLG with their family members DC has actually found this helpful: "It's an outlet for us besides just having them. God help them, but it's just somebody else to talk to. I just say we'll put the world to right. It's a good thing."

She also really values the Irish connection of this group and LIHH. She thinks the group being Irish 'helps too'. "Maybe it goes over people that might not be interested in our reminiscing." The Irish company helps: "I think it's the friendliness. There's a friendship there...we have more in common shall we say."

For AM and TC's family member he enjoyed the IMLG at the start 'it was wonderful' (TC) but as his dementia progressed the group became less appropriate for his needs. He used to wander off or as a result of the disease get aggressive. The staff team at LIHH confirmed that the group was established for those people in the early stages of dementia or who have moderate memory loss. There is a recognition that as the disease progresses there is a gap in community provision for Irish people who have advanced stage dementia and for the families trying to manage the symptoms and personality changes that come with this.

“That’s the main thing they could offer (IMLG) and it wasn’t meeting his needs. We were out of the loop then. An organisation that would have been right up our street couldn’t offer anything to help us and we were becoming more desperate because there was nowhere. Everywhere we turned to weren’t meeting his individual needs. His more complicated and complex needs. It was so difficult...he was isolated, mother was isolated.”

TC suggests that staff at LIHH consider training in restraining if they are to consider having people at the IMLG in more advanced stages of dementia that might get frustrated and react.

By the time TC’s father moved to Donisthorpe Hall she said her ‘mother felt forgotten.’ AM did feel that some support for herself as an Irish carer would have been useful at this point. Something like a coffee morning: “2 hours in the morning or afternoon, and that carers and people could go. And then you wouldn’t be ashamed to be going and listening to them talking... (because everyone) was in the same boat.”

AM would also have valued a visit from a LIHH worker or somebody from the church at the time: “at least to have a little chat. Just to talk and toss things over, and see if we’re getting the right help and the right everything.” TC felt that a visit like this needed ‘to be giving something, not just passing the time.’ i.e. a few hours sitting service or advice.

AM was very vocal about the value of the Irish specific Memory Loss group: “They’re all Irish at heart really. All the older ones have been here so long. So much to do with the Irish centre and that all their lives. You can feel free with your own can’t you?”

SH valued the support from LIHH. Her husband used to attend the IMLG as mentioned above and the Irish aspect was very important to them both. Dan McGuire used to visit her husband (he has now left the organisation) and SH praised Dan’s visits as he would chat about Ireland with her husband. “In a very short time we had a contact from Irish Homes and there was a lovely man there called Dan who used to call. He was super – really, really nice.”

Section 6: The Importance of being Irish

All of the interviewees felt that the provision of support from an Irish organisation was very important. It short-circuited in many ways the discussions they had to have with LIHH as ‘they all understand you’ and ‘you can feel free with your own’. This did not stop them being happy to explore support from non-Irish organisations – but there were many instances where they felt the support from LIHH was more appropriate to their cultural needs and the needs of the person experiencing the memory loss – a connection and understanding not experienced via other support options available in Leeds.

6.1 Did being Irish make any difference to how participants were treated in diagnosis and post-support?

All people who were interviewed agreed that they had never experienced any difference in treatment because of their Irishness. If anything the majority had praise for the care they / or their

family member had received. However, there were culturally sensitive issues specific to people's Irish ethnicity that did arise in diagnosis and post-support that clearly had an impact for some people – such as spelling or generic support groups' activities being too broad and lacking in relevance for Irish people.

"I wouldn't say. No, I didn't find that. I found everybody very helpful." (DC)

"I never found anything about being Irish never came up to me in this country, and never found anybody against Irish." (AM)

The only issue that arose during diagnosis was the issue with some of the tests. One family also recounted a very specific issue with one of the questions in the test: "He made me laugh. There was always one question that he always got wrong and it was because he wouldn't have known the answer in the first place. It was how to spell world. He used to pronounce the world 'world' He used to spell it WORALD....Every time he was asked, whether 70 or 83, he couldn't spell it...considering they were only educated until they were 13. A lot of their intelligence was practical or vocal. It wasn't that they had a great grounding in spelling." (TC)

KM also highlighted, as mentioned previously, the issues her father had in relation to not being able to read and write and in turn understand the tests – however this issue is not necessarily Irish specific.

