

Date: Monday, 5 September 2022

Time: 2.00 pm – 3.45 pm and optional walk around Grainger Market afterwards

Location: The Electra Room, The Catalyst, 3 Science Square, Newcastle Helix, Newcastle

Roche is part of the ILC Partners Programme and kindly supported this event.

Although the sound and image quality is patchy (especially for the first 10 to 15 minutes) a recording of the full meeting can be viewed [here](#)

Welcome and introductions

Johnny Timpson OBE, Financial Inclusion Commissioner, and member of the Prime Minister's Champion Group on dementia opened the meeting and invited in-person and virtual attendees to introduce themselves.

Please see below for a full list of attendees and apologies.

Why are we here?

Ailsa Forbes, ILC Retail Impact Fellow outlined the ILC's work on dementia and spending and to pioneer solutions in a society where everyone can thrive regardless of age. She explained that following the event we hoped to better understand how businesses, retail and services can support people living with dementia and their carers in the Northeast.

Nick Kelly, ILC and former Parliamentary Researcher for Baroness Sally Greengross gave a brief overview of the ILC and Sally's interest in dementia over the last 25 years. Sally had long advocated for dementia care and research, in to overcome barriers faced by people with dementia and their carers for their own benefit and that of the economy as a whole.

Context:

Professor Dame Louise Robinson set out the context of the numbers of people living with dementia in the North East. She said finding local facts and figures was difficult. Figures from Alzheimer's Research UK suggest that, nationally, 1.33% of the population are currently living with dementia currently.

She suspected that within the North East, there was a substantial variability which appeared to correlate with life expectancy across the region. For example, in wealthier areas such as Hexham, almost 2% of the population were living with dementia, but in more deprived areas, such as Easington Gate, just over 1% of the population had been diagnosed.

We know that the biggest risk factor for all forms of dementia is increasing age which is not modifiable. However, the important brain health research she and her colleagues are involved in, based on large population samples across all ages, shows there are other risk factors for dementia. These include high blood pressure, smoking, obesity, poor diet, long-standing depression, limited social networks, deafness, physical instability etc. These findings are potentially the most revolutionary aspect of dementia research in the last decade and mean clinicians can start encouraging younger populations to assist their brain health.

Professor Robinson noted that there were still no medical remedies that have made an impact. Alternatively, working with new organisational structures such as integrated care boards where public health and social care could come together earlier to encourage people to live well and reduce the risk of dementia as they age, could have an impact. These have previously been implemented for conditions such as strokes and heart disease.

She expressed concern about the care and support received by people with dementia and their families, following diagnosis, and discussed her [research](#) into post-diagnostic care pathways. The research has shown that the geographical inequalities known to exist, were much worse than first thought and that post-covid, the situation has deteriorated. It was more challenging to access services such as memory assessment clinics due to increasing demand and reduced financial budgets. People were being transferred to private community care without specialist support and follow-up, previously available five or ten years ago. Most of the support was in the first year or two after diagnosis, yet as the condition worsened and the demands on the families increased, support was harder to get often being fragmented and fragile. The study looked for examples of good practice in post-diagnostic care that were and sustainable to develop a best practice model for post-diagnostic dementia care.

She felt best practice was "not rocket science" and did not necessarily require substantial research funding. Many lessons could be learnt from the support given to illnesses such as cancer. For example, if you were diagnosed with dementia, you should be put in touch with an Admiral Nurse in the same way that if you have cancer, you are automatically connected with a MacMillan Nurse.

Living well in the community – Ailsa Forbes brief overview of ILC's research on dementia and spending. She explained that the ILC was working on various research projects with partners like Newcastle and Stirling Universities, Alzheimer's Society and abrdn Financial Fairness Trust to help encourage a better understanding of the economic importance and needs of consumers.

Previous ILC research finds that spending by consumers aged 50 and over is expected to rise to 63% of total consumer spending by 2040. So, it's no surprise that KPMG has advised businesses to focus on an ageing consumer base than millennials to drive growth. Given that 1 in 3 people over the age of 80 live with dementia, it's clear that to attract an ageing consumer base retail and banking services need to consider inclusion for people with dementia.