TC felt strongly that being Irish had impacted on her father's support after diagnosis: "It was a major factor, I felt. A lot of the help that we would've benefitted from that was available didn't really work for him because it wasn't; geared up for somebody with his cultural background. Such as going to Bay Tree, the day centre, there was such a mix of cultures there, which is wonderful in theory, but in practice when you are trying to meet individual needs, it was too broad a range to help dad. The books that were available ...or the games they played, looking back in time, the reminiscence, that was all to do with English history, like the World War or living through those times, which was totally different history to dad who was brought up in a rural area, farming. Nobody understood what he would be trying to talk about or relate to it, and he couldn't relate to them."

A couple of other interviewees also mentioned that they had tried generic memory loss support services and groups but felt that they did not connect with their family member in a way that was relevant to the person they were caring for.

6.2 Has being Irish affected your memory loss experience?

None of the individuals felt that their Irish ethnicity had affected access to any services or their treatment around memory loss. However there were a number of cultural areas specific to the Irish community that clearly affected people's experiences of memory loss and dementia including:

- the feeling of guilt about considering more permanent care options such as a care home and duty of care to their family member;
- for the Irish Traveller family the lack of confidence and trust in using doctor's within their culture especially by men;

- the importance of cultural touchpoints such as Irish music or language in connecting with someone experiencing memory loss – particularly in advanced stages
- the positive role and continued recognition of the Catholic religion, mass and its prayers It provides comfort and familiarity, especially recitation of prayer by the person even in advanced stages of memory loss. Although not identified in these interviews it is important to note that for some Irish Catholics the connection to the church may have negative memories – especially if they experienced institutional abuse.

TC noted how she felt her Irish background had informed how the family felt a duty of care to their father: “I think, because of being the family we are and probably a lot to do with it being Irish and with that generation where we are influenced by the old generation, we tried to cope and felt it was our duty, as a family, to look after our own and not have them in a home or anything else. I would advise people to say that isn't the way ahead. You think you're doing the right thing by your father or your loved one, but it isn't always the right thing for them.”

KM also spoke about this: “Someone said, ‘Why don’t you send him to a care home?’ We said, ‘We can’t. Out of 11 kids – if one of us can’t look after him, 1 of us or 2 of us, we have to forget about it’.”

When asked if being Irish is an important consideration in their care going forward most replied that it wasn’t – but this might be because they have not really thought about it in detail before:

“No, never give it a thought.” (MC) But aspects of Irish culture were clearly key parts of people’s day-to-day lives for example MC accesses the GAA football matches online so he can watch the Irish teams play

KM really highlighted how being an Irish Traveller affected the confidence and trust in going to a doctor: “We live in a prejudice world and a lot of doctors look at you like you have 99 heads... Men still don’t bother today going to the doctors – ‘I’m alright’...”

DC felt that being Irish and having the Irish connection was important in her husband’s care moving forward: “He was brought up in an all Irish community, even an Irish speaking community. When he came to London, he was speaking Irish. Even last night when we were here, I was amazed, to get some Irish (language on the radio) even though I don’t understand it. I shall have to get an Irish record or video as somebody came on and sung an Irish song and they talked about it before and he was laughing and happy with it. He likes the music anyway, the Irish.” When prompted about whether he was speaking Gaelic DC said: “Yeah, kind of saying things.”

One aspect that did come up quite frequently in the interviews was the role that the Catholic religion plays in people’s lives. In particular many of the people affected by memory loss can remember their prayers and find mass a comforting, familiar experience. Many in the North Leeds community are also aware and some attend the Dementia Mass that is held at The Immaculate Heart Church in Moortown on a Thursday for people and their carers.