Around 80% of people with dementia surveyed by the Alzheimer's Society list shopping as one of their favourite activities but around 63% of people with dementia believed shops aren't doing enough to help people with the condition. While 16% of people with dementia surveyed no longer take public transport. One bad experience is enough to just put you off and almost one in four people surveyed no longer went shopping.

There is meaningful un-broadcasted work occurring in this space, a national scheme, highlighting dementia-friendly retail outlets by front entrance signage, for example.

Main discussion: How can businesses, retailers, and services (financial, travel, tourism, entertainment) better support people living with dementia and their carers?

- 1) What are the challenges locally?
 - a) For people living with dementia and their carers?
 - b) For business and services?
- 2) What works and what needs to work better?
- 3) What should/could be scaled up – and how?
- 4) Can we learn anything from what hasn't worked?

Main points raised:

Impact of cost of living on people's spending habits.

The retail sector was facing many challenges, including requests for deposit demands from energy companies which were being for up to a year in advance. Ensuring retailers can stay open to continue to trade would be hard-hitting.

Government action would be crucial. If the triple lock pensions policy is continued and adjusted to help with cost of living, this may mean older people may be better off than other younger consumers. Other unsubstantiated factors include the finance of social care.

Financial inclusion

In Scotland, Social Security Scotland is the default security framework that aims to treat people with dignity, fairness, and respect, delivering services in a way that ensures people can get the financial support they are entitled to. Financial authorities should be proactively reaching out to families now to make sure that they are accessing the raft of UK and benefits and grants that are entitled to and help them to respond to the cost-of-living challenges. For example, social tariffs schemes to help build the financial resilience of families that are more vulnerable.

Due to inclusion campaigns, the financial services regulator has now stipulated that designing any new product/services or reviewing existing products/services, there must be stipulation that these are design inclusive and informed by lived experience.

Funding

This is always a major issue to all of us who want to improve in the future and there is more to be done with additional funding. Small initiatives can help, for example, in Newcastle slow shopping made a difference not just to people living with dementia but people with other cognitive disabilities.

Local services

As people's dementia progresses, their geography decreases, spending more time locally. Although there is best practice where banks have hosted Dementia Friends sessions, the fact

remains that many people are unable to speak to a human being at their local bank branch. Where amenities are poor, it becomes harder for people to engage with services and projects.

Role of carers

Many people have left the workforce to care for people with dementia as informal unpaid carers. This has a huge impact on the economy and employers are not taking advantage of supporting carers for our older population in order for them to remain in work. The lack of flexible working opportunities hits people at the lower end of the pay spectrum.

Public transport

For people with dementia, changes to public transport can be disorientating. Strategic conversations need to take place on how to manage this, informing people, for example, if bus routes have changed

Training

The rapid turnaround of young staff in sectors such as hospitality and banking make training difficult. It is important to embed an awareness of the needs of people with dementia in the culture of organizations, not just in employee training. If we resolve this for dementia, we resolve this not just for cognitive impairments but for neurodiversity and a range of conditions.

Banks are national and therefore employee training tends to be similar in the south of England as in the North East. However, training should reflect local knowledge. This gives training a local context and makes it more meaningful.

Training should involve people with lived experience.

Tourism and travel

Businesses that demonstrate best practice should be celebrated at awards ceremonies. Then these exemplars can be used to inspire others.

A more positive approach that rewarded dementia-friendly transport systems, restaurants, hotels, tourist attractions etc might encourage others more effectively.

Role of schools

The National Curriculum should cover the natural process of ageing to ensure there is improved intergenerational awareness. It was felt that intergenerational work could be the magic bullet in terms of greater awareness and understanding and assist in combating loneliness.

Prevention

Historical public health services had expedited successful prevention work, but the focus has since shifted.

Employee Resource Groups

Invariably the resource groups within larger companies are focused on specific issues such as gender, ethnicity, sexual orientation. Often the ERG missing is a focus on disability, including dementia. There is a coordination role for local government because the small employers, are lacking an ERG because of size. Alternatively, there could be a Newcastle Traders ERG or a Tyneside Traders ERG.

Awareness and labelling

We need to do more about raising the profile of non-visible disabilities. How do we recognize a person with an unseen non-visible disability and how do we recognize their carer? One of the attendees noted "When I was caring for somebody, I didn't need to have a label as a carer. What I needed to know was where did I go to get the information, I needed at the time I needed it."

It was important not to stigmatise. People living with dementia just want to feel safe and able to do the things they enjoy doing – they don't necessarily need labelling. Not all customers like to be labelled as disabled or vulnerable even though they have an underlying disability, disabilities or limiting health condition. It is not necessarily their disability that is disabling - it's the barriers they face in trying to interact with products and services that are the disabling factors.

People with dementia need to be better understood and allowed leniency in certain circumstances, for instance, if they forget to pay.

Intersectionality and coproduction

It was important to be culturally curious, be culturally appropriate and to understand what you're doing. Not enough work is done talking to people with lived experience.

In Newcastle, efforts were being made to identify the key points, in developing a strategy for the city around dementia, particularly around post-diagnostic support. Somebody can live with dementia for a long time, so what does post-diagnostic support mean in reality?

Impact on others

Any disability such as dementia goes through the family like a wrecking ball. Within the sphere of one person with a diagnosis, ten other people carry it with them to various degrees. Everybody close to someone with dementia is affected but small adjustments can make the person with dementia's world much easier.

Role of the voluntary sector

The voluntary/community sector plays a huge role in supporting people in communities and it is important to include voluntary organisations in the conversation.

Impact of devolution and role of local authorities

There's a lot of cross-thinking and joint working between authorities in the North East, but it could always be better. Integrated Care Boards have replaced Clinical Commissioning Groups and cover a larger area so might encourage greater collaboration.

Newcastle East - Inclusive, Healthy, Vibrant High Streets project

Karen Inglis outlined a two-year [project](#) focusing on improving several high streets in Newcastle like Shields Road. She also described the work of Cllr Karen Kilgour who since 2016 had championed Newcastle being a dementia-friendly City.

Why is dementia different?

There has not been that moment of positive social change around dementia. It is not clear whether ageism is involved, but change is too slow. Sometimes dementia seems to fall between the older person's agenda and mental health. The youth hold substantial power for social change and working with younger children might well produce a key step forward.

What happens next?

The ILC will be holding further events in Cardiff, Edinburgh and Stirling and will publish its [dementia and spending](#) research findings later this year. The ILC will also be working with Newcastle University and the Alzheimer's Society to help share the results of the [Pride](#) programme early in 2023.

Visit to Grainger Market

Karen Inglis, Dementia Friendly and Community Wellbeing Lead, Newcastle showed us the dementia-friendly spaces at Grainger Market. Excellent initiatives like those set up by Newcastle City Council at Grainger Market are not rocket science and don't necessarily require big budgets but can make a positive difference to the whole community.

Attendees and apologies

Apologies were received from Reshma Begum, Federation of Small Businesses, Vivienne Jackson, Programme Manager, abrdn Financial Fairness Trust; Dawn McNally, Chief Executive, Age UK North Tyneside; Michelle Rainbow, Skills Director, North East LEP,

- **Johnny Timpson OBE** – Financial Inclusion Commissioner and a member of the Prime Minister's Champion Group on dementia

Johnny Timpson is a financial leader and business strategist with extensive work in the voluntary and financial sector. After leaving the Scottish Widows in 2021 after 33 years, he now works as an independent consultant specialising in inclusion, diversity, and intersectionality. Among other positions, Johnny is a Cabinet Office Disability and Access Ambassador.

- **Professor Dame Louise Robinson** - Professor of Primary Care and Ageing, Newcastle University

Professor Dame Louise Robinson is Regius Professor of Ageing, an academic GP and Professor of Primary Care and Ageing at Newcastle University. Her research programme focuses on improving quality of life and quality of care for older people, especially those with dementia. She leads 1 of 3 UK Alzheimer Society Centres of Excellence on Dementia Care.