“There was one thing about and he never forgets and that is when we go to church on a Sunday. He knows every prayer. Every prayer and everything. Even when he goes up to Communion and the

priest says and he answers the priest. That is one thing I could never understand – how he actually can remember every word of the prayers.” (MH)

When DC spoke about religion she said: “That’s very important to him, even now.” She highlighted that her husband often does the sign of the cross and: “He follows the mass and gets up at the right time and down at the right time...I don’t prompt him. He does it himself. Sometimes he’s up there before me.”

6.3 Perceptions about memory loss and dementia in the Irish community

We asked the participants of the study about perceptions of memory loss in the Irish community in order to understand about any prejudices or pre-conceived ideas the community might have about memory loss.

“Well I don’t know. I think it’s gotten more common now – you would hardly hear about it years ago. You would just say he was raving for the Alzheimer’s. The same with cancer. They wouldn’t talk about cancer you see but then there is so many dying of it.” (BH)

“When we were young and we were brought up like that – oh he is not a full shilling...before it was swept under the carpet. It was a mental illness or anything like that. All the families wouldn’t talk or let them know.” (MC)

KM highlighted the same challenges in the Irish Traveller community: “It’s not only my Father that have that; there may be more people on site that we don’t know about. A lot of people is ashamed to admit that their family might have it...what’s to be ashamed of? A sickness...he can’t help the sickness...”

DC feels that the Irish community “are frightened of it...I might have been more frightened if I’d not known it was in more or less all the family, his family...I don’t think the Irish do talk about it or it isn’t there. Like me, probably saying that it’s senile. I don’t know.”

SH noted: “It was awful the way they were about it. I never understood that. It’s like someone having a baby out of marriage and people worrying about what the neighbours think and I think what the heck – the neighbours would be the least of my worries. You don’t want it to happen to you but if it did you deal with it.”

Section 7: Future needs

7.1 What would make life easier for you / the person you’re caring for to remain independent for as long as possible?

There was a diverse response to this question from the individuals. Most responded practically with one person noting that their daughters deal with the financial and care side of things between them such as arranging for their father’s Power of Attorney: “If he goes into care everything will go. I mean I do want them to have something.”

KH highlighted that she is waiting for a swivel chair to be installed in the bath to help her wash her husband. She has been informed that he will be assessed in 12 weeks – when ultimately the need is immediate. Although she deals with this via humour: “I said he’ll be very dirty by then.”

DC was keen to keep her husband at home as long as she could and they have adapted the house and brought the bedroom downstairs to make it easier for him: “I’m happy to have him as long as I can with it. As long as he can get up, that’s the reason we have the physio so he can keep up the walking.”

7.2 Carer’s Needs

The carers that were interviewed were all very accepting of the situation they found themselves in and showed a very loving attitude to caring for their family member. Most did share some of the pressures that come with being a primary carer and acknowledged there might be some ways that additional support might be useful – most of their suggestions evolved around more frequent breaks / respite for the person they were caring for – whether daily or for a week or two:

“I think the visiting part for somebody to come and sit I think could be a bit more.” (KH)

“The only thing anyone else could do, but he wouldn’t have it would be to give me a night’s sleep.” (SH)

As KH highlighted: “You’re a long time in your own house that is the only thing for both of us not just himself.” DC also noted the same issue: “I think when they get to a stage that we’re at now; I don’t think we need anything else at this stage except to change the 4 walls.”

Some of the ladies also suggested just more informal social outings such as coffee mornings for people in a similar situation. AM felt that in hindsight it would have been lovely to have more coffee mornings where the carers could go with the person they were caring for: “then you wouldn’t be ashamed to be going into and listening to them talking...where the carer could have the craic (enjoyment) with the other carers and not have to worry about what the patient was saying.”

In an informal way and due to the lack of transport the Irish Memory Loss Group has started to become a group for the carers as well as for the person with memory loss as for the carers it makes sense to stay there rather than go away and come back again.

For those with family they noted that their own family support network was highly valued: “My relations are supportive enough. I just want to get on as long as possible. If I need (help) I’ll ask. (BH)

However even when there was a strong family network in the circumstances of for example AM she did note that it would have been nice to have a visit from someone – possibly from LIHH “Just to touch in and see how things are...so you are not forgotten...and to know that if you had any questions there was someone there that could answer them for you, for advice and things like that.”

7.3 What kind of support service would be important moving forward?

No one explicitly said that future support had to come from an Irish organisation but they did note the Irish connection made a difference.

The potential need for a care home at some stage came up frequently with mixed thoughts from the interviewees.

AM highlighted how they had resisted moving her husband to a care home initially: “It was a June day when he went up there...oh my gosh, just lovely but it felt we were putting him into prison, you know...We never thought we should send him away like that, but looking back now, he should have been there before that...he never asked to come home from there.”

When KM was asked if her father might settle in a care home she said: “No, He’d rather be dead. I know...in 6 months’ time, he’d rather be dead because he’s not used to that environment...he’s a Travelling man, he’s lived on the roadside all his life. He lived in a caravan. Now he have a house... but he still have a caravan and he looks out on that caravan every day.” They are considering day care in Morley or Middleton to give her mother more frequent breaks however.

KH highlighted some of the barriers to accessing the support available: “When they say well you could go to a day centre, the thing with the day centre is the time picking up and the time dropping off. Because they said ‘Oh well he can be dropped back any time after dinner’.”

DC felt: “There’s only so much people can do for you because a lot of it is at night, during the night.”

TC noted that some training about what to expect would have been helpful: “I don’t think we would have thought ‘we’ll be fine.’ I think we would have taken everything on offer. How valuable it would have been, I don’t know. We seem to learn on the job a lot better than, either reading from a textbook or from other people. I think you only really would’ve taken it on board if somebody had been through it themselves. So they weren’t just giving you theoretically ideas.”

Section 8: Additional insights

There were a few additional areas that came to prominence in the conversations including:

- The ability to retain a good sense of humour about the situation
- The emotional and physical toil and empathy the carers and family members show
- Advice for people about to embark on a memory loss journey with a family member or friend.

8.1 The ability to retain a sense of humour

MH relayed a story about her husband wandering off from hospital and walking from Leeds to Bradford before he was found. On his return to hospital they said “we’ll have to come home with your husband to see if he can negotiate the stairs. I said if he can walk to Bradford he can manage the stairs.”

In some instances there was humour about the situation from the person experiencing the memory loss. BH, CH's husband noted: "She says, 'Why do you get up so early?' I say, 'Well if I lay there, I start worrying about everything...' She says: 'Why? I don't worry about anything?' and laughs.

8.2 The emotional strain

The emotional and physical strain that comes with caring for someone 24/7 was apparent. Many spoke of their tiredness – especially if their loved one was prone to being up a lot at night - as well as the sadness felt watching a loved one deteriorate.

"It's hard to watch your father go like that because me daddy was a clever man all his life and then that to happen to him you think, it's a really cruel world out there." (KM)

MH agreed it was a tough job being a carer: "It is but you know I always think this way. People say to you, 'Well, wouldn't you be better if he was in a home?' I think you can't compensate for an empty chair."

SH also noted: "It is terribly sad...when he is pretty good we could always have a conversation and one day I said I was feeling a bit down and I said: 'We were lucky that this didn't happen to you or me (I always put myself into the conversation) when we were over in Ireland. I said we had 22 wonderful years half the year every year,' and he just said: 'Well I'd like a few more' and I said 'So would I but we are doing fine and you never know one of these days we might go back.'"

AM really felt the isolation when people stopped calling: "He'd say, 'Why doesn't anybody come to see us anymore?' He'd sit in the front room there and look out the window. He loved visitors and he would be calling people in off the street."