- **Norma Redfearn** – Mayor of North Tyneside

Norma Redfearn CBE was re-elected as Mayor of North Tyneside for the third time in May 2021. In 2019, she was appointed Deputy Mayor of the Combined Authority, as well as Cabinet member for Housing, Land and Development.

- **Cllr Karen Kilgour** – Deputy Leader, Newcastle City Council, and cabinet member for a Healthy, Caring City (attended virtually at the start of the meeting but the poor sound quality meant it was too difficult to continue to take part)

Cllr Karen Kilgour is a former local government officer with long experience of campaigning for equalities. In her current role as Deputy Leader, she looks after the council's resources and ensures they are used wisely. She is also responsible for ensuring that the council has a performance regime which is driving change and improvement.

- **Cllr Glen Sanderson** – Leader, Northumberland County Council (attended virtually at the start of the meeting but the poor sound quality meant it was too difficult to continue to take part)

Councillor Glen Sanderson is the Leader of Northumberland County Council. In the North of Tyne Combined Authority, Councillor Sanderson is the cabinet member for Culture, Creative and Rural.

- **Ian Thomas** – Designation Director, Newcastle Gateshead Initiative

Ian Thomas has been working for the Newcastle Gateshead Initiative for over 11 years, and has been acting as the Destination Director, since September 2021. He has 20 years of research experience, including related to developing customer experience.

- **Andrew Keilty** – Medical Affairs Partner, Roche

Andrew Keilty has been working for over seven years at Roche, where he has been acting as a Medical Affairs Partner since October 2020. He applies a strategic outlook and therapeutic area knowledge to implement projects that address the medical needs of clinical practice, ensuring the optimal use of Roche medicines.

- **Trudie Hills** – Customer Disability Manager at Lloyd's Banking Group

Trudie Hills has worked with Lloyds Banking Group since 1982 and currently acts as the Customer Disability and Mental Health Manager. She is a member of the Prime Ministers Champion Group for Dementia and led the introduction of the Sunflower Lanyard initiative for hidden disabilities.

- **Nigel Hullah** – Co-Chair of Three Nations Dementia Working Group (attending virtually)

Nigel Hullah is the Co-Chair of Three Nations Dementia Working Group and, since January 2021, is a member of the European Working Group of People with Dementia. He was diagnosed with early onset dementia in 2013, having become fully engaged with social justice and human rights of people with dementia.

- **Karen Inglis** – Dementia Friendly and Community Wellbeing Lead, Adult Social Care and Integrated Services, Newcastle

Karen Inglis is the Dementia Friendly and Community Wellbeing Lead, Adult Social Care, and Integrated Services for Newcastle City Council.

- **Malayka Rahman-Amin** – Alzheimer's Society (TBC)

Malayka Rahman-Amin is the Research Evidence Manager at the Alzheimer's Society since January 2021, where she joined in September 2014, and develops strategies and processes for getting dementia research knowledge taken off the shelf and put to use.

- **Ailsa Forbes** – Retail Impact Fellow, ILC

Ailsa Forbes joined ILC in July 2022 as Retail Impact Fellow. She worked extensively in the heritage and tourist sector as a retail buyer and product developer specialist. Abbey Road Studios, Courtauld Gallery, Royal Collection Trust, London Fashion Week, V&A, and the Wellcome Collection are some of the exemplary organisations she has been involved with.

- **Nick Kelly** – ILC and Parliamentary Researcher

Nick Kelly is a researcher who has worked in Parliament and with the ILC-UK since 2020. He has worked on various dementia research projects and has been involved with the All-Party Parliamentary Group for Dementia with a long-standing interest in dementia policy.

- **Emily Evans** – Communications and Engagement Officer, ILC

Emily Evans started at the ILC-UK as the Communications and Engagement Officer in April 2022. Ever since she has taken over from Sophia Dimitriadis as project lead on various aspects of ILC's work on dementia.

- **Andrea Juste** – ILC Summer Intern

Andrea Juste joined the ILC-UK in July 2022 as a Summer Intern. She has been working as a journalist and content strategist for over ten years, and has a keen interest in longevity, the ageing process, and its impacts not only on the individual but also on society.

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[Spending and dementia roundtable - Newcastle, 5 September 2022 - YouTube](#)