For TC just sharing her story as part of this research was of value. She reflected: "There were so many times we were just so close and we wouldn't have had that opportunity if he didn't have dementia. He needed us and we always needed him...It comes and goes and it's forgotten. It's obviously not, to us. To share it with somebody else, and just talk about it is absolutely lovely. Thank you for the opportunity."

8.3 Advice interviewees would give to people who may be about to embark on a memory loss experience

TC in particular provided three valuable areas of advice for people about to experience memory loss within their family or friends network:

- a) **Think about a care home before it becomes a crisis:** "We tried to cope and felt it was our duty...I think that dad would've benefited more by going into a home, earlier, and we thought he would benefit by being with us longer, to be with his loved ones...I think slightly earlier would have been better, and not to feel guilty about making that move of a loved one going into a nursing home. Because I think that he was happier there."

- b) **Think about how you may have to communicate differently with the person experiencing memory loss:** “When you are dealing with people with dementia, to not try and keep communicating with them as they used to be....They will still argue black is white, whatever it was I would try and get on their level or even lower than their level so they feel they are not being dominated...Give them space and be very gentle with them. Softly, softly approach.” (TC)
- c) **Concentrate on some of the positive aspects of your relationship happening in the present:** “I would say to other people while be it may be very negative, what's going on. It's not something you would choose for your dad, or whatever. At the same time, there's so many positives from it. Try and concentrate on the positives. When you got him at the moments he was so loving. To be able to have those as memories, now that he has gone, some people, their dads are taken from them quickly whereas we had many years of cherished moments...so many times where we were just so close and we wouldn't of had that opportunity if he didn't have dementia.”

Section 9: Staff and Volunteer contributions

As part of the research the two members of staff that facilitate the Irish Memory Loss Group, alongside a long-standing volunteer were interviewed:

- Caroline Murphy, Older Person’s Support Worker and Activities Co-ordinator
- Philippa Dowson, Community Support Worker
- Breedge Walsh (BM), Volunteer

Caroline and Philippa have been working with the organisation for a number of years – 16 years and 10 years respectively. Both have been facilitating the IMLG for about three years alongside their wider advice and support work in the Irish community. This support work ranges from signposting people to wider services and support available to attending doctor/ hospital appointments.

The team often recognise early signs of memory loss on normal visits about other issues where the person mentions being confused or forgetting things and they will then gently encourage them to get it checked out. Having this trusted relationship at an early stage means they can try and help achieve early diagnosis so their support work goes beyond intervening at a memory loss crisis point.

Both members of staff and the volunteer felt the Irish aspect of the organisation – especially in its memory loss support - is very important. One example Caroline gave was in relation to a lady that attends the IMLG: “She resorts back to her younger days when she learnt Gaelic at school and spoke Gaelic in the home...sometimes she will recite a poem in Gaelic...a lot of people love the Irish music as well...you do feel like the Irish effects of the work that you do in that group rings out.” Philippa also mentioned another lady who responded positively when the Irish Arts Foundation came to play some live Irish music for the group: “Then she started to sing and she was singing in Irish and it was fantastic because she absolutely came to life and without that if you just sat her in a room and played Cliff Richard or something random that is not going to happen.”

Caroline and Philippa both highlighted how they took on the responsibility of facilitating of the Irish Memory Loss Group once the previous designated Dementia Worker left the organisation due to funding availability. LIHH recognised the continuing need for such a culturally specific group for the community and wished to ensure that the social support available through the group continued.

This also coincided with the launch of a national campaign within the Irish community called 'Cuimhne', (the Irish word for Memory), (pronounced queevna) led by Irish in Britain (the national representative body for the Irish community in Britain) in partnership with The Irish Post (the leading Irish community newspaper in Britain).

The IMLG had actually started in 2009 as a result of one of the interviewees (AM) mentioning to an LIHH worker at the time that she knew of four men within the Irish community including her own husband who would benefit from an Irish specific memory loss group. Over the last seven years 12 individuals with dementia and 2 carers have benefitted from attending the group with a current number of between 8-10 attendees (including carers).

The IMLG is about creating a safe and trusted environment for people to share memories of Ireland, their emigrant experience and culture and, more recently, for Irish carers to attend and get support from each other.

The staff and volunteer highlighted some **key benefits** that they have noted from the group being specifically for the Irish community:

The value of it being in a familiar community space (The Irish Centre, Leeds): "They absolutely love it and are really appreciative of the fact it is there. I think the fact that it is at the Irish Centre as well helps as it is an environment they would have been familiar with as well throughout the years. Today is St Patrick's Day so we cooked them bacon and cabbage and a load of spuds which is brilliant...it's things like that that make us stand out from anywhere else." (Philippa)

The size of the group: "I think it's a bit more personalised in that there is a smaller group and for somebody with dementia going into a big crowded room it can be a very scary thing...I think we are aware of their issues and the people attending the group." (Caroline)

"I just think that one-to-one and having time to sit and chat with someone where there is not a load of other distractions it is really good and helps them feel valued." (Philippa)

The value Irish carers get from the group: Many of the interviewees had spoken about the value of being able to share experiences with other carers specifically from the Irish community at the IMLG. Many will already know each other or each other's families and staff also noted: "I think the fact they come week on week is positive and its often an effort for the carer to get the person they are caring for ready and out yet they make the effort each week...it gives the carer a bit of a break too."

BM, the volunteer, who is also Irish further endorsed the importance of the Irish focus of the group: "Oh, it's very important because there is a place up in Headingley, and they meet people like that have worked in factories, in the mills, sewing machines and things like that. They'd have nothing in

common with the Irish crowd that worked on the buildings and roads, and those that worked in hotels and things...because they have grown up and grown old together.”

When exploring some of the barriers staff felt might prevent people from the Irish community coming to the group there were a few common issues:

- **Wider promotion of the group** – better publicising of the group amongst the Irish community as well as amongst health and social care professionals (Adult Social Care, memory clinics) so they could refer Irish people they come across with memory loss issues.
- **Reminding people that it is on** – for some with memory loss problems who live on their own a simple reminder is often needed each week or support in arranging transport to attend.
- **The limitations of care the group can accommodate:** “The only thing about the group is that we can only take people who are in quite early stages of dementia. We are not set up to deal with anybody sort of at the latter stages.” (Philippa)
- **People not wanting to admit there is anything wrong or get support:** “Maybe it’s just the fact that they don’t want to admit to themselves or their families, maybe trying to cover up. I mean there is a great thing about pride isn’t there – ‘I’m ok’ – and that is a really strong ethic within Irish people but they have had to get on and had to manage. They don’t want to feel like they need support because they have always been the people supporting other people and I think it’s really difficult for them to say ‘ok, I really do need help.’
- **The staff: attendee ratio:** Both members of staff commented that in their experience, if the group is to further develop and accommodate individuals in advanced stages of dementia then additional staff and training will be required to meet the person’s individual’s needs.
- **Lack of transport to and from the group:** With the loss of the LIHH minibus it has meant individuals and their carers have had to sort alternative transport. Some carers can drive, others get taxis and whilst a positive outcome is the carers note the value they find in talking to other carers at the group – the cost of transport was also noted as potentially prohibitive from some.

Both staff members and the volunteer had benefitted from previous training and understood how to access resources to support their work. They all felt they could benefit from additional and continual dementia training.

In asking about the current gaps in service LIHH might have for Irish people experiencing memory loss they were very clear that the primary resource that would make a difference would be a specialist worker to support individuals and their carers. With an ageing population and large proportion of the Irish community in Leeds over 65, memory loss is becoming an increasing issue.

At the point of writing this report (Aug 2016) LIHH had just recruited a Dementia Services Development Manager who started work on the 30 August 2016.

In addition they also noted wider promotion of the support LIHH can offer presently and more support for Irish carers were two more priorities that need addressing. Caroline noted: “I think we will probably need specific dementia workers that just deal with dementia and then they could offer a lot more help to the carer...I think the carer can be more isolated because there is not a lot of help or respite.”

Finally BM, the volunteer, summed up the value of LIHH's culturally sensitive support: "It's very important because as soon as somebody opens their mouth, they have an Irish accent and you feel at home. You're at ease straight away."

Section 10: Conclusions

Following a review of the findings from the research interviews there a number of conclusions that can be drawn in helping to understand the importance of the Irish cultural heritage, connection and community for Irish people experiencing memory loss and these have been outlined in the Executive Summary.

Appendix 1: Media consent form

Photography

Filming

Audio

Give Permission for Leeds Irish Health and Homes to use <input type="checkbox"/>
--

Name:

Telephone number:

Email:

Signed:

DOB:

Date of agreement:

Leeds Irish Health and Homes (LIHH) often takes photographs and video films for publicity purposes. In order for LIHH to use those photographs and/or video(s) in LIHH's printed publications, website, social media sites or any other means of mass communication, requires your permission to comply with the Data Protection Act 1988. Please read this form and conditions of use before signing and dating this form in agreement.

I understand that LIHH may wish to use photography/filming/audio footage featuring my image and/or my voice in local, regional or national publicity in order to promote the charity.

I understand that any photography/filming/audio may be used on YouTube, Facebook, the LIHH website, social network sites, printed publications, displays or advertising in local, regional or national media.

I understand that websites and other online media can be seen throughout the world and not just in the United Kingdom, where UK law applies.

I reserve the right to instruct LIHH to cease using the footage featuring my image and/or voice at any time.

I have read and understood the conditions of use outlined here.

Conditions of use

This 'Digital media consent form' is valid for five years from the date of signing. The consent will automatically expire after this time.

We will not re-use any images after this time.

We will not include details or full names (which means first name and surname) of any child or adult in an image on video, on our website, or in printed publications, without permission.

We will not include personal e-mail, postal addresses, telephone or fax numbers on video, on our website or in printed publications.

Appendix 2: Discussion Guide for Research

NB – Questions will be adapted at interview stage if we are interviewing a carer so they refer to the person they are caring for...

Introduction

- Explain why we are doing the project
- Thank individuals for their participation
- Explain the media consent form and get them to sign
- Explain that we would like to record the interview and potentially use their audio transcription or video depending on what they agree to

Background

- tell me a bit about yourself
- what is your Irish connection / heritage
- briefly explore career and work history
- tell me about your family
- what age are you
- tell me about your overall health during your life
- how long have you lived in Leeds and where

Awareness and Diagnosis

- What made you think you were having memory problems? This question should cover symptoms. Prompt question - how did you feel?
- What did you think was happening to you? Did Alzheimer's or dementia occur to you at the time?
- did you go and see a doctor?
- tell me about that experience
- have you been medically diagnosed with Alzheimer's or dementia- if so when did this happen?
- what did you know about Alzheimer's or dementia before your diagnosis?
- what does Alzheimer's / dementia mean to you?
- tell me a bit about what happened after the doctor diagnosed you?
- Did you tell your family and friends about your memory loss?

Impact on relationships

Depending on the answer they give above about telling people about their Alzheimer's or memory loss explore:

- a. why they haven't told people and the challenges of that or
- b. if they did tell people how did they tell them what were their reactions, and did it help for others to know?

Support from diagnosis

- Once you were diagnosed what help did you get?
- Who helped you? and how? Depending on the answer to this explore the areas of support noted
- Do you think being Irish made any difference to how you were treated? Was it taken into consideration by the support providers e.g NHS, doctors /social care - explore further depending on answer
- Did you receive support from any other organisations? If yes, explore what and how valuable this support was? How did you find out about this support?
- Explore if the Irish organisation is more important than support received from non-Irish specific organisations or individual
- What is that you like about the Irish organisation - how does it help you and your memory?

Importance of being Irish

- explore the link to their Irish background
- In what way is being Irish important in relation to your experiences of health and social care support for their memory loss?
- Is being Irish an important consideration in your care going forward? - if yes why
- Has being Irish affected your experience of your memory loss experience – what do they like about the services they access? What do they dislike about the services?
- how do you think the Irish community (generally or in Leeds) feels about memory loss and dementia - explore answers further

What are your needs moving forward?

- what would make life easier for you to remain independent for as long as possible
- If you are a carer what support needs do you have as an individual and a carer of someone with memory loss?
- what kind of support service would be important to you?
- prompt if Irish specific service is not mentioned

Is there anything else you would like to share with us?

Thank you for participating and explain that the report will be written up and shared at an event at the end of April.

Appendix 3: Ethical Statement

Leeds Irish Health and Homes and the commissioned researcher Anna Franks agreed to deliver the research within the suggested ESRC Framework for Research Ethics.

These principles ensure that we will:

- Design the research and review its progress to ensure integrity and quality of the findings.
- Ensure that all staff and volunteers working on the project and interviewees are fully informed about the purpose, methods and intended uses of the research.
- Ensure that all involved are fully informed of their participation in the research entails and what risks, if any, are involved
- Obtain informed consent from all participants ensuring they are happy to be part of the research and share their experiences. Consent will ideally be signed by the participant, but may be given verbally and witnessed by two people. While every effort will be made to ensure the person with memory loss has the capacity to give on-going consent, permission may be obtained from the carer if appropriate
- Participants will be assured at every stage that they do not have to answer a question if they don't want to or are able to end their participation if they wish without affecting any of the services they may be using.
- Ensure that during the research the interviewer is fully aware and responsive to any expressions by the informant of being upset, distressed (emotionally or physically) or reluctant to respond to a particular question and take action accordingly, such as postponing or termination of the interview
- Where requested respect the anonymity of research respondents in the reporting back of experiences.
- Keep the research interview to an appropriate length of time that is manageable for the participants.
- Should safeguarding issues emerge, the interview should be terminated, and LIHH Adult Safeguarding Policy guidelines will be followed.

These principles ensure that we will:

- Design the research and review its progress to ensure integrity and quality of the findings.

- Ensure that all staff and volunteers working on the project and interviewees are fully informed about the purpose, methods and intended uses of the research.
- Ensure that all involved are fully informed of their participation in the research entails and what risks, if any, are involved
- Obtain informed consent from all participants ensuring they are happy to be part of the research and share their experiences. Consent will ideally be signed by the participant, but may be given verbally and witnessed by two people. While every effort will be made to ensure the person with memory loss has the capacity to give on-going consent, permission may be obtained from the carer if appropriate
- Participants will be assured at every stage that they do not have to answer a question if they don't want to or are able to end their participation if they wish without affecting any of the services they may be using.
- Ensure that during the research the interviewer is fully aware and responsive to any expressions by the informant of being upset, distressed (emotionally or physically) or reluctant to respond to a particular question and take action accordingly, such as postponing or termination of the interview
- Where requested respect the anonymity of research respondents in the reporting back of experiences.
- Keep the research interview to an appropriate length of time that is manageable for the participants.
- Should safeguarding issues emerge, the interview should be terminated, and LIHH procedures for the Adult Safeguarding Policy will be followed.

With thanks to all the participants and people who have contributed to this research. Your insights, your experiences and honest portrayal about the challenges of memory loss and the value and importance of the Irish dimension in provision of culturally sensitive care around dementia and Alzheimer's will make a difference for people in the Irish community in Britain.

Teresa Charlesworth
Dorothy and Tom Costello
Michael and Evelyn Costello
Philippa Dowson
Sabina Harrison
Bill and Catherine Heffron
Maura Henry
Kathleen and Paddy Howley
Kim Moloney
Agnes Mone
Caroline Murphy
Ethna Stanton
Breedge Walsh

And also to those who contributed their story anonymously.

August 2